

Engaging Clinicians in Cocreating Health

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A thesis submitted for the degree of Doctor of Business
Administration in Public Services Management at the
University of South Wales

Declaration

This work has not previously been submitted for a degree or diploma in any university. To the best of my knowledge and belief, the thesis contains no material previously published or written by another person except where due reference is made in the thesis itself.

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Signature :

A handwritten signature in blue ink, appearing to read 'AJP', with a horizontal line underneath.

“Man's consciously lived fragility, individuality, and relatedness make the experience of pain, of sickness, and of death an integral part of his life. The ability to cope with this trio autonomously is fundamental to his health (Illich, 1976)”

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Abstract

This thesis contributes to the wider debate on Prudent Healthcare and Relational Practise. The study aimed to determine how to engage clinicians in cocreating health by developing a framework for cocreating health to support the patient-clinician interaction and to identify the factors in its successful implementation in health services. The interaction between patients and clinicians is at the heart of health care. They are the first point of contact and a familiar interaction with the health service for most patients. Within UK health services there are three hundred million consultations held every year. Consultations happen in a variety of contexts, locations and with many different clinical professions. The overwhelming majority of these interactions follow a set pattern, the rules of engagement, which governs how patients are examined, histories established, symptoms described, test results discussed, progress monitored, treatment options given and decisions made. However, the traditional medical model of consultation can reinforce a power imbalance between clinician and patient, and create paternalistic relationships that reduce patients' control, leading to their 'systematic disempowerment'. Cocreating health is about enablement, viewing patients as assets not burdens and seeks to support them to recognise, engage with and develop their own sense of resourcefulness building on their own unique range of capabilities. Cocreation means that health care services support people's individual abilities, preferences, lifestyles and goals. In a cocreating health model of interaction, patients work with a supporting clinician. Such interactions consider the patient's life goals, how they plan to work towards them and what support they need to help her get there. Working in cocreation, a clinician would support patients to think about goals that are meaningful and adaptive. A number of elements of cocreating health such as self-supported management and decision support have previously been developed. However, these have generally been implemented within the context of the traditional 'medical model' of consultation.

In the development of the cocreating health framework, a mixed qualitative and quantitative approach was taken to explore different aspects of cocreating health and to triangulate knowledge obtained from the different methodologies. Principles of grounded theory were used in the qualitative research. Data and insights were obtained in two phases. In the first phase, over thirty workshops were held with over five hundred participants from Welsh Government, local authorities, voluntary sector and across the NHS in Wales including policy makers, leaders of health services and clinicians. Insights from these participants combined with knowledge gained from the literature review were used to develop a cocreating health framework for testing. The initial data suggested that for clinicians, working collaboratively with patients in agenda setting was the most unfamiliar and potentially transformative element of cocreating health. Accordingly, training was arranged for one hundred and sixty four clinicians whose attitudes towards cocreating health were explored using questionnaires. In the second phase, semi structured interviews were held with thirty one participants from

professional backgrounds of doctor, nurse and therapist and at levels of policy maker, leader and clinician to determine their insights on the test cocreating health framework. These insights were used to refine the framework and develop a number of methods to convey the framework to different audiences. The cocreating health framework contains seven elements namely ; preparation; agenda setting; information gathering; discussing options; agreeing the way forward; implementation; review and further actions, with each of these elements supported by reflective learning and service improvement. Insights were obtained from these same thirty one interviewees on factors relating to implementation of the framework. These insights led to development of a grounded theory model for implementation of cocreating health. This model has its roots in the theory of planned behaviour and describes elements of clinician attitude, clinician norms and controls impacting on the intention to cocreate health with action factors of patient self-efficacy, the cocreating health framework and leadership support leading to actual cocreating health behaviours. The most significant issues perceived in cocreating health were found to be ; conflict between the cocreating health framework and the current 'medical model'; power relationships; the context of the interaction; patient self-efficacy; clinician understanding of cocreating health; the conflicting expectance of patients about the clinician's role; time constraints and ; clinician training.

Implementation of the cocreating health framework was examined through the lens of normalisation process theory. Results of this suggested that neither patients, clinicians nor health systems and currently sufficiently 'activated' for successful widespread implementation of the cocreating health framework. It was concluded that implementation of cocreating health requires willing advocates to embed cocreating health approaches within their multidisciplinary team work, collecting evidence and case studies to generate 'permission' and buy in from influential leaders. Rather than attempting to 'persuade' highly experienced clinicians with many years of working to the medical model, this research suggests that cocreating health would be more successfully implemented in the initial training of clinicians in the curricula of medical schools, schools of nursing and training of other clinical groups. The research explores the properties of an 'activated' health system, that would provide clinician training in the elements identified in the framework, patient education programmes, appropriate employer expectations set through policy, information technology such as an electronic patient record and sources of information about clinical conditions that are openly available to both patient and clinician to read from and write to, and adequate time and flexibility for appointments. Finally, the sociological characteristics of cocreating health interactions between patients and clinicians were described within a symbolic interactionist paradigm.

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Chapter One : Introduction

“The relationship between doctors and patients is at the heart of our health system. If we want a different health system, we need a different type of relationship.” (Fischer and Ereaut, 2012)

The purpose of this chapter is to introduce the thesis and its different chapters. The first section sets out the background to the research and the concepts of patient-clinician interaction and cocreating health. The second section presents the justification for the research, describing a need for a fundamental shift in the way clinicians interact with patients to deliver on a policy requirement for cocreating health. The third section discusses the inherent strengths and weaknesses of the current ‘medical model’. In the last section the research questions to be addressed are stated, a brief outline of the methodology is given and there is a brief outline of the structure of the thesis. Finally, key findings are presented, with an overview of why this thesis makes a significant contribution to policy, to health practice and to knowledge.

1.1 Background to the Research

This study aimed to determine how to engage clinicians in cocreating health by developing a framework to support the patient-clinician interaction and to identify the factors in its successful implementation. .

The interaction between patients and clinicians is at the heart of health care. They are the first point of contact and a familiar interaction with the health service for most patients. Within UK health services there are over a million consultations held every 36 hours, or about 300 million every year (Royal College of General Practitioners, 2012). People with chronic conditions account for more than 50% of all general practice appointments, 65% of all outpatient appointments and over 70% of all inpatient bed days as well as 70% of the total health and social care spend. Consultations happen in a variety of contexts, locations and with many different clinical professions. The overwhelming majority of these interactions follow a set pattern, the rules of engagement, which governs how patients are examined, histories established, symptoms described, test results discussed, progress monitored, treatment options given and decisions made. However, the traditional medical model of consultations

can reinforce a power imbalance between clinician and patient; can create paternalistic relationships that can lead to the 'systematic disempowerment' of patients (Fischer and Ereaut, 2012). The nature of the interaction between patient and clinician in the 'consulting room' sets the tone for interactions throughout the system. According to Fischer and Ereaut (2012) *"not only is the quality of the direct interaction reduced by the current dynamic, but also that the adaptive capacity (ability to innovate) of the NHS is handicapped by the current dynamic (protected doctor and disempowered patient)."*

In the traditional medical consultation there are basic 'rules of engagement', a defined set of interactions in which the clinician diagnoses the problem, plans the treatment and prescribes the solution. The issue for patients is that not only do they lack control in these interactions, but unlike clinicians they are often unclear about what the rules are. In the view of Fischer and Ereault (2012), for patients it often feels as if doctors have a 'map' that they cannot see and clinicians can find that the rules of the game often prevent them from building productive relationships with patients, many of whom have complex health problems with complex causes, that cannot be easily understood within the confines of the consultation.

However, if clinicians see their role as facilitating, supporting patients to develop self-efficacy, consultations as the basic building blocks of interactions between patients and practitioners carry enormous potential as a space in which to jointly assess needs and capabilities; identify health and wellbeing goals; develop and design a plan for treatment; review progress and evaluate success (Horne et al, 2013). According to Horne and colleagues, a partnership approach to consultations has a number of core features, namely: Changing the conversation to focus on patients' goals and outcomes; Changing the format to provide flexible, alternative structures according to what is most useful to the patient, not most convenient to the institution and; Changing relationships to value patient experience and new professional and non-professional roles as sources of expertise.

An alternative viewpoint is that the medical model uses minimal clinician time, is highly effective, efficient and partly responsible for increasing longevity in Western countries. It might be claimed that a major factor in this success is short, 'medical' consultations

in which a patient consults an expert specialised practitioner who provides immediate advice or treatment. Such an arrangement is highly valued by patients and healthcare professionals. In the context of an acute illness where the patient's concern is 'please save my life', urgency in care is crucial and there are few appropriate options, this is an appropriate model and could be considered 'clinician centred' (Collins, 2014). However, in other contexts where there are preference-sensitive options and outcomes are highly dependent on patients taking responsibility for their own health, it is argued that a person-centred cocreation approach is appropriate where the patient is treated as a person, not primarily as a bundle of diagnoses or symptoms. This means the clinician and healthcare system paying attention to 'what matters to the patient', their family and carers. In each of their interactions 'what matters' will depend on the context of the interaction.

A person-centred health care system is one that supports people to make informed decisions about and successfully manage their own health and care other than at the time of very highest dependency. Cocreation means that health care services support people's individual abilities, preferences, lifestyles and goals. In a cocreating health model of interaction, patients work with a supporting clinician (Collins, 2014). The way that patients articulate 'what matters to me' depends on the context of their interaction with the health service and is highly dependent on the mind-set and skills of the practitioner. 'What matters' may be straightforward or it may not be attainable. A cocreating health interaction can help patients to adapt, should their 'life plan' be beyond their grasp. Cocreating health is about enablement, viewing patients as assets not burdens and seeks to support them to recognise, engage with and develop their own sense of resourcefulness, and to build on their own unique range of capabilities (Collins, 2014).

A cocreating health approach requires a change in behaviour and mind-set from patients and clinicians, supported by a system that facilitates this interaction. Although a number of individual elements of cocreating health such as self-management support and supported decision making are described in the literature, they have been employed separately within the context of the 'medical' consultation.

The current health service priority is to service need on presentation but there is little focus on increasing the capability of individuals or communities or holistic patient management. The majority users of health services are people who have a number of different chronic physical and mental health conditions with intermittent exacerbation which is risk managed and stratified by clinicians. People can access a number of different clinicians in multiple specialties and these conditions may be managed in isolation. They can end up being admitted to hospital and can have long length of stay for a number of factors. In essence this 'system' can convert people from a state of independence with intermittent management of chronic conditions to one of dependence (Charmaz, 1983).

Health services face tension between political and citizen demand for improved and expanded 'Healthcare', no change in familiar local services and constraints on public expenditure requiring 'efficiency savings'. As far back as 2006, the Beecham Review for the Welsh Government called for "a fundamental transformation from the model inherited from the post-war years to one sustainable in the early twenty first century". Beecham stated a requirement to change the relationship between services and the public, and a need for "greatly enhanced efficiency" in order to improve services. Beecham pointed out that users of Healthcare services are increasingly displaying consumerist behaviour, particularly increased expectation linked to the rise in consumer choice (Beecham, 2006, p3). Beecham (Beecham, 2006, p3) also signposted the need for a more collaborative approach in the design and delivery of public services: *"Increasingly complex social goals, especially preventive measures, cannot be achieved by doing things to people as opposed to doing things with them."* And pointed to *"the recent notion of 'co production': of active consumers who achieve desired outcomes jointly with the service providers"* as something that will influence the transformation of public services" (Beecham, 2006, p3)

1.2 Principles of Cocreation

The principle of cocreating value was introduced in 2004 in the management literature and was subsequently further developed to co-create value for all stakeholders and applicable to any organisation (Prahalad and Ramaswamy (2004)), service, industry, and health services (McColl-Kennedy et al (2012), Hardyman et al (2014)). The Social

Care Institute for Excellence set out the principles of cocreation for public services (SCIE, 2013) :

- Acknowledging people as equal partners in the design and delivery of services, not passive recipients or burdens.
- Rather than starting with needs which is the traditional deficit model, co-created services start with people's capabilities and look for opportunities to develop these.
- Co-creation is about a mutual and reciprocal partnership, where professionals and people who use services come together in an interdependent relationship recognising that the expertise of each is important in delivering effective services and improving outcomes.
- Engaging peer and personal networks alongside professionals as the best way of transferring knowledge and supporting change.
- Blurring the distinction between professionals and service users, and between producers and consumers of services, by reconfiguring the way services are developed and delivered.
- Enabling professionals to become facilitators and catalysts of change rather than just providers of services.

1.3 Justification for the Research

For health services to transform themselves consistent with the principles of co creation, it is argued that they need to give more emphasis to supporting, educating and informing people about how to live better quality lives. In particular, such a transformed service would equip people with complex and long term physical and mental health conditions with skills to better look after themselves (Coulter et al, 2013). In co-creation, clinicians bring technical knowledge, patients bring their knowledge about themselves and together they devise and agree the goals and actions to be taken-such as an activity plan, taking medication or having an operation.

The aim of cocreating health is to enable people to have the best quality of life they can and achieve the outcomes that matter to them. Potentially this could encourage people to engage with the health system earlier, leading to earlier diagnoses and improved health outcomes. If these benefits are realised, services would be more

cost-effective and communities would view health as an individual and collective responsibility rather than the domain of experts. Increasing demand would be effectively managed by engaging and empowering people as effective partners in their own healthcare.

Hibbard and colleagues (2010) reported that for many clinicians, working in partnership with activated patients presents a transformational shift, which is currently highly uncomfortable. The Royal College of Physicians considers (Royal College of Physicians, 2005) that clinicians will need to develop new knowledge, skills and behaviours to manage the increasing demands of chronic disease. Blakeman and colleagues (2006) demonstrated that although patient self-management is valued by General Practitioners, it has low priority within medical consultations and MacDonald et al (2007) showed that clinicians tend to use didactic approaches rather than engaging patients in problem solving or using more interactive methods. Hibbard and colleagues (2010) concluded that clinicians value most highly the patient behaviours that focus on following medical advice. The paradox then is that although patient activation is highly correlated with good outcomes, clinicians themselves often have low commitment to supporting patients to self-manage their health.

This work aims to produce a cocreating health framework that guides clinicians to support patients in developing effective self-management by acquiring the skills and knowledge to be able to manage their condition and to confidently manage new issues as they arise. This framework would help clinicians to support patients to decide on options, to take actions to change their health behaviours and to increase self-efficacy.

The second research aim was to identify the facilitators and barriers to implementing the cocreating health framework. By understanding these practicalities it was intended to develop a grounded theory model for implementing cocreating health in practise. This would provide the contribution to knowledge for the doctoral thesis.

1.4 Existing Models of Patient-Clinician Interaction

The 'medical' model of consultation, based on a clinician achieving a physiological understanding of a patient is a core building block of Western healthcare systems.

This model has been widely adopted by medical practitioners and copied by nurses, therapists and healthcare scientists. This model is efficient in that it can be completed within five minutes, easily timetabled and repeated continuously. In the context of a skilled practitioner making decisions about best treatment for a patient in an acute crisis, this model is entirely appropriate (Collins, 2014). The ability to place your trust in the hands of an expert practitioner who can ‘fix you’ is highly valued by many people, particularly older people who may lack health literacy or self-efficacy. However, in the context of a patient not in an immediately life threatening situation, or who has chronic symptoms but no outward sign of illness, such an approach cannot provide effective long lasting management of the patient’s health or wellbeing. In such situations, patients may attend numerous appointments with different practitioners and risk being perceived as problematic or troublesome, and clinicians risk appearing incompetent or not compassionate.

This work aims to develop a ‘cocreating health’ framework of patient-clinician interaction that challenges the strongly embedded roles of patient and clinician and the power structures in which the clinician’s practice and the patient’s health problems are contextualised. In particular, this aims to address issues posed by the current ‘medical model’, where patients can give negative accounts of their medical consultations. They report having been met with scepticism and lack of interest in understanding their unique and complex circumstances, or having been reproached for their poor health behaviours. Patients sometimes describe that they need to work hard to appear credible to gain the clinician’s engagement so that their complaints could be perceived as ‘real’ conditions and not as signs of mental imbalance. Clinicians give accounts that their consultations are difficult, they describe experiences of helplessness, powerlessness and frustration to provide high quality treatment and care within current structures and limited time available for consultations.

1.5 Structure of the Thesis

This study aimed to determine how to engage clinicians in cocreating health by developing a framework for cocreating health to support the patient-clinician interaction and to identify the factors in its successful implementation in health services. A literature review was first conducted of existing patient-clinician interaction

models. Following the initial literature review, a series of workshops was held to explore concepts in cocreating health arising from the literature and a test cocreating health framework was developed. From the insights developed, a mixed quantitative/qualitative research methodology was chosen to explore and refine the cocreating health framework and to determine issues in implementation. For the qualitative research, grounded theory principles were used and analysis of semi-structured interviews led to development of a finalised cocreating health framework. Participant insights also resulted in the generation of a grounded theory model to explain the barriers and facilitators in cocreating health. The analysis pointed to significant differences between professional groups. Doctors were found to be less 'activated' towards cocreating health, but their 'permission' for patients and other clinical professionals to cocreate health was found to be a vital factor. It was found that outside inpatient and life threatening care situations, around 80% of patients could be engaged in cocreating health immediately, another 10% would engage following a period of reflection and only 10% were expected to never engage with clinicians in cocreating health. Key conclusions were that many people want to play a more active role in their health care, and there is growing evidence that elements of cocreating health such as shared decision making and self-management support can improve patient experience, care quality and health outcomes. This supports a shift to a cocreating health approach containing elements of relational care, a bio psychosocial philosophy with clinicians supporting patients to prepare for their interaction, to be involved in agenda setting, for joint decision making, self-management support and health behavioural changes. This thesis contributes to practise through the development of a cocreating health framework containing seven elements, supported by reflective practise and service improvement. It contributes to knowledge through devising a model to describe clinician behaviours. Through engagement with policy leaders and senior clinical and management leaders, it is considered that this work contributed to the development of policy on 'Prudent Healthcare'. Implementation of the cocreating health framework was examined through the lens of normalisation process methodology suggesting that health systems, patients and clinicians are currently in a pre-contemplation phase of behavioural change in respect of cocreating health.

Chapter Two : Review of the Literature on Patient-Clinician Interaction, and Cocreating Health

2.1 Introduction

This study developed a cocreating health framework for patient-clinician interaction and determined the factors related to its implementation in health services. This chapter sets out a literature review, conducted prior to data collection that examines the current clinician 'consultation' models only. This was limited to consciously avoid influencing the development of insights from the grounded theory methodology used later in the research.

When a theme had been identified from insights gained from interviewing participants, further literature was examined around concepts such as the sociological understanding of patient-clinician interaction, some key elements of cocreating health such as self-management support, supported decision making, health behavioural change, clinical audit and service improvement, symbolic interactionism, the theory of planned behaviour, normalisation process theory, pace-complexity and clinician 'activation'. Finally, the seven elements of the cocreating health framework along with the supporting aspects of reflective practice and service improvement were grounded in a further review of the literature. The literature around themes and elements derived from the research is reported in the analysis chapter in the context of the findings.

2.2 Literature Review Carried out Prior to Data Collection

2.2.1 Principles Inherent in Current 'Medical Consultation' Models of Patient-Clinician Interaction

In his 'hierarchy of human needs' Maslow (1954) argued that all humans needs can be classified as a 'hierarchy' using a pyramidal model where fundamental needs are at the bottom of the pyramid and must be fulfilled before a person can address fulfilment at the next level. In the pyramid model higher needs are later evolutionary developments, and so they can develop later in an individual although their fulfilment creates greater happiness and individual growth and require a better external environment. For example, this hierarchy suggests that an older person in poor quality

housing with social issues such as a low level of income who repeatedly presents to a clinician with acute temperatures, coughs and colds would not be receptive to self-management advice (which demands high self-respect and esteem to put into practice) as they are focused on concerns that their basic physical needs (adequate food and warmth) and shelter needs (good housing and adequate finances) are not being met and may be the underlying cause of their ill health. Communication between patients and clinicians is a complex human interchange and Maslow's theory began to help clinicians understand patients' human context and the complexity of the social determinants of health. The criticism of Maslow is that human beings have greater complexity and variety, attaching greater or lesser importance to the defined 'needs' over time and that higher order needs may require satisfying before lower order needs. Currently, health services can be said to be built around satisfying the lower, physiological and nutrition needs and the concept of Maslow's hierarchy is consistent with the current 'medical' model of consultation.

This Western clinical model is based on the 'rational reductionist' philosophy that a diagnosis must be made before safe and effective treatment can be decided. In this model, each new patient presents as a new problem to be analysed, understood and rationally solved. Practitioners of this method tend to assume that many patients have one of a number of familiar and well understood problems and look to make a diagnosis by assigning patients to a diagnostic category. This is done by comparing the information presented by a patient with a general clinical knowledge held by a clinician to arrive at a 'good enough' match.

This process, taught to this researcher in his clinical training has four steps, each of which must be completed in a specific sequence :

1. Collect data about the specific problem and the context of that problem to reach a diagnosis.
2. Compare the data with existing information to reach a decision.
3. Deliver the appropriate treatment to both resolve the symptoms and address the root cause
4. Collect further information to monitor the effect of the treatment and maintain improvement.

The first two steps are normally combined because each problem is unique and the exact process of collecting information is dependent on the actual data. There is a cycle of question, answer, interpretation, next question that continues until the root cause is discovered with sufficient accuracy and giving sufficient confidence that a treatment decision can be made. This individualised, interactive, diagnostic process is more efficient and effective than a blanket non-interactive approach but requires a sufficiently well trained, experienced practitioner to both be effective and efficient.

The third step, of acting on the decision normally has two parts-the psychological and the physical. The psychological element requires providing an explanation of the past, an outline of the present options and a prediction of the possible future outcomes. This aspect is a critical part of the value expected by the patient, requiring a dynamic process where the clinician has to be flexible in order to deliver the information in a way that suits the individual patient. The delivery of the medical model of healthcare can be distilled down into the bespoke application of a common body of knowledge to individual, unique patients, one at a time. This process requires the time of practitioners who are skilled in the art and supported by processes that create a context conducive for that valuable work to be done.

The fourth step is critical for safety and learning because the actual outcome provides feedback on the accuracy of the diagnosis and the effectiveness of the treatment. The monitoring is for the intended positive outcome and any unintended negative outcomes since both offer opportunities for further learning and improvement.

Traditional 'consultation' models assume that clinicians and patients share the same goals but that only the clinician is sufficiently informed and experienced to make decisions and that patient involvement is limited to giving or withholding consent. Flynn and colleagues (2006) have shown that although some patients do not want to play a part in decision making, the majority want to understand the causes of their condition, become informed about prognosis and treatment options, participate in decision making and to engage in promoting their own management and recovery. Coulter and Magee (2003) found that around three quarters of patients expect to make their own preference-sensitive decisions. It is clear that clinicians currently underestimate patient's motivation to be actively involved in decision making about their own health and do not adequately support patients to understand their own

condition (Coulter, 2011). It is known that patient's preferences for participation in decision making may change with disease progression, being higher in diagnostic phases than in advanced stages of disease (Davey et al, 2001 ; Beaver et al, 1999). Although younger and better educated people are more likely to seek an active role (Coulter, 2011), age is not a consistent predictor (Kennelly and Bowling, 2001 ; O'Connor et al, 2003) and clinicians often wrongly assume that older people are incapable or unwilling to make decisions about healthcare (Coulter, 2011). The attention of clinicians is often focussed on the disease rather than the person and this leads them not to explore patient's values and preferences (Corke et al, 2005). In a review of observational studies of communication between clinicians and patients, Stevenson et al (2004) found that whilst most patients are keen to take an active role in their health, this is not encouraged by clinicians who tend to dominate the interaction to the detriment of outcomes.

2.2.2 Existing Patient-Clinician Interaction Models

At the beginning of the 20th century, the popular view of a clinician was of the 'good' doctor acting as an 'applied scientist' or engineer in a patriarchal way in the 'best interest of the patient' (Tudor-Hart, 1988). By the end of the 20th century there was increasing evidence that the science and technology of medicine could not always provide a solution to people's problems, and that patients' unquestioning trust in medical professionals had been undermined by the practice of a few doctors such as Shipman (Scambler and Britten, 2001). Social change and increasing public access to information are increasingly challenging the 'traditional medical model' of consultation.

Szasz and Hollender (1956) described three models of patient-clinician interaction:

1. Activity-passivity, the patient is a passive recipient of the clinician's actions
2. Guidance-cooperation, where there is an imbalance of power in which the patient is expected to cooperate in whatever action the clinician considers appropriate
3. Mutual participation, defined as a partnership in which the clinician supports the patient to help themselves

There is an argument in favour of passive receipt in emergency situations where clinicians need to act very quickly and in which the patient lacks the capability to be actively involved. The traditional paternalistic medical model of 'guidance-cooperation' is currently very widely applied in situations where mutual participation would more likely lead to better outcomes for patients and clinicians.

Balint (1957) defined holistic medical care as an approach which considers all aspects of a person's health, including the physical, psychological, emotional, social, spiritual and cultural. Balint was amongst the first to point out that doctors have human feelings and those feelings play an important part in the consultation. Balint's work suggested that a system based solely on biomedical diagnosis was inadequate for successful patient-clinician interaction. Balint used case discussion and feedback to enable doctors to work with a dynamic bio-psychosocial view and created a training programme to enhance the capability of clinicians for 'practical brief psychotherapy' in consultation. Balint's work provided an understanding of the emotional content of clinician-patient interactions and the clinician's pivotal role in trying to make sense of undifferentiated illness working from a wider bio-psychosocial perspective. Balint highlighted the importance of active listening and pointed out that advice and reassurance are the two most common forms of psychotherapy used by clinicians. He described the 'apostolic function': an expression of the clinician's individual way of dealing with his/her patients, and their unrealistic expectation of the patient based on their own values. Balint pointed out that avoidance of self-examination and apostolic fervour are often linked, that all clinicians have limitations and need to be aware of them. Balint, described the 'clinician as a drug', noting that no pharmacology of this important drug exists yet, no guidance whatever is contained in any textbook as to the dosage in which the clinician should prescribe himself, in what form, how frequently, what his curative and maintenance doses should be. He further noted that: there is a lack of any literature on the possible hazards of this kind of 'medication', the various 'allergic' reactions an individual may encounter and any undesirable side-effects. Balint also recognised that patients can provoke feelings in clinicians as a result of their interaction and if these are acknowledged, they can be used in the consultation dynamic to benefit the patient. A criticism of Balint's approach is that although it explores the clinician-patient relationship, it remains clinician-centred.

Berne (1964) used the framework of 'transactional analysis' to provide an overview of what is happening in the patient-clinician interaction. Berne argued that patient-clinician interactions normally take the form of 'games' where the goal of each participant in the interaction is to obtain as many 'satisfactions', gains or advantages as possible from their transactions with others. Within Berne's theory the aim of any social contact is to achieve somatic and psychic equilibrium. Berne considered that a person's body language and the quality of conversation relate to a state of mind called an 'ego state': a coherent system of feelings, related to a coherent set of behaviour patterns. Berne described three different ego states, which could be inconsistent namely: Parent or authority figure who is both critical and caring and streamlines routine decision making, conserving time and energy ; Adult who is logical, autonomous, provides an objective appraisal of reality, is essential for data processing and risk assessment and who regulates and mediates between the other two states and : Child who has relics of behaviour that was fixed in childhood and provides intuition, creativity, spontaneity and enjoyment. Berne considered that at any instant a person will be acting as one of the above, but he or she will shift through the spectrum of each ego state in time, although individuals differ in their flexibility. In the 'medical consultation model', patient-clinician interactions are conducted with a Parental clinician and a Child-like patient, but this transaction is not always in the best interests of either the patient or clinician. A co-creating health model would require changing the dynamics and asking the patient to give a more adult view of his/her needs, concerns and expectations, the child : parent interaction is transformed into a more balanced adult: adult interchange where self-management and the various treatment options can be discussed in context.

In "Doctors talking to patients" Byrne and Long (1976) analysed verbal behaviours of doctors in consultation and concluded that the doctor was 'both a product and a prisoner of his medical education' and authoritarian teaching and role-models fostered a predominance of doctor-centred behaviour. They described a spectrum ranging from a heavily doctor-dominated consultation, with any contribution from the patient excluded, to a monologue by the patient without input from the doctor. Between these extremes, they described a gradation of styles from closed information-gathering to non-directive counselling, depending on whether the doctor was more interested in

developing his own line of thought or the patient's. They considered that this did not enable doctors to deal with the psychosocial components of patients' problems, echoing Balint's findings of the 'Apostolic function' of doctors. They found that doctors seemed unable to engage with psychological disease or the psychological aspects of disease, and 'worked through a frame of reference which required both patients and illnesses to fit a pre-judged pattern . . . which has a great deal to do with the ways with which doctors learn to cope with the diagnosis of organic illness', i.e. working solely from a biomedical model. Byrne and Long (1976) commented that few doctors were able to reflect on the dynamics and process of the patient-clinician interaction. They described six phases performed by the doctor within the process of consultation :

1. Establishes a relationship with the patient.
2. Attempts to discover, or actually discovers, the reason for the patient's attendance.
3. Conducts a verbal or physical examination or both.
4. The doctor, the doctor and the patient, or the patient (in that order of probability) consider the condition.
5. The doctor, and occasionally the patient, details further treatment or further investigation.
6. The consultation is terminated, normally by the doctor.

Byrne and Long classified the fourth phase, patient-centred behaviour by the clinician as 'optional' and commented that it was relatively easy to derive these steps but much more difficult to practice them in logical sequence.

The bio psychosocial model (bps) proposed by Engel (1977) suggests that biological, psychological (thoughts, emotions, and behaviours), and social factors, all play a significant role in health and wellbeing. Engel considered that health is best understood in terms of a combination of biological, psychological, and social factors rather than purely in biological terms. This contrasts with the traditional, reductionist biomedical model of medicine that suggests every disease process can be explained in terms of an underlying deviation from normal function such as a pathogen, genetic or developmental abnormality, or injury (von Bertalanffy, 1975). There is evidence that

the bps model was employed in ancient Asian (2600 B.C.) and Greek (500 B.C.) communities, exemplified by the Latin phrase 'mens sana in corpore sano'. Similarly, traditional Chinese Medicine is based on the principle of moving 'Qi' or 'vital force' to rebalance the mind, body and spirit.

The biological component of the biopsychosocial model seeks to understand how the cause of the illness stems from the functioning of an individual's body. The psychological component of the biopsychosocial model looks for potential psychological causes for a health problem such lack of self-control, emotional turmoil, and negative thinking. The social part of the biopsychosocial model investigates how different social factors such as socioeconomic status, culture, poverty, technology, and religion can influence health. Philosophically, the biopsychosocial model states that the workings of the body can affect the mind, and the workings of the mind can affect the body (Engel, 1980). The biopsychosocial model suggests that patient perceptions of health and threat of disease, as well as barriers in a patient's social or cultural environment may influence the likelihood they will engage in health-promoting or treatment behaviours (Engel, 1988). It is known that psychosocial factors can cause a biological effect by the patient developing an internal model accepting risk factors that lead to an increased likelihood of poor health. Examples include depression that by itself may not cause liver problems, but lead to alcohol abuse, and therefore liver damage and type 2 diabetes resulting from obesity and physical inactivity.

Stott and Davis (1979) developed a theoretical framework in which they noted "The exceptional potential in each primary care consultation" and described four areas that can be systematically explored within routine patient-clinician interactions : Management of presenting problems : Modification of help-seeking behaviour : Management of continuing problems and : Opportunistic health promotion. They considered that management of presenting problems is the main activity, where the clinician seeks to define the 'reason for attendance' formulated in bio-psychosocial terms, the effect on the patient and the patient's ideas, concerns and expectations. In modification of help-seeking behaviours, patients would receive advice, information and support in managing some problems themselves. In management of continuing problems, patients gain understanding of self-management options within a long-term agenda of resource management. Opportunistic health promotion was described as

'Offering advice about diet, exercise, habits or relationships . . . to help patients make appropriate lifestyle choices'. Stott and Davis noted that this implies mutual adult respect (an 'adult to adult' interaction as defined in the Berne model, rather than a 'parent to child' one). Stott and Davis recognised that both modification of help-seeking behaviour and opportunistic health promotion are often areas which are neglected by clinicians, and suggested that they could be considered as working in a longer time frame, the end product of multiple consultations or continuity of care.

Helman's Folk Model (1981) provided a contribution of the application of anthropology to understanding health problems and their management, recognising that 'Doctors and their patients, even if they come from the same social and cultural background, view ill health in very different ways.' Helman believed that the success of the consultation depends on bridging these two positions. Helman (1981) describes the teaching in medical schools where students are encultured into an applied science by studying the phenomena of sickness and ill health. In this training, occurrences are subjected to rational objective measurement, and become facts, a 'biomedical consensus statement'. In this way, as 'all facts have a cause', the clinician's role is to discover the chain of causal events and so provide a diagnosis, prognosis and management. Where such an outcome cannot be achieved, the problem is labelled idiopathic (science underdeveloped and as yet unable to provide an explanation) or psychogenic (driven by the mind, not the body, and beyond the remit of such clinicians). The traditional biomedical model has difficulty accommodating the feelings, beliefs and psychosocial issues (as they are difficult to quantify) which inform the personal experience and bring meaning to health and illness. Helman (1981) considered that the explosion of technology has made clinicians reductionist, whilst the patient's view of being unwell is more global. Helman (1981) recognised that Illness represents the subjective response of an individual and those around them to their being unwell. In particular, Helman drew attention to the importance of the way in which the patient interprets the origin and significance of ill health, the way in which this affects behaviour and relationships with other people; and the various steps they take to remedy the situation. As the meaning that the patient gives to an experience is related to their individual social and cultural background, together with their personality, the same disease can produce a completely different effect on each

individual. Helman pointed out that the individual's response to 'illness' is part of the human repertoire of responses to adversity and as such has psychological, moral and social aspects. According to Helman (1981), 'a person is defined as being "ill" when there is agreement between his/her perceptions of impaired well-being and the perceptions of those around him/her . . . becoming ill is always a social process'. This is in sharp contrast with the narrower biomedical view. In Helman's (1981) patient-clinician interaction model, the clinician needs to acknowledge these frames of reference, and both participants must actively work to build on what they bring to the consultation to produce an integrated individualised patient-centred outcome. In Helman's (1981) view, each culture has its own language of distress, which integrates subjective experience, and social acknowledgement of ill health. The clinician must recognise the significance of verbal, non-verbal, somatic, or psychological cues within the consultation and consider the patient's story or narrative

From his model, Helman (1981) suggests that clinicians can improve their interactions with patients by adopting a number of strategies :

1. Understanding the patient's meaning of illness rather than labelling the disease with a diagnostic category.
2. Improving communication and recognising the 'language of distress' of their patients.
3. Increasing reflexivity and gaining awareness of their own viewpoint in terms of culture, values, prejudices.
4. Treating illness and disease and also the patient not just the pathology.
5. Respecting diversity
6. Reflecting on the context and the patient's internal context and the setting of the consultation itself to determine any wider influences, to consider where the balance of power lies and whether there should be any balance of power.

Helman's (1981) model promoted an holistic approach centred on the patient's narrative and emphasised lay theories of illness, which involve the individual, the natural world and their social world in contrast to purely clinical considerations.

Pendleton, Schofield, Tate and Havelock (1984, 2003) developed a framework of patient-clinician interaction, "The Consultation - An Approach to Learning and Teaching" by defining seven 'tasks' to be achieved in a consultation originating from the patient's needs and the aims of the clinician. The aim was to understand the 'problem' and so understand the reason for attendance in terms of the patient's problem and perspective through the doctor and patient having a dialogue. Within the conversation, there were seven requirements :

1. Defining reasons for the patient's attendance, including; the nature and history of problems ; their aetiology ; the patient's ideas, concerns and expectations ; effects of the problems.
2. Consideration of other 'problems, both continuing problems and risk factors.
3. The clinician choosing with the patient an appropriate action for each problem.
4. Achieving a 'shared understanding' of the problem with the patient.
5. 'Involving' the patient in the management and to encourage and enabling them to accept appropriate responsibility. Agreeing the actions and responsibilities for the doctor and patient in relation to targets, monitoring and follow-up.
6. Using time and resources appropriately (both in the consultation and in the longer term).
7. Establishing or maintaining a relationship with the patient to help achievement of the other tasks and considering other problems not yet presented, ongoing problems and risk factors.

This model moved away from the traditional patriarchal, authoritarian biomedical practice and acknowledged the importance of patients and clinicians working cooperatively to define 'problems' and their management. The Pendleton (2003) model focussed on both patient and clinician dynamics where the goal of the consultation was not only to identify and meet patients' needs, but also to empower

them by enhancing their understanding and ability to manage their own health. In this model, each consultation reinforced a 'cycle of care' where clinicians were encouraged to assess their own style of interaction and develop insight into their feelings, attitudes, strengths and weaknesses. This enabled clinicians to be more aware of their emotional state, health, availability of time and organisational issues which can influence clinicians positively or negatively towards a patient's issues. The Pendleton model gives opportunities for clinicians to have better job satisfaction.

Apart from defining the components of a successful patient-clinician interaction, this approach encourages clinicians to consider a person-centred partnership model.

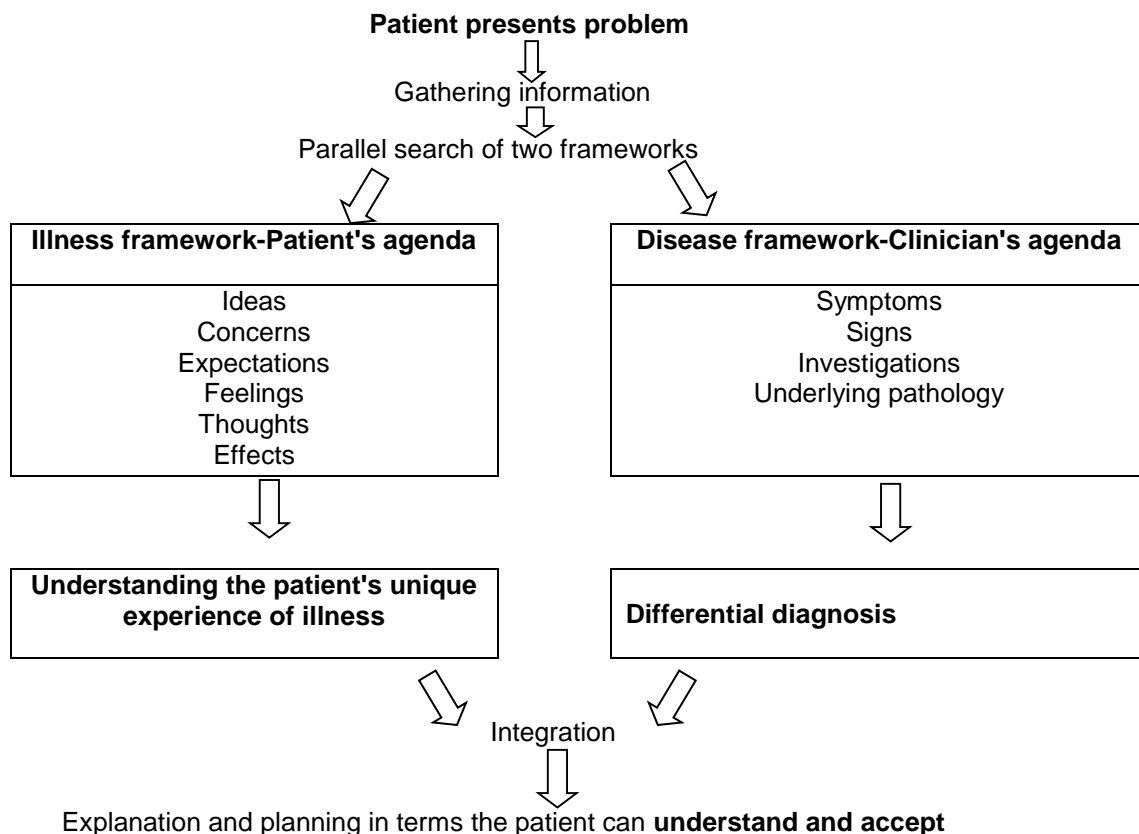
Neighbour (1987) developed a pragmatic holistic five stage model that defined checkpoints: "where shall we make for next and how shall we get there?" and examined what occurs within the consultation and the clinician behaviours that impact on this :

1. Connecting, that is establishing rapport and getting on the same wavelength as the patient.
2. Summarising, to help the clinician decide if they know why the patient has come, including the reason for attending as well as the patient's ideas and concerns regarding their 'problem' and their expectations of how they expect the clinician to help.
3. Handing over, by sharing information and determining if the patient has understood and accepted the management plan proposed by the clinician. This follows assessment of the problem and formulation of a diagnosis or problem list then negotiated and agreed a management plan.
4. Safety netting, that is have all the likely outcomes been anticipated and discussed, have probabilities been examined and risks considered. This phase also included the organisation of an appropriate time for follow-up.
5. Housekeeping, where the clinician reflects on whether they are in good condition for the next patient. This includes an assessment of their own stress levels, whether they are able to be receptive to the next patient and in a position to offer 'a caring and compassionate state of mind 'uncontaminated' with personal preoccupations'.

Neighbour (1987) understood that every clinician needs to be psychologically 'fit' for the next patient interaction and not transfer feelings from the previous one. Neighbour's model emphasises the importance of building clinician's skills to achieve desired anticipated outcomes for patients, preparing themselves in advance and then using their inspiration, trusting their own intuitive and unconscious processes to function appropriately and automatically. Neighbour's model provided a basis for understanding the dynamics of the patient-clinician interaction and the resultant internal dynamics of the clinician. Neighbour also emphasised the importance of the clinician identifying non-verbal cues from patients that can be used to identify the patient's 'hidden agenda' or unspoken main reason for attending.

In "The Disease - Illness Model", shown in Figure 2.1 below, McWhinney (1984) proposed a "transformed clinical method" of "patient-centred clinical interviewing".

Figure 2.1 "The Disease - Illness Model"



Reference : McWhinney (1984)

This is clearly differentiated from the traditional "clinician-centred" method that attempts to interpret the patient's illness only from the clinician's perspective of disease and pathology. The disease-illness model attempts to provide a practical way of using these ideas in everyday clinical practice.

Cohen-Cole (1991) developed "The Three Function Approach to the Medical Interview" that was adopted by The American Academy as their model (in Table 2.1, below) for teaching the Medical Interview : (1) Gathering data to understand the patient's problems : (2) Developing rapport and responding to patient's emotion and ; (3) Patient education and motivation.

Table 2.1 : The Three Function Approach to the Medical Interview

| | Functions | Skills |
|---|--------------------------|---|
| 1 | Gathering data | (a) Open-ended questions (b) Open to closed cone (c) Facilitation (d) Checking (e) Survey of problems (f) Negotiate priorities (g) Clarification and direction (h) Summarising (i) Elicit patient's expectations (j) Elicit patient's ideas about aetiology (k) Elicit impact of illness on patient's quality of life |
| 2 | Developing rapport | (a) Reflection (b) Legitimation (c) Support (d) Partnership (e) Respect |
| 3 | Education and motivation | (a) Education about illness (b) Negotiation and maintenance of a treatment plan (c) Motivation of non-adherent patients |

Reference : Cohen-Cole (1991)

Emmanuel and Emmanuel (1992) described four models to describe patient-clinician interactions : paternalistic, informative, interpretive, and deliberative. Each of these is set out in Table 2.2 below together with its relevance to the patient plan :

Table 2.2 : Patient-Clinician interactions

| Model | Patient values | Physician's duty | Concept of patient autonomy | Concept of physician's role |
|----------------------|--|---|---|------------------------------------|
| Paternalistic | Objective, shared by physician and patient | Promote patient's well-being regardless of patient's current preferences | Assenting to objective values | Guardian |
| Informative | Fixed and known to patient | Provide factual information | Choice of, control over medical care | Competent technical expert |
| Interpretive | Vague, conflicting, requires elucidation | Provide factual information and help to elicit and interpret patient's values | Self-understanding relevant to medical care | Counsellor or adviser |
| Deliberative | Open to development and revision thru dialogue | Provide information, elicit and interpret values, articulate and persuade re: most admirable values | Moral self-development relevant to medical care | Friend or teacher |

Reference : Emmanuel and Emmanuel (1992)

Stewart and co-workers (1995, 2003) developed a `patient-centred clinical method after McWhinney (1984) drew attention to the fact that patients' problems had both breadth (bio-psychosocial elements) and depth (personal meaning). There are six components to this patient-centred and cooperative model where the third component is central to the six components of clinician-patient interactions :

1. Exploring both the disease and the illness experience including history, physical, laboratory tests, dimensions of illness (feelings, ideas, effects on function and expectations).
2. Understanding the whole person by exploring life history, personal and developmental issues, the proximal context such as family, employment, social support and the distal context for example culture, community, ecosystem.

3. Finding common ground by examining problems and priorities, goals of treatment and/or management and roles of the patient and clinician.
4. Incorporating prevention and health promotion within the interaction by discussing health enhancement, risk avoidance, risk reduction, early identification of potential health risks and complication reduction.
5. Enhancing the clinician-patient relationship by considering compassion, power, healing, self-awareness, transference and counter-transference.
6. Being realistic by optimising time and timing teambuilding and teamwork and wise stewardship of resources.

This patient-centred method was designed to address both the patient's agenda and experience of illness and the clinician's bio-diagnostic agenda and has been influential in education and research. The patient-centred clinical method requires that the clinician elicit and work through the patient's agenda and also be aware and careful of their own agenda and how this can influence the outcome of the consultation. The model shares common features with the contemporaneous Pendleton (2003) and the Calgary and Cambridge (1996) frameworks. Stewart and co-workers also highlighted the need to determine why the patient was presenting at that time. Kurtz and Silverman (1996) set out the Calgary and Cambridge observation guide to the 'Medical Interview' to structure the teaching and learning of communication skills with an emphasis on developing core communication skills, which then form a foundation for addressing attitudes and issues encountered in practice. Riccardi and Kurtz (1983) noted that accuracy, efficiency and supportiveness were goals that clinicians attempt to achieve in consultations and identified generic principles for good communication including importance placed on interactions, reduction of uncertainty, identifying planned outcomes, recognition of the dynamics of the consultation itself and mutual interaction of the individuals involved. The Calgary and Cambridge method is based on 'a patient-centred approach that promotes a collaborative partnership'. Its proponents saw a need to move away from medical paternalism and concentrate on what clinicians can do within the interaction to facilitate their patients' involvement'. The Calgary and Cambridge framework has five main tasks and seventy individual skills. The main tasks are:

1. Initiating the session: establishing initial rapport and identifying the reason(s) for the consultation.
2. Gathering information: exploration of problems including active listening, facilitation, and open questioning ; understanding the patient's perspective, covering ideas, concerns, expectations and effects on the patient's life and ; providing structure to the consultation such as summarising, sequencing, sign-posting and timing).
3. Building the relationship: developing rapport with the patient by displaying empathy, support and sensitivity.
4. Explanation and planning: such as providing the correct amount and type of information, aiding accurate recall and understanding ; achieving a shared understanding incorporating the patient's perspective. Planning would include shared decision making, discussing opinion and significance of problems, negotiating a mutually agreed plan of action and discussing investigations and procedures.
5. Closing the session: including summarizing, contracting and `safety netting'

This approach builds on other patient-centred models with each skill discussed in terms of the evidence supporting it, and describes a variety of methods by which the goal of an effective consultation may be achieved. The model requires the what ?, why ?, and how ? Questions inherent in patient-clinician interactions to be explored and answered.

In the 'care aims model', Malcomess (2005) set out a means of defining the purpose of intervention of health care. The care aims model uses seven labels to guide the planning, delivery and outcome measurement of care which clarify and make explicit the purpose of each episode of care undertaken with a patient. The care aims are defined as : Prevention, to decrease the risk of future harm, and/or preventing any anticipated difficulties, complications or impacts ; Stabilisation, to stabilise functional ability or slow down the deterioration or loss of function ; Participation, to support the patient to participate more in their activities of daily living ; Resolution, to support the patient in developing wellbeing, problem solving skills to become curative ; Improvement, to support the patient to increase their skills and improve their condition

towards rehabilitation ; Adjustment, to support the patient to gain acceptance of their condition and the impact of this on their life as a result of a change in feelings, attitudes or insight ; Comfort, to support the patient in achieving reduced pain or discomfort whilst acknowledging that their condition or overall impact of these hasn't changed. The care aims model has been shown to change the way therapists work, clarifying patient expectations and clinician responsibilities (McCarthy et al, 2010).

Effective clinical practice requires narrative competence, that is the ability to acknowledge, absorb, interpret, and act on the stories and issues faced by others. Working with the patient's narrative is implicit in patient-centred approaches. 'Taking a history' starts with actively listening to the patient's story, and understanding its personal meaning. Agreeing on the management of the problem involves exploring the patient's ideas, concerns and expectations. Reassurance, advice and counselling can only be effective if they are framed from the patient's narrative. Launer (1999) highlights 'a tension between the complex narrative that a patient brings into the consulting room and a clinician's understanding of what is really going on as formulated in a diagnosis or an idea about pathology'. A patient's narrative describes their personal experience of being unwell and understanding this narrative can help clinicians to approach patient's problems holistically, and point the way to solutions. To understand and accept a patient's moral choices, a clinician needs to acknowledge that the illness narrative has several potential interpretations depending on perspective but that the patient is the ultimate author of their own text. Narrative is fundamental as it 'deals with experiences, not with propositions'. Sampson et al (2013) had shown that a patient's sense of enablement increases with a longer consultation time, continuity of care and getting appropriate treatment when required. The categorisation of clinicians as 'high' or 'low' enablers has been found to be strongly correlated with their ability to demonstrate empathy. An empathetic clinician can empower the patient and enable them to 'move on' from their problem productively.

Paget et al (2011) considered that good health care is predicated on a strong patient-clinician partnership 'in which the insights of both parties are drawn upon to guide delivery of the best care, tailored to individual circumstance'. They considered effective communication between patient and clinician to be important in establishing this partnership. To this end, they set out the basic principles and expectations for patient-

clinician communication to be mutual respect, harmonized goals, a supportive environment, appropriate decision partners, the right information, full disclosure, and continuous learning. Drawing from these principles, the basic individual and mutual expectations of both patients and their clinicians were considered to be :

- Mutual respect, for the special insights that each brings to solving the problem at hand where each patient and clinician engage as full decision-making partners. The clinician is asked to enhance healthcare decision making through the exchange of information and by supporting the development of a partnership relationship based on trust and focused on the whole patient. This includes considering psychosocial needs, identifying and playing to the patient's strengths, and building on past experience to meet immediate need and anticipate future concerns. The clinician would determine the patients' ideas, preferences, and values; living and economic contexts that may affect health or decision making; the basis and evidence for alternative choices and recommendations; and uncertainties related to the proposed course of action.
- Harmonised goals to achieve a common understanding of and agreement on the care plan with shared understanding of options and the associated risks, benefits, and costs, as well as patient preferences and expectations. Explicit within this would be an explicit determination of the shared agenda and goals. The clinician would take into consideration patient's health, lifestyle, and economic preferences and accommodate language or cultural differences and level of health literacy.
- A supportive environment paying attention to patient culture, skills, convenience, information, costs, and implementation, ensuring the ability of the patient and clinician to speak openly about sensitive issues.
- Appropriate decision partners to ensure that the patient has access to clinicians with appropriate skills, that alternative clinician opinions are considered and that there is good among all relevant clinicians. This emphasised the importance of understanding by both patient and clinician in arriving at the most appropriate

decision. In particular, understanding of patient options : how specific they are to individual circumstances; the risks, benefits, and costs; and the need for review.

- The right information, sharing relevant information as the basis for shared decision making, clinicians providing evidence concerning risks, benefits, value, and costs of alternative options. It was emphasised that all options should be discussed to bring out patient preferences, goals, and concerns and to explicitly consider the impact of various options on these. The clinician should encourage patients to share their perceptions, symptoms, and personal practices that may have affect the condition and its management.
- Transparency and full disclosure to ensure the patient understands the limits in practise and system that may affect the range of options or the effectiveness of their delivery. Similarly clinicians are encouraged to support patient openness on all relevant circumstances, preferences, medical history. To allow the most appropriate care to be identified.
- Continuous learning that Identifies and implements a system of feedback between patients and clinicians on status, progress, and challenges in the development of a learning relationship that is flexible and adaptable to changing situations.

Paget and colleagues (2011) considered that implementation of these principles should be tailored to need and circumstance. Such contexts would include the reason for the interaction such as prevention, chronic condition management or whether there was an acute or urgent episode. Similarly taken into account should be the number of decisions to be made during the interaction, certainty, uncertainty, and relevance to the available evidence, decisions related to a preference-sensitive arena or choice and access to and use of sources of information such as the Internet. It was also considered important to modify the interaction dependent on patient characteristics such as level of physical or mental capability, communication capacity including language, literacy/numeracy, speech disorder and receptiveness to engagement.

2.2.3 Relational Practise

In considering relational practise, Wensing et al (1998) demonstrated that the most important patient priorities within their interaction with clinicians are ; humaneness ; competence/accuracy ; patient's involvement in decisions and ; time to care. As older people become increasingly frail, they place particular importance on the nature of their interaction with their clinician. The concept of clinicians building a relationship as equal partners with patients, treating, managing and preventing disease has been encapsulated by Delbanco et al (2001) as 'Nothing about me without me'. Increasingly, healthcare organisations require clinicians to focus on improving interactions and relationships with patients, their families and carers Brady and Frampton (2009) suggested 'The change in human interactions that is the core of the patient-centred approach requires a monumental shift in attitudes'. Berwick (2009) has described person-centred care as 'the experience of transparency, individualization, recognition, respect, dignity, and choice in all matters, without exception, related to one's person, circumstances and relationships in health care'. Whilst Coulter (2011) suggested that 'person-centred patient-clinician interaction is, responsive to physical, emotional and social needs and interactions that are informative, empathetic and empowering with both parties' values and preferences taken into account'. Coulter (2011) points out that there are key themes that emerge when patients are asked about their priorities including ; security of knowing that services will be available when needed ; that their views and preferences will be taken into account ; that they will be supported to help themselves and ; that they can access reliable information about their condition and treatment options. In a synthesis of the literature, Coulter (2011) described the key components of person-centred care as : Good communication, emotional support and empathy ; Provision of reliable and comprehensible information ; Involvement in decisions about treatment and care ; Education and support for self-care ; Personalisation of services, coordination and continuity ; Attention to physical comfort and pain relief ; Attention to privacy, confidentiality and dignity ; Involvement of family and friends and ; Fast access to appropriate help and advice when needed

There is growing evidence that person-centred care leads to better outcomes including patients more likely to trust clinicians (Keating et al, 2002), patients sustaining agreed

treatment plans (Haynes et al, 2008) and less likely to die following acute illness (Meterko et al, 2008). Most patients would like their clinicians to provide them with more information about their condition and treatment choices and would like a partnership approach in their interaction with clinicians (Grol et al, 2000). This is particularly important where there is more than one reasonable course of action, when patients need to understand risks, benefits, outcomes from making these 'preference-sensitive' decisions (O'Connor et al, 2009). Current evidence demonstrates that very few patients making serious 'preference-sensitive' decisions are fully informed (Fagerlin et al, (2010), Zikmund-Fisher et al, 2010).

Alexander and colleagues (2012) considered patient-clinician role relationships as a complex, multidimensional construct. Their analysis described four dimensions of this relationship:

- quality of the interpersonal exchange between the patient and clinician,
- fair and respectful treatment of the patient by clinicians,
- involvement of the patient in treatment goal setting, and
- frequency of clinician communication with the patient outside of the visit.

Interpersonal Exchange is related to the extent to which clinicians actively solicit and listen carefully to patients' concerns, preferences, and questions, and effectively address these needs (e.g., explain things clearly), establishing a supportive context for patients to shift from the traditional passive role to one where they participate more actively in their health and health care (Blanquicett et al. 2007; Berry et al. 2008). High-quality clinician communication skills such as listening, coaching, questioning, and explaining have been linked to higher levels of patient compliance with treatment plans, improved self-management of disease, greater recall of important treatment information, and improved mental and physical health status (Ratanawongsa et al. 2008).

The literature suggests that a cocreating health framework may be particularly suited to the context of clinicians supporting patients with long term conditions. People with long term conditions have the greatest healthcare needs of the population using 50% of all GP appointments and 70% of all hospital bed days and their treatment and care

absorbs 70% of acute and primary care funding. It is clear that current models of managing long term conditions are unsustainable as more people have multiple chronic conditions. Current systems can fail to provide integrated care for patients with chronic conditions and are characterised by :

- Services dealing with single conditions only with corresponding risks from polypharmacy.
- Lack of care coordination resulting in people being unaware of whom to approach when they have a problem.
- A lack of integration between physical health and mental health services for the 50% of people with long term conditions who have both.
- Fragmented care with a lack of integration between healthcare and social care or other social determinants of health. and failure to work in partnership with third and voluntary sectors.
- Lack of informational continuity with care records which can't be accessed between settings, or to which patients themselves don't have access.
- Services that are reactive failing to identify vulnerable people who might require additional support to prevent exacerbation
- Services which treat people as passive recipients of care rather than supporting self-care.

These concerns led to the development of the House of Care model that requires informational continuity by which people have access to information about their conditions and how to access services and for clinicians to have the right information and records needed to provide the right care at the right time. It also requires management continuity, that is a coherent approach to the management of a patient's condition and care spanning different services, achieved through people and providers collaborating in drawing up collaborative care plans. Lastly it needs relational continuity in there being a consistent relationship between a person, family, and carers and one or more clinicians over time, so that people are able to turn to known individuals to coordinate their care.

2.3 Existing Approaches to Cocreating Health

The Health Foundation (2008) developed a Co-creating Health program based on Wagner’s (1998) Chronic Care Model. The Chronic Care Model (Figure 2.2) draws on knowledge of the significant difference to patients’ health outcomes made by the way in which clinical teams interact with patients. The Health Foundation considered that there are two critically important aspects of clinician-patient interactions in that : “they should be characterised by collaboration and partnership” ; and “they need to be structured around explicit, evidence-based processes that help patients to self-manage their condition effectively”.

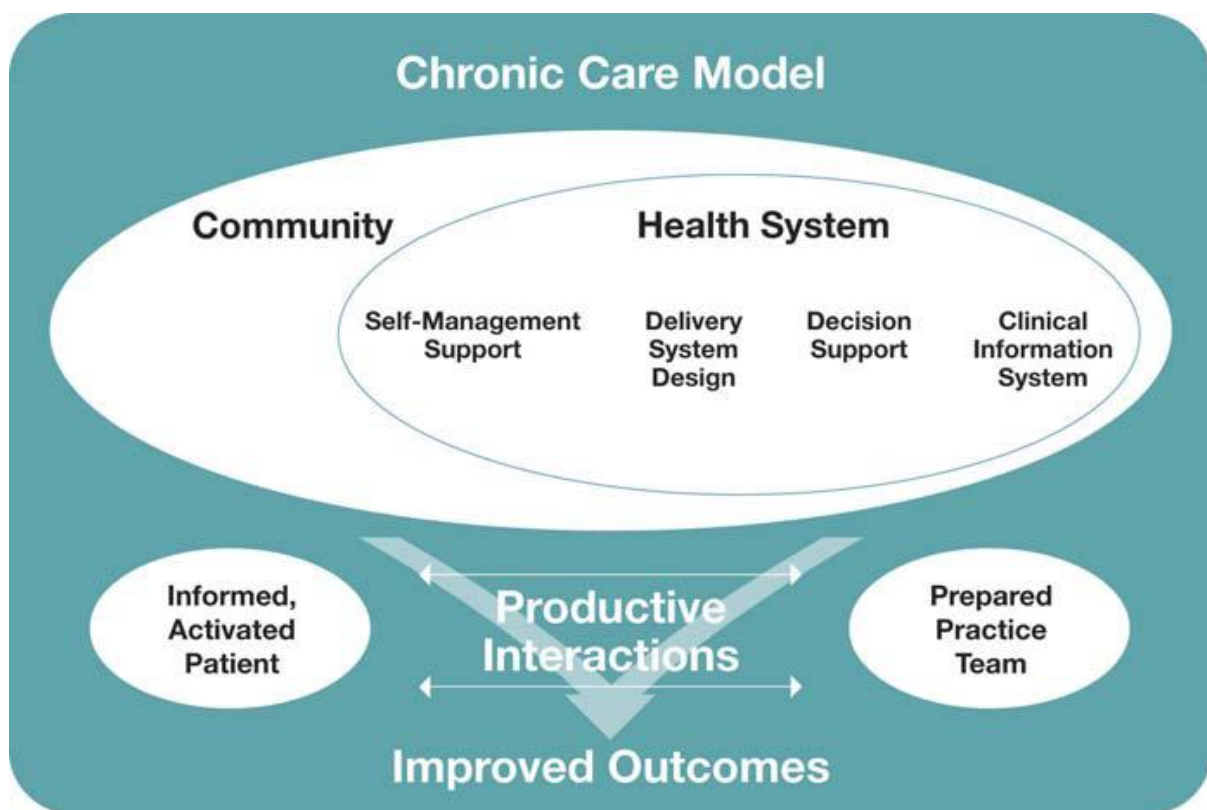


Figure 2.2 : Wagner’s Chronic Care Model

The Health Foundation’s “Co-creating Health” programme has the aim of “enabling clinicians and patients to make their interactions as productive as possible”. The programme aimed to transform patient-clinician interaction through the integration of three integrated support programmes. These were enhancing clinicians’ communication and shared decision making skills, improving the ability of people to self-manage their long term conditions, and increasing the effectiveness of health service organisations in supporting people to take a more active role in managing their

health. The programme provided training, the advanced development programme for clinicians in the development of collaboration and on building the required enablers such as joint agenda setting; goal-setting and goal follow-up. The agenda setting element recognised the importance of clinicians and patients jointly agreeing the aims of each interaction. It was acknowledged that when joint agenda setting does not happen effectively, patient satisfaction is low and they are less likely to become 'active patients' and may not comply with treatment advice, make lifestyle changes and may be lost to follow up. The work of the Health Foundation demonstrated that by first establishing the patient's perspective, clinicians can understand and work with the patient's own motivations and interests, improving both patient experience and clinical outcome. There is strong evidence that patients with a chronic condition most effectively make health-improving changes by choosing their own achievable goals. For patients with chronic conditions, achieving their own goals is the first step towards increasing their self-efficacy by improving self-management skills and developing confidence in their ability to improve their own health.

The Health Foundation reported a number of learnings from delivering the ADP (Health Foundation, 2012). These included that time and effort is needed to encourage clinicians to change, to teach and share skills, and to sustain change over time. It was found that it was essential to support clinical champions who had attended the ADP and changed their own practise to promote the value and feasibility of self-management support. Impact of the ADP was greater when whole teams were engaged and these supported each other within a shared aim. Maintaining the core content whilst adapting training to meet local needs was found to be important in engaging clinicians. Following initial training, coaching support, action learning sets and visual prompts were required for clinicians to implement and maintain their skills. Lastly, it found that clinicians are more likely to test changes in their practise if there is minimal administration required and tools are available.

An independent review of the cocreating health programme undertaken by Wallace and co-workers (2012) reported "limited evidence that clinicians who attended the ADP increased their reported use of a wide range of practices in self-management support". This review demonstrated a significant difference in application of self-management skills following the ADP amongst different professional groups with. doctors starting

with the lowest use of clinical self-management skills before training and making proportionately the biggest gains. Clinicians who were allied health professionals and psychologists were more likely to report practicing self-management support and the use of the enablers particularly goal follow-up after completing the ADP. Nurses were more likely to use them than doctors. Wallace and colleagues found that clinicians who had previously attended similar training to the ADP, those who worked more frequently with patients with long term conditions, and those who were more confident and valued self-management support, demonstrated greatest change in practise after attending the ADP. The work of Wallace and colleagues (2012) also found that clinicians who had autonomy with peer and leadership support were more likely to provide self-management support to patients following training. They concluded that training for clinicians in learning, developing and maintaining agenda setting, goal setting and goal follow up should target motivation and the factors that support motivation, such as working with colleagues who value the same skills, support autonomous practise and build confidence through feedback from colleagues and patients.

In the preface to the report by Wallace and colleagues, the Health Foundation commented on the challenges to changing the model of professional practise, from one where the clinician is the expert advisor to one where their role is to cocreate health. The commentary acknowledged the limitations of training and clinicians concerns about risk and patient safety affecting their ability and willingness to adopt self-management support and other patient-centred practices

2.4 Rationale for Developing a Cocreating Health Framework

Development of an appropriate cocreating health framework to support patient-clinician interaction may clarify for both what is important, increase understanding of the complex determinants of good health, and provide a framework for action. The WHO definition of good health is 'a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity'. The literature review above suggests that in cocreating health, both parties must be appropriately prepared for the interaction, having considered the information to hand and being prepared emotionally. For patients this means having completed all the appropriate

documentation, having considered their narrative and as best they can, being prepared to take responsibility for management of their own condition and having an appropriate level of health literacy to be able to understand their condition. For clinicians, this means providing patients with information prior to the interaction and clearing their mind of the psychological remains of the previous patient interaction to ensure it has no detrimental effect on the next, to be non-judgemental and without prejudice.

The literature demonstrates that good communication between patients and clinicians is fundamental to success of the interaction. Both will need to establish a rapport and develop an appropriate ongoing relationship towards meeting an agreed agenda. Both patients and clinicians need to feel comfortable to ask each other open, leading and closed questions, to demonstrate active listening by the use of appropriate open body language and verbal/non-verbal prompts with good eye contact is essential. Summarising each other's points helps demonstrate active listening and aids clarity in understanding the agreed way forward. Clinicians and patients cocreating health require empathy towards the other's position and in particular a shared language. Traditional models use alienating medical terminology which can frustrate and confuse patients. Within cocreating health, jargon is avoided and explanations given in language the patient understands with sensitivity to the amount and kinds of words used with people with different intellectual capacities. Cocreating health requires sharing information between both parties, respecting that the patient through their experience is the 'expert' in their own lives, attitudes to risk and the clinician has technical expertise, knowledge of health, clinical practise and of navigating through complex health systems.

A number of authors demonstrated that, within the agreed way forward, it is important for there to be an agreement around when patients should come back for further discussion of results or if their illness has not improved. This provides peace of mind for both parties, not least the clinician, especially where uncertainty is involved. The process of agreeing appropriate and realistic further interactions allows both parties to monitor progress over time which is very helpful in determining causes of symptoms and deciding on the way forward.

A cocreating health framework might support clinicians to measure success from the patient perspective using patient defined outcomes. It could prompt clinicians to assess the level of patient engagement using the patient activation measure and assigning them to a category of activation. It is known that patients at low activation can feel overwhelmed, have low confidence in their self-management, undertake a passive role and have limited problem solving skills leading to repeated experience of failing of management of their condition. Conversely, patients at high activation demonstrate improved clinical outcomes, improved quality of life, and reduced use of healthcare resources. However, a human conversation supported by the cocreating health framework results in demand driven by outcomes that patients value. A cocreating health framework could help clinicians support people to develop knowledge skills and confidence to manage their health conditions. With current 'medical consultation' models at least 40 per cent of the population have low or no self-confidence to self-manage their condition and believe that their health is a problem for the system, not themselves whilst another 30 per cent have little confidence to self-manage. Low ability to self-manage is highly correlated with poor outcomes.

2.5 Conclusion

In starting this work, a review was completed of the literature concerning patient-clinician interaction models only. The traditional 'medical consultation' model is well known, taught in medical, nursing and healthcare professional schools and understood by patients. The literature reviewed above shows development of a number of holistic patient-centred and partnership models of patient-clinician interaction within the 'consultation'. Early medical models were paternalistic, based around the hierarchical thinking of Maslow and concentrating on the bio-physical aspects of safety and physiological needs. Following on from this, the need for clinicians to consider patients' psycho-social needs was identified in models such as those of Engel (1977). Relational practise requires clinicians to be empathic, having the ability to 'put themselves in the patient's place and act with a blend of understanding and caring, demonstrated to the patient in actions and words. The rationale is that when patients recognise and respond to empathy, this will improve satisfaction, diagnostic accuracy and outcomes. In particular, the model proposed by Paget et al (2011) contains much

of the thinking of earlier models on developing partnership set out by Helman (1981), Neighbour (1987) and Pendleton (2003) whilst not incorporating the thinking of the biopsychosocial model of Engel (1980), Max-Neef (1989) on human needs or Conway and White (2006) who first considered cocreating health. For clinicians trained in the medical model with its application of objectivity and having an internal model of professional detachment, difficulties might be anticipated in moving towards empathic behaviours in a different clinical framework that engages emotion. However, from the viewpoint of a reflective practitioner and as an executive leader, the researcher understood that the literature demonstrated a gap between clinical interaction models defined in the literature and an understood policy need for clinicians to work in coproduction with patients. This study aimed to close that gap. This literature review framed the research aims of this doctoral thesis, to develop a cocreating health framework and to understand the issues in its implementation.

Having collected and analysed data in the first data collection phase from workshop participants and then interviewees, a further literature review was completed to examine the literature arising from themes and insights identified. These themes included aspects of cocreating health. The first two stages in literature review, when combined with insights from workshop participants allowed the construction of an initial cocreating health framework for testing. Following semi-structured interviews, a final literature review was completed to examine specific elements of the final cocreating health framework and to inform discussion and conclusion. This placed the findings of the research back into the context of existing literature.

A synthesis of the three parts of the review of the literature has demonstrated that in developing a cocreating health model of patient-clinician interaction an understanding and application of a number of theoretical and practical constructs is key. In particular, the cocreating health model of patient-clinician interaction model incorporates key learning from the literature around relationship-centred practise.

Chapter Three : Research Design and Methodology

3.1 Introduction

This study aimed to determine how to engage clinicians in cocreating health by developing a framework for cocreating health to support the patient-clinician interaction and to identify the factors in its successful implementation in health services. Although some elements of cocreating health are implemented by some clinicians in their interactions with patients, this is currently carried out within the context of the 'medical model'. Implementation of a number of cocreating health elements within a framework is novel. This chapter begins with a description of the aims and objectives of the study. The research design arose from understanding the literature, the gap in the literature and continuous evaluation of insights through a first phase of interaction with participants. It was considered that using principles of grounded theory methodology would be appropriate since cocreating health is an emerging concept, there was no evidence of cocreating health elements implemented outside the 'medical model' in the literature and it was considered that a model of implementation might emerge from the data. Grounded theory was understood to be a method that facilitates understanding and explanation, especially when there is a paucity of research in an area. It was considered to be a comprehensive methodology holding value and applicability to this research design (Glaser, 1998). It was felt appropriate to apply principles of grounded theory in this research since it is known to be inductive, developmental, representing the views of the participants relative to a substantive area of interest and results in a systematic set of conceptual hypotheses from data area (Glaser, 1992). The intention was that any resulting substantive theory would be action oriented, providing a conceptual framework to create systemic change centred on cocreating health (Glaser, 1992).

This study does not use classic grounded theory design but instead takes the interpretivist approach described by Charmaz (2006) in using a set of grounded theory guidelines that provide the framework and approach to discover a theory. Charmaz (2006) suggested the adoption and adaptation of the guidelines in order to fit diverse research needs, approaches, and assumptions; "My approach explicitly assumes that

any theoretical rendering offers an interpretive portrayal of the studied world, not an exact picture of it”.

At the outset, an interpretivist research paradigm (Cicourel (1964), Garfinkel (1967)) was chosen to reflect the cocreative nature of the study. This was based on a relativist ontology, which assumed that reality is constructed through the meanings and understandings developed socially and experientially and a subjectivist epistemology that assumes that we cannot separate ourselves from what we know. The consequences of this were an intention that findings would emerge as the research proceeded through dialogue in which conflicting interpretations were negotiated among stakeholders. In carrying this out, it was important to ensure an open dialogue with participants and stakeholders to develop a well informed and sophisticated understanding of cocreating health. It was understood that all interpretations for this research were located in a particular context or situation and time, and are open to re-interpretation and negotiation through conversation. Using an interpretive approach, the study relies heavily on naturalistic methods such as workshops, interviewing participants and analysis of the existing literature to ensure strong adequate dialog that allows cocreation of a meaningful reality. In this way it was intended that meanings were emergent from the research process. It was understood that interpretivist positions are founded on the theoretical belief that reality is socially constructed and fluid with knowledge negotiated within cultures, social settings, and relationship with other people. In designing the study, the advice of Angen (2000) was taken in that : there was careful consideration and articulation of the research question ; conversations with participants were carried out in a respectful manner ; the researcher attempted to develop awareness and articulation of the choices and interpretations made during the research and evidenced taking responsibility for those choices ; it was intended to develop a written account containing persuasive arguments ; results were widely disseminated and ; there was careful consideration given to both ethical validity and substantive validity.

In the first phase of the work, carried out between October 2012 and October 2013, the principles within cocreating health arising from the literature were discussed by this researcher, widely across Wales in a series of thirty two workshops and meetings.

A number of concepts emerged and were discussed in a number of forums including meetings of the Executives of NHS Wales, the wider public sector in Wales at the PSMW Summer school, local meetings of clinicians, leaders and managers within ABMU Health Board, statutory advisory groups including Welsh Therapies Advisory Committee and Welsh Scientific Advisory Committee, professional body meetings and in individual discussion with opinion leaders of the NHS in Wales. Following these discussions, an initial test construct was developed to describe the elements of a 'cocreating health' framework. The initial test framework was modified following input from expert peer feedback and from dissemination in a 1000 Lives 'how to guide' published in November 2013. The cocreating health framework was continuously revised following this feedback and a version developed for testing in this research was completed in December 2013.

Initial discussion and literature review had identified clinician perception of their role as key to changing from a 'medical' consultation model of interaction to a cocreating health interaction. Between September 2011 and July 2014, training courses in self-management support were provided to clinicians of all professions within a South Wales Health Board. This training was set up with the aim of training clinicians in supporting patients to develop self-management skills. Questionnaire data from participants was gained from October 2013 to February 2014 to explore clinician's attitudes towards supporting patients to become engaged in their own healthcare and how clinician's knowledge and attitudes had developed following the training. In addition, a questionnaire was developed to determine the extent to which clinicians currently employ elements of cocreating health within their practise. Questionnaire data was obtained from one hundred and sixty four respondents.

Information from both the action research in developing the test framework and insights from questionnaire data were used to develop the initial questions for individual semi-structured interviews and the initial coding framework for subsequent qualitative analysis.

In the second phase of data collection, individual semi-structured interviews were carried out with thirty one participants between January and July 2014. Insights gained from workshop participants were that there were different perspectives on clinician-patient interaction from Medical, Nursing and Allied Health Professional

Groups. Similarly, there were different perspectives from clinicians within these professional groups and managers working at policy, leadership or clinical levels. To investigate these different perspectives, semi-structured interviews were undertaken from clinicians in these three different clinical groups and from different levels of policy makers, senior leaders and clinicians. Interviewees included policy makers within Welsh Government, Professional leads, Independent policy advisors, Clinical leaders, Clinical Executive Directors, officials of professional bodies, chairs of advisory committees, heads of professions and individual practitioners within Welsh Health Boards. A summary of the different phases of the research with characteristics of the samples are described in Table 3.1 below :

In selecting interviewees, care was taken to obtain a balanced sample within the constraints of an appropriate sample size. That is, three different clinical groups with three different levels gives nine possible characteristics of interviewee. These are shown in Table 3.2 below. Three individuals within each clinical group and level gave an intended sample of 27 interviewees. An additional four interviewees were selected to ensure that perspectives from clinicians within both primary care and secondary care were obtained. This was facilitated by the integrated nature of Health Boards in Wales with responsibility for delivering services across Primary and Secondary care. To ensure the views of primary care doctors were captured, four of the doctors selected had recent experience in general practice and three others had experience delivering services in primary care settings.

Table 3.1 : Sample Characteristics

| | Description | Sample | Dates | Outcome |
|--------------|--|--|-------------------------------|---|
| First Phase | Thirty two Workshops comprising community health council, summer school, Welsh government advisory committees, National meetings and conferences, clinician workshops, National meetings of NHS Wales Executives, National Improvement workshops, Local GP Committees, National medical Committees | Insights from Over five hundred participants from Welsh Government, Local Authorities, NHS Wales Executive Directors, Clinical leaders, policy leaders, improvement specialists, clinicians in primary and secondary care, patient groups, voluntary groups, Welsh LHB groups | October 2012 to October 2013 | Draft Cocreating Health Framework Produced |
| | Seven Cohorts of Training in elements of Cocreating Health | Questionnaire data from one hundred and sixty four clinicians with roles as secondary care consultants, general practitioners, ward nurses, practice nurses, clinical nurse specialists, audiologists, dietitians, physiotherapists, occupational therapists, orthoptists, podiatrists, speech and language therapists | October 2013 to February 2014 | Exploration of clinician attitudes towards cocreating health |
| Second Phase | Thirty one semi-structured interviews | Nine doctors, nine nurses, and fourteen allied health professionals from levels of policy, leadership and clinician | January 2014 to July 2014 | Refinement of Cocreating Health Framework, Determining Implementation factors, developing grounded theory model |

Table 3.2 : Interviewees selected for semi-structured interview

| | Policy Maker | Leader | Clinician |
|----------------------------|--|---|---|
| Doctor | <p>Medical Policy Advisor to Welsh Government (Secondary Care Background)</p> <p>Public Health Advisor to Welsh Government (Primary Care Background)</p> <p>Medical Policy Advisor to Welsh Government (Primary Care Background)</p> | <p>Medical Director of Health Board (Secondary Care Background)</p> <p>Deputy Medical Director of Health Board (Primary Care Background)</p> <p>Clinical Director (Primary and Secondary Mental Health Care)</p> | <p>Consultant Clinician in Gynaecology (Secondary Care Background)</p> <p>General Practitioner</p> <p>Consultant Psychiatrist (Primary and Secondary Care Background)</p> |
| Nurse | <p>Nursing Policy Advisor to Welsh Government (Primary, Secondary Care and Academic Background)</p> <p>Nursing Policy Advisor to Welsh Government (Primary Care and Academic Background)</p> | <p>Director of Nursing of Health Board (Primary Care Background)</p> <p>Clinical Director of Health Board (Primary Care Background)</p> <p>Improvement Advisor (Secondary Care Background)</p> <p>Clinical Lead of Service (Secondary Care Background)</p> | <p>Clinical Nurse Specialist (Secondary Care Background)</p> <p>General Practice Nurse</p> <p>Clinical Nurse Specialist (Secondary Care Background)</p> |
| Allied Health Professional | <p>Allied Health Policy Advisor to Welsh Government (Primary and Secondary Care Background)</p> <p>Health Policy Advisor to Welsh Government (Academic Background)</p> | <p>Director of Therapies and Health Science of Health Board (Primary and Secondary Care Background)</p> <p>Chair of National Professional Body (Primary and Secondary Care Background)</p> <p>Director of Therapies and Health Science of Health Board (Secondary Care Background)</p> <p>Policy Advisor to Welsh Government (Workforce and Organisational Development-Primary and Secondary Care Background)</p> | <p>Occupational Therapist (Primary Care Background)</p> <p>Physiotherapist (Secondary Care Background)</p> <p>Dietitian (Primary and Secondary Care Background)</p> <p>Physiotherapist (Secondary Care)</p> <p>Expert Patient Programme Tutor (Primary Care Background)</p> <p>Speech and Language Therapist (Secondary Care Background)</p> <p>Dietitian (primary and Secondary Care Background)</p> |

At least two weeks prior to undertaking the interviews, interviewees were provided with a copy of the test framework and a brief description of its cocreating health elements. Immediately before the interviews, participants were informed of the nature of the study, consent obtained both to ask the questions and to record the interview electronically, and it was ascertained that the interviewee had read the information about the framework.

3.2 Aims and Objectives of the Research

In determining how to engage clinicians in cocreating health, this study had two objectives namely:

- The development of a cocreating health framework to support the patient-clinician interaction.
- To identify the factors for successful implementation of a cocreating health framework in health services.

Within these broad aims, there were some more specific objectives, specifically to:

- Hold workshops and deliver 'free-writing' exercises with a broad range of stakeholders including patient groups, social service professionals, political, clinical, and management opinion leaders to gain insights about cocreating health within healthcare services.
- Conduct interviews with staff at the level of policy, leadership and individual clinicians within different professional groups to identify factors that would influence embedding the cocreating health framework within routine clinical practice.
- Develop a grounded theory for the implementation of the cocreating health framework in health services
- Examine the potential for embedding cocreating health in the practise of clinicians through the lens of normalisation process theory

3.3 Insights gained on the Elements of Cocreating Health

Insights gained from workshops, the researchers own clinical practise and review of the literature on consultation models and previous work on shared decision making and self-management support suggested that there might be a number of elements related to cocreating health. Broadly, these elements were preparation, agenda setting, gaining information, discussion of options, agreeing the way forward, taking action, review of outcomes, clinical audit and service improvement.

3.4 Rationale for Using Mixed Quantitative and Qualitative Methodologies

To address the stated aims and objectives of this research, it was considered that in the main phases of the research, both qualitative and quantitative data would be necessary. Quantitative methods were used to explore potential elements of cocreating health and to develop insights from training clinicians in self-management support. Qualitative methods were employed in the individual interviews, workshops and free writing exercises to explore emerging concepts and themes in-depth, consistent with the principles of cocreation and grounded theory. Yin (1994) suggests that discovery is facilitated through the research process, rather than by following a rigid experimental design. This principle guided the choice of workshops as the first stage of the research. Workshops were chosen initially to engage a large number of participants in actively cocreating this research and gaining 'buy in' to the concepts of cocreating health generated. The intention of the workshops was to gain insights through difference and diversity of participants, using democratic techniques to even out differences in power and roles, allowing participation by different sizes and structures of groups to explore and work with complex issues and to ensure that the thoughts of the researcher did not bias the outcomes of the workshops. The workshops had a number aims, firstly to a clear understanding of the broader goals of the research project and wider stakeholders within cocreating health. This helped the researcher to develop a clear sense of what cocreating health might accomplish. The second stage aim of the workshops was to identify stakeholders and facilitate their participation in the research. Stakeholders broadly representative of different interests were considered to be any person, group, or institution that affects or would be affected

by cocreating health. By bringing diverse views early to the research it was hoped to increase the chances of a more comprehensive identification of issues in cocreating health. It was also considered important to gain broad stakeholder involvement to build relationships between diverse groups, and between these groups and the researcher. Stakeholder participation in the workshops facilitated active involvement right from the conceptual stages of the research and included engagement in identifying the research questions, implementing and using the products of the research and in this way building trust in cocreating health. Insights from workshop participants resulted in significant modification of the initial research design and methodology.

3.5 Quantitative Methodology

Insights gained from the workshops suggested a transformational aspect of cocreating health in clinicians supporting patients in jointly setting the agenda for the interaction, developing options and agreeing outcomes. The information gained from the workshops was that such practise is rare within health services and so a training course was developed in partnership with the Health Foundation who had experience of delivering such courses. This course was developed specifically to introduce clinicians employed within a South Wales Health Board to the principles of self-management support and developing clinicians to embed these skills in their own practise.

Quantitative data was obtained by questionnaire. A number of different questionnaires were considered including the validated 'PSMS' questionnaire developed by Kosmala-Anderson and colleagues (2011). The PSMS comprises three subscales of ; clinical self-management support covering building an equal doctor-patient relationship, using four behaviour change processes of agenda setting, goal setting, problem solving and follow up and exploring patient's self-management strategies ; patient centeredness covering customising the treatment to a patient's preferences ; and taking an individualised approach. The measure was designed to be used to:

- (1) Assess clinicians' training needs in relation to self-management support for LTCs,
- (2) Evaluate the effectiveness of training for clinicians in self-management support,

(3) Assess clinical teams' performance in supporting self-management for LTCs,
(4) Measure self-management support provision in quality improvement initiatives in healthcare settings. The PSMS was not chosen for this study since it had been created for the specific context of clinicians working with patients with long term conditions and the present study was more generic, it examined issues relating to self-management support where the current study had a number of other elements of cocreating health, no data were available for comparison and it has 18 items which was considered to be onerous on clinician's time.

This study used the unvalidated questionnaire developed by the Health Foundation to measure change in clinicians following their 'Advanced Development Programme'. This was chosen following review of the literature since it had been consistently used for the ADP and it was initially hoped to make comparisons with other available data and has only 14 items. The concept of 'clinician activation' arose early in the workshop discussions. The second questionnaire chosen was the 13 item validated 'Clinician Activation Measure' or CSPAM developed by Hibbard and colleagues (2010) to investigate clinician 'activation'. This questionnaire was chosen since it measures in general terms the commitment of clinicians to support patients in managing their own health. It is a companion to the 'Patient Activation Measure' or PAM. Patient activation has been demonstrated to correlate highly with patient outcomes. The standard CSPAM questionnaire uses terms specific to medical clinicians and was adapted for this research by changing terms such as 'doctor' to 'clinician' and anglicising the language. Correspondence with Professor Hibbard determined that the small changes made would not alter the content validity of the questionnaire. A research licence was obtained to administer this questionnaire to seventy five UK clinicians on the condition that the data was then shared with Professor Hibbard. A third, unvalidated questionnaire was designed by this research to determine whether clinicians used each of the elements of cocreating health proposed by this research in their current practise. Each of the questionnaires used is shown in Appendix 1.

Questionnaires were delivered to participants immediately before starting the course and after completion to gain an understanding of the effect and importance of training to cocreating health. All questionnaires employed in this study were developed using a scale invented by Likert (1931) for the assessment of attitudes

The statistical package, SPSS-PC was used for quantitative data analyses. There is debate about whether Likert data should be analysed with parametric statistics such as the *t* test or nonparametric statistics such as the rank-based Mann-Whitney-Wilcoxon (MWW) (Carifio & Perla, 2008; Jamieson, 2004). Clason and Dormody (1994) found that of 95 Likert scale studies 13% used a nonparametric test and 34% a parametric one. With five-point Likert items, Rasmussen (1989) concluded that parametric tests are more powerful (i.e., exhibit a lower Type II error rate), except when the sample pairs are taken from the most no normal combination of distributions, such as from a uniform distribution and a mixed-normal one. No large differences were found between parametric and nonparametric tests regarding the occurrence of false positives (i.e., the Type I error rate). It is well established that the *t* test has a power advantage for normal distributions with equal variances and that it is robust to modest deviations from the test assumptions (Baker, Hardyck, & Petrinovich, 1966; Glass, Peckham, & Sanders, 1972; Heeren & D'Agostino, 1987; Posten, Yeh, & Owen, 1982; Sawilowsky & Blair, 1992; Sawilowsky & Hillman, 1992; Stonehouse & Forrester, 1998; Sullivan & D'Agostino, 1992; Wetherill, 1960).

Many authors state that nonparametric tests are preferred when sample size is small and that the *t* test becomes superior when sample size increases, as a result of the central limit theorem (Lumley, Diehr, Emerson, & Chen, 2002). A number of authors agree that MWW is identical to performing a *t* test after ranking over the combined samples (Conover & Iman, 1981; Fagerland & Sandvik, 2009; Zimmerman & Zumbo, 1993). The *t* test assesses differences in means, whereas MWW assesses differences in mean ranks.

A study by de Winter and Dodou (2012) showed that the power differences between the *t* test and MWW were minor and exceeded 10% for only few of the 98 distribution pairs. In many cases, the Type II error rate of the *t* test and MWW was close to 0%, indicating that differences between samples were large enough to be detected at the $\alpha = .05$ level by either method. The *t* test was found to be superior to MWW also for severe violations from the test assumptions (such as when comparing samples from the strong multimodal with strongly agree distribution). Another noteworthy result of this study was that the Type I error rate was close to the nominal value of 5% for all sample sizes and for all combinations of distributions. These results indicate that, for

both the *t* test and MWW, researchers working with Likert item data do not have to be worried about finding a difference when there is actually none in the population.

In this case, since the sample size was large ($n=164$) and the data was matched pairs from the same subject, it was considered appropriate to use a matched pairs *t*-test to examine differences before and after training. Using this parametric test was considered appropriate since the power of the test was considered higher than a non-parametric test and the possibility of either finding a difference where there was none or missing a significant difference was considered minimal.

3.6 Qualitative Methodology

Qualitative methods were used in this research to explore views of the cocreating health framework at policy lead, senior leadership and clinician level and to understand the issues in introducing a cocreating health model of patient-clinician interaction (Creswell, 1998). This researcher attempted to build an holistic picture by analysing the words and detailed views of participants to meet the central research objective and questions (Crabtree & Miller, 1999; Denzin & Lincoln, 2000). The emerging qualitative data provided breadth and depth to describe a clear picture of the issues in implementing cocreating health (Symon & Cassel, 1998). Collis, Hussey and Hussey (2003) have argued that qualitative research provides a strong basis for analysis and interpretation because it is grounded in the natural environment of the phenomenon.

The use of both qualitative and quantitative methods was intended not only to provide a more in-depth data set but also to support the validation of findings and thus increase the reliability of the research (Yin, 2003). Although heavily weighted towards qualitative methods the addition of quantitative data from questionnaires helped to explore the anticipated variety of themes arising in the first stages of the research process.

3.6.1 Grounded Theory Approach and Relevance to Symbolic Interaction

The principles of grounded theory were employed to develop the test framework and to determine factors in implementation. As such, the intended outcomes of the research were not rigidly defined at the beginning of the work and were co-created by the participants engaged in the study. This methodology was chosen since the intended outcome of this work was a framework that would become widely accepted and embedded within the interaction between patients and clinicians and this required ownership and buy in from a wide range of stakeholders at policy, leadership and clinician levels.

Use of the principles of grounded theory in this study (Strauss and Corbin, 1998) arose from immersion in the data, consideration at each stage of collection of emerging themes and the use of these to refine and expand on factors that arose, resulting in the development of a model. The previously examined literature did not contain detailed knowledge regarding the specific factors and factor relationships that comprise the implementation of a different interaction between clinicians and patients. The iterative process of data collection, coding and analysis led to a theoretical explanation of clinician interaction grounded in data collected from participants. In this study the principles of grounded theory were used to develop a model of the process by which clinicians adopt and maintain a cocreating health interaction with patients.

Grounded theory is considered a 'respectful' methodology with roots in symbolic interactionism in which the participants' views are sought, listened to, and valued. "Grounded theory has the purpose of generating concepts and their relationships that explain, account for and interpret the variation in behaviour in the substantive area under study, which behaviour is most often hinged around processing a problem for the subjects (Glaser, 1992, p. 19)." Although not a classic grounded theory approach, this study used the principles of grounded theory identified by Hutchison et al, (2011) shown in Table 3.3.

Table 3.3 : Characteristics of a Grounded Theory Study

| Characteristics | Details |
|---|--|
| An iterative process | A process whereby early data collection and analysis informs subsequent sampling and analytical procedures (theoretical sampling) and the analysis always remains open to new emergent possibilities. This process necessitates concurrent involvement in data collection and analysis phases of the research. |
| Sampling aimed at theory Generation | All sampling decisions made are a function of the research question and the ongoing theoretical development. As a result grounded theory research involves both purposive and theoretical sampling. |
| Creating analytical codes categories from the data itself | The analytical process through which concepts are identified and their properties and dimensions are discovered in the data. These should be representative of the data itself and cover a wide range of observations. |
| Advancing theoretical development throughout | A range of techniques can be used to advance theory development during each step of data collection and analysis. The techniques depend on the epistemological and theoretical stance of the researcher. |
| Making systematic comparisons distinctions | Making comparisons at every stage of the analysis (e.g. within and between cases or over time) helps to establish analytical by identifying variations in the patterns found in the data |
| Theoretical density | It is commonly accepted that there must be evidence of theoretical density or depth to the observations presented, resulting in the presentation of a theory from which hypotheses can be generated. This should also include evidence of theoretical saturation. |

Reference : Hutchison et al, 2011

To organise data, store codes and enable analysis, this project used nViVo version 10. Kelle, (1995) has suggested that Computer-Assisted Qualitative Data Analysis Software (CAQDAS) has the potential to turn qualitative research into a rigid automated process that neglects the role of human interpretation and reflection. Others have pointed out that CAQDAS can allow users to do complicated analyses without fully understanding the principles of the techniques they are applying (Johnston, 2006; Richards, 1998; Weitzman, 2000). However, Bazeley (2007) demonstrated that electronic systems for recording, sorting, matching and linking can greatly increase the efficiency of data analysis and Bringer et al., 2004; Bringer, Johnston, & Brackenridge, 2006a, 2006b; Johnston, 2006 showed that CAQDAS can greatly improve the data handling/analysis process if used appropriately. Bringer et al. (2006) demonstrated that CAQDAS can be used successfully to facilitate a grounded theory investigation by using nViVo to move the analysis move beyond thick description to an explanatory model grounded in the data. They showed how NViVo can facilitate many aspects of the iterative process associated with grounded theory and can help provide a transparent account of this, which enhances study validity (Bringer et al., 2004).

Data stored within nViVo for this study included transcripts of interviews, free writing scripts, workshop notes, and some memos. In this way, nViVo was used to store data, to visualise connections between codes, to identify themes and to generate a theoretical model to explain the data relating to implementation of the cocreating health framework. It is acknowledged that because of the lack of familiarity of the researcher, this study did not utilise the full features of nViVo version 10, such as the model building tool, relationship nodes, coding stripes, sets, coding queries, matrix coding queries, to support a grounded theory approach to the study.

It was recognised that the grounded theory must be readily modifiable when new data presented variations in emergent themes. In this research, integration, saturation and densifying made the grounded theory credible. Since these four criteria were met, it is asserted that the grounded theory developed of factors influencing implementation of cocreating health provides a conceptual approach to action and control in the substantive area of cocreating health (Glaser, 1992).

It was also understood that a grounded theory must also meet the two prime criteria of good scientific inducted theory; being parsimony and scope (Glaser, 1992). The grounded theory developed in this study is considered parsimonious because it accounts for significant variation in behaviour in cocreating health with a relatively small number of themes. The methodology employed allowed new themes to emerge through constant comparison and to be further investigated and incorporated into the model. Through immediate analysis of recently collected data, the researcher was sensitised to the data and constantly considering themes and their interrelations, and captured them by coding and memoing and analysed them with theoretical codes. Throughout this work there was a process of validation of data fit and relevance by saturation, relationship to the core themes and integration into the emerging theory (Glaser, 1992).

The assumptions of symbolic interaction and use of the principles of grounded theory were considered an appropriate perspective for use in developing a cocreating health framework and determining factors for its implementation. Symbolic interaction assumes that individuals construct their social reality through a process of interaction. People attach symbols to other individuals and their physical environment through this process of interaction and then act on the basis of these interactions. Symbolic interaction acknowledges that perceptions, understandings, and actions change over time as clinicians encounter the concepts within the cocreating health framework and new information is subsequently integrated. Symbolic interaction supports exploration of experiences, actions, and variations across time and context (Crooks, 2001). A basic assumption in grounded theory is that a social psychological or social structural process, in this case symbolic interactionism, occurs in the process of cocreating health and this accounts for all of the data.

The use of the principles of grounded theory in this research supported the researcher to understand the working lives and activities of clinicians; to understand clinicians own particular points of view and allowed clinicians to conceptualise their behaviour as meaningful and as a direct expression of their world views (Crooks, 2001, p. 17).

3.6.2 The Grounded Theory Process

The principles of grounded theory used in this research included: 1) simultaneous collection and analysis of data, 2) a two-step data coding process, 3) comparative methods, 4) memo writing aimed at the construction of conceptual analyses, 5) theoretical sampling to refine the researcher's emerging theoretical ideas, and 6) integration of the theoretical model of implementation (Charmaz, 2006). The constant comparative method is a major technique of grounded theory and was achieved by: a) comparing different people at the levels of policy, leadership and clinician, such as their views, situations, actions, accounts, and experiences; b) comparing data from clinicians across different professional groups; c) comparing emergent theme with theme, d) comparing data with theme and, e) comparing an emergent theme with other themes (Charmaz, 2006 p. 515, Glaser, 1978, 1992).

Operationally, Glaser and Strauss (1967) define a theme as a conceptual element of the theory. A property is a conceptual characteristic or element of a theme. Glaser (1992) later defined a theme as a type of concept, usually used for a higher level of abstraction, and a property as a conceptual characteristic of a theme at a lesser level of abstraction than a theme.

In this research, analysis began early during the grounded theory process by simultaneous coding as the first data were collected. Theory development began with open coding as the initial step of theoretical analysis. This researcher began with no preconceived codes and attempted to remain entirely open to data analysis. During open coding the data were broken down into themes, closely examined and compared for similarities and differences (Glaser, 1992). Using line-by-line coding this researcher continuously considered what meanings were being made of the data, asked questions of it, and identified gaps to focus subsequent data collection. In this way the codes provided insight into how clinicians are currently practising and what was happening in their interaction with patients. Open coding was completed when it provided a core theme. A selective coding process was employed, delimitting coding to only those variables that related to the core theme. This core theme became a guide to further data collection and theoretical sampling. Codes, memos and integration were developed in relationship to the core theme. In this intermediate step between initial coding and the developing grounded theory, memo writing was continuously

used for “the theorizing write-up of ideas as they emerge while coding for themes, their properties and their theoretical codes.” (Glaser, 1992). This memo writing was helpful in forming emergent ideas about the data, providing an analytic course, helping to refine categories and defining the relationships among various categories. The memo writing was also helpful in giving a sense of confidence and competence in this researcher’s ability to analyse data (Charmaz, 2000, p.517-518).”

As themes became refined, a developing theory began to emerge, conceptual gaps in the data were identified. Theoretical sampling was used to fill these conceptual gaps. Theoretical sampling represents a process of data collection for generating theory by simultaneously collecting, coding, comparing data with data, and developing a provisional set of relevant themes for explaining the data.

It was appreciated that a solid grounded theory required a process of theoretical sampling back into the field to gain more insight about when, how, and to what extent the emerging themes were pertinent and useful. Theoretical sampling was employed to refine ideas, to identify conceptual boundaries and pinpoint the fit and relevance of rather than to increase the size of the original sample. As the research proceeded, the process of theoretical sampling became recursive. Theoretical sampling on any theme ceased when it became saturated, and it was then elaborated and integrated into the emerging theory (Glaser, 1992).

Throughout the grounded theory process, the researcher attempted to demonstrate a sense of theoretical sensitivity to know, understand, gain insight and creativity and to continue with the skills that are necessary in generating themes and hypotheses according to the emergent theory. “It is a personal attribute of the researcher who has the ability to give conceptual insight, understanding and meaning to the substantive data” (Glaser, 1992, p. 27). At the start of the study the meaning of the data was not obvious. Patterns were sought from the meanings related to the expressed views of the participants (Glaser, 1992). The researcher attempted to ensure that his assumptions, experiences and prior knowledge were not of the participant’s perspective. As the analysis continued, this researcher began to have an understanding and sensitivity to what was in the data, what the core themes were, and the emerging process leading to generation of a theory. Care was taken to ensure that

data were never forced into a theme or property during line by line coding. New themes and properties were developed as they arose. The initial literature review provided an overview of the previous models of patient-clinician interaction to avoid contaminating the researcher's mind with preconceived assumptions about the data. Memo writing was employed to enhance theoretical sensitivity. As the themes became saturated, memos were rewritten in a more analytic form within a theoretical outline to prepare for the analysis of results. These memos were sorted and assigned to new themes.

In coding related to the development of the cocreating health framework itself, the rigid coding structure related to the elements of the test framework was maintained. During data collection and immediate coding, the process of memoing identified a smaller number of core themes related to implementation of the cocreating health framework. When the core themes emerged, open coding from the initial coding structured ceased and selective coding began. Selective coding was used as a technique for delimiting the data after substantive codes emerged. Coding was delimited to only those variables that related to the core themes in such a way as to unify a parsimonious theory. The core themes were observed to account for most of the variation in views of participants. The core themes had several important functions for generating the grounded theory including integration, densification, saturation, and completeness.

3.6.3 Grounded Theory Principles

The methodology for this study consisted of: ongoing literature review, data collection, theoretical sampling, the interview process, data management and data analysis including substantive and theoretical codes.

3.6.3.1 Phased Literature Review

For this study, a preliminary literature review of existing consultation models was carried out. Qualitative and quantitative studies were read and reviewed for their theoretical and empirical context. The literature review identified a gap in setting a framework around elements initially considered relevant in cocreating health. The grounded theory approach was used to identify significant elements of cocreating

health. The advice of Glaser (1992) was taken with the researcher reviewing the relevant literature arising from themes within the data only after coding began to generate ideas and to integrate the emerging theory to show its contribution to the existing literature, not to seek verification of hypotheses or findings. In beginning this grounded theory study, an approach was taken to first collect data and begin initial open coding. The open coding was used to compare data items as they arose whilst generating themes, continuously analysing the data immediately after collection and considering whether this was generating theory. Mid-way through the second phase of data collection, when theory emerged that seemed sufficiently grounded in core themes this triggered a substantive literature review of the themes and theoretical insights generated. These included the fields of patient-clinician interaction, supported decision making, self-management support, change theory, behavioural change, audit, action research, cocreating health, symbolic interactionism, patient and clinician activation, normalisation process theory, and theory of planned action. This researcher was not aware of this literature prior to interviewing participants in the second phase of data collection. By not knowing this literature, the researcher avoided unknowingly constraining or inhibiting his effort to generate themes, their properties, and theoretical codes into any preconceived concepts, assumptions or ideas that did not overall generate a good fit, work or relevance to the emerging theory. Once a grounded theory had emerged from the data, a detailed, relevant literature review was completed.

3.6.3.2 Data Collection

The data collection process consisted of two phases. The first phase, consisting of a series of workshops, stakeholder meetings, free-writing exercises and questionnaires was designed to explore elements that might be relevant to cocreating health and to determine if there were themes for exploration in the interviews within second phase of data collection. In the second phase, semi-structured interviews were held with thirty one participants in clinical professions of doctor, nurse and therapist and with managers at the levels of policy, leadership and clinician to explore the test framework and determine implementation factors. The final cocreating health framework and implementation factors were shared with peer experts, with interviewees and discussed at two workshops.

3.6.3.3 First Phase Data of Collection

In the first phase of data collection, thirty two workshops and stakeholder meetings (Table 3.1) were held to discuss the principles of cocreating health and issues in implementing such an approach in the NHS. Patients' insights on cocreating health were gained through discussion with the local Community Health Council and representatives of the Educating Patients Programme. Multi-disciplinary team perspectives were gained through arranging meetings with the local cardiac rehabilitation team and Liaison Psychiatry team. Workshops engaging senior leaders included NHS Wales Executive Directors, Public service leaders from across Wales at Public Service Management Wales summer school. Additionally, elements of cocreating health and associated principles were discussed at meetings arranged for Health Policy leaders. The methodologies used were to provide an introductory presentation on the principles of cocreating health and then invite discussion amongst the participants whilst the researcher took written notes. When a significant theme arose in discussion, the researcher prompted further conversation amongst the participants. At each workshop, one participant volunteered to capture salient elements of the discussion on a flipchart, to feedback to the group who then provided a sense check and agreed additional material. The flipcharts were taken by the researcher and typed verbatim. In addition, in six of the workshops, participants were asked to complete a 'free writing' exercise according to Goldberg's rules (Goldberg, 1986). Participants were asked to write their thoughts on cocreating health for ten minutes, to keep their hand moving for this time, not to pause to stare into space or to read what they had written, and to pay no attention to grammar, spelling, punctuation, neatness, or style. These notes were then transcribed by the researcher.

As each of these workshops concluded, the notes were transcribed and entered as files into nVivo. The data sources were identified within nVivo as either the researcher's notes, participant's flipchart or free-writing exercises. Immersion in the data by immediate consideration, analysis, identifying themes and memoing produced an initial coding structure. The initial coding structure is shown in figure 3.1 below. In developing codes, care was taken to achieve the minimum number of different codes and to ask questions of the data : of what general category is this item of data an instance ; what does this item of data represent ; what is this item of data about ; of

what topic is this item of data an instance ; what question about a topic does this item of data suggest ; what sort of answer to a question about a topic does this item of data imply ; what is happening here ; what are people doing ; what do people say they are doing ; what kind of event is going on (Charmaz, 2006). Thinking about these questions helped to move beyond thick description to a micro-analysis of the data (Corbin & Strauss, 2008).

Each data file was subject to line by line coding within the initial coding structure and new codes developed as new themes were identified in the data. During the initial coding, memos were recorded to facilitate analytical thinking. Each time a node was created a new memo was written with analytical ideas designed to stimulate further exploration of concepts.

Figure 3.1 Initial Open Coding Structure

| |
|--|
| Name |
| Cocreating Health Elements |
| Agenda Setting |
| Agree Way Forward |
| Discussion of Options |
| Implementation |
| Information Gathering |
| Further Clinical Information |
| Further information gathering by patient |
| Preparation |
| Clinician Evaluating Information on Patient |
| Clinician Understanding Benefit or Risk of Interventions |
| Electronic Information Available |
| Patient Health Literacy |
| Patient Reading to Understand Condition |
| Review Achievement Of Goals and Further Actions |
| Service Audit |
| Service Improvement |
| Implementing Cocreating Health Elements |
| Barriers |
| Communication |
| High Level Support |
| Individual Internal Model |
| Conflict with Existing |
| Consistent with Existing |
| Need for mutual support |
| Return to medical model |
| Transformational |
| Large Scale |
| Leadership |
| Mutual Organisational Support |
| Need to Develop Evidence Base |

| |
|---|
| Normalising |
| Organisational Change |
| Realisable Benefits of Cocreating Health |
| Regulatory Framework |
| Supporting Infrastructure |
| IT |
| Patient Held Record |
| Seamless Across Boundaries |
| Pace-Complexity |
| Benefits of Engaging with Complexity |
| NHS Financial Cost |
| Societal Cost |
| Time Management |
| People |
| Age Context |
| Clinician Improved Job Satisfaction |
| Clinician Morality |
| Clinician Permission |
| Clinician Profession |
| Doctor |
| Nurse |
| Scientist |
| Therapist |
| Clinician Reflection on Current Practise |
| Risk Management |
| Clinician Regulation |
| Clinician Training |
| Community of Practice |
| Embed in Initial training at start of career |
| Need to Practise new ways of working |
| Release for Training |
| Training Quality |
| Whole MDT |
| Benefits of whole MDT trained |
| Difficulties due to partial training within MDT |
| Whole Profession |
| Doing Too Much to People |
| Empowerment |
| Patient Capacity to Understand Options and Set Agenda |
| Patient Conflict with expectation of clinician role |
| Patient Deference to Authority |
| Patient Group Work |
| Patient Health Behaviours |
| Patient Improved Clinical Outcome |
| Patient Improved Experience |
| Patient Improved Quality of Life |
| Patient Self Efficacy |
| Patient Socio-Economic Context |
| Patient Training |
| Power Relationships |
| Relationship Centred Practise |
| Place |
| Welsh Context |
| Public Service Context |
| Strong Deference to Authority |

It was recognised that many participants of these workshops were either policy leads in Welsh Government or senior leaders from the NHS in Wales. To gain additional insights from a larger number of practising clinicians, in addition to qualitative data collected during these workshops, quantitative data were obtained using validated and unvalidated questionnaires from clinicians undergoing training in self-management support skills arranged by the researcher. These clinicians were a self-selected group responding to an advert displayed on the intranet of the Health Board. Discussion in the workshops had determined that working with patients to set a joint agenda was the most unfamiliar and potentially transformative element of cocreating health. Lack of familiarity in eliciting the patient's agenda was considered to result from initial clinical professional training for many different clinical professions that largely attempt to follow the traditional medical consultation model. A detailed exploration was made of whether staff from a variety of professional backgrounds with initial training in the traditional medical consultation model could be successfully trained in working collaboratively to set the agenda. In particular this aspect studied whether there are differences between professions in their responses to training and whether they were 'activated' towards engaging in partnership with patients in cocreating health.

The Health Foundation had established and evaluated 'the advanced development programme' to train clinicians to support patients in self-management (Wallace et al, 2012). One of the trainers involved in this programme, with a supporting actor, was commissioned by this researcher to deliver this training to seven cohorts of clinicians employed by the Health Board. This training was delivered to 196 clinicians over three half day sessions spaced a month apart to allow consolidation of skills. Of these, 164 clinicians attended at least two out of three training sessions. Each of these 164 clinicians completed the 'longitudinal questionnaire' that had been validated and used by the Health Foundation to evaluate this training. Of these, 129 completed the longitudinal questionnaire before and after training. In addition, a questionnaire was developed by this researcher to investigate whether respondents were using elements of the cocreating health framework in their clinical practice. 83 clinicians completed this questionnaire. A small sample of 15 clinicians were asked to complete this cocreating health questionnaire before and after training to determine the magnitude of change in practice provided by the training.

An anglicised version of the Clinician Activation Measure (CS-PAM) questionnaire of Hibbard et al (2010) was developed by this researcher and used to determine attitudes of clinicians towards engaging with patients in self-management. Correspondence with Professor Hibbard determined that the small change in wording for CS-PAM would not alter the questionnaire validity. A licence was obtained to deliver 75 CS-PAM questionnaires and respondents were randomly selected from the 164 clinicians who had attended at least two out of three training sessions. The anglicised CS-PAM was delivered alongside a questionnaire developed by this researcher to determine which elements of cocreating health were in place within the respondent’s clinical practice. Methodology related to quantitative analysis is described later.

Analysis of the qualitative and quantitative data obtained during the first phase of data collection was used for two purposes related to the initial research questions. Firstly, the elements of cocreating health emerged and were then described within a cocreating health framework for testing in the second data collection phase (Figure 4.1). This test framework was published within a ‘tools for improvement guide’ ‘coproducing services, cocreating health’ which provided a detailed description of the elements. This aspect was designed to fulfil the first research aim of developing a cocreating health framework. For analysis within nViVo, initial coding followed the themes of the cocreating health test framework elements (Table 3.4).

Table 3.4 : Elements of the Cocreating Health Framework used for coding in second phase

| |
|--|
| Theme 1 : Preparation |
| Theme 2 : Agenda Setting |
| Theme 3 : Gathering Further Information |
| Theme 4 : Discussion of Options |
| Theme 5 : Agreement of way forward |
| Theme 6 : Implementation of agreed actions |
| Theme 7 : Review and Evaluation of Outcomes |
| Theme 8 : Clinical Audit |
| Theme 9 : Service Improvement |

Secondly, analysis of coded data within nViVo produced themes for exploration in the interview phase and to develop a modified coding structure from the themes that arose

(Table 3.5). This aspect was designed to meet the second research aim of determining the factors relating to implementation of the cocreating health framework.

Table 3.5 : Implementation themes arising from First Phase Data Collection

| |
|---|
| Theme 1 : Clinician Attitude to Cocreating Health |
| Node 1.1 : Evidence Base |
| Node 1.2 : Clinician Training-use information from questionnaires |
| Node 1.3 : Communication |
| Theme 2 : Clinician Norms |
| Node 2.1 : Patient Expectations |
| Node 2.2 : Peer Expectations |
| Node 2.3 : Policy Expectations |
| Node 2.4 : Context |
| Theme 3 : Clinician Controls |
| Node 3.1 : Current Practice |
| Node 3.2 : System Factors |
| Node 3.3 : Patient Factors |
| Node 3.4 : Clinician Factors |
| Node 3.5 : Time Available |
| Node 3.6 : Infrastructure |
| Node 3.7 : Risk to Patients |
| Node 3.8 : Power Relationships |
| Theme 4 : Enabling Factors |
| Node 4.1 : Cocreating Health Framework |
| Node 4.2 : Patient Activation |
| Node 4.3 : Resources |
| Node 4.4 : Team Support |
| Node 4.5 : Leadership Support |

Themes from both the test cocreating health framework and implementation were used to draft initial questions for semi-structured interview within the second phase.

3.6.3.4 : Second Phase Data Collection-Gaining Insights on the Test Cocreating Health Framework and Issues in Implementation.

The first phase of data collection was carried out to widely explore the views of clinicians working in coproduction. To explore these broad themes in depth, a second phase of data collection was necessary. This second phase of exploration was guided both by analysis of data from the first phase and from the initial literature review. Analysis from the first phase of data collection suggested different emphasis in views from participants at the clinician, leader and policy making levels and between different clinical groups of doctor, nurse and allied health professional. To explore these,

participants were chosen from these three different levels and three different clinical groups.

Semi-structured interviews using questions derived from themes arising from the first data collection phase were used in order not to limit participants to predefined issues or categories of investigation and to allow for flexibility and interpretation. Interviews were conducted through face-to-face conversations between individual participants and the researcher (Gubrium & Holstein, 2002). A number of different types of interviews namely structured, unstructured and semi-structured were considered. Structured interviews were considered but rejected since these are based on questions that are asked of each and every participant, where there is no variation in the questions between participants and therefore limited ability to explore emergent themes. Unstructured or informal conversation interviews that have no predetermined set of questions (Crabtree and Miller, 1999; Patton, 2002) were also considered but rejected due to the fact that themes had arisen from the first data collection phase and potential difficulties in analysis with a limited number of participants. Semi-structured interviews were chosen since these strike a balance between a structured interview and unstructured interview. The questions in the semi-structured interviews were open ended thus not limiting the participants' choice of answers (Gubrium & Holstein, 2002, McCracken, 1988). Interviews were guided by the emergent themes and to answer the research questions but were conducted in a way to allow the discovery of new ideas and themes. The interview guide was modified as real time data analysis and coding proceeded to iteratively refine questions that were not eliciting relevant information and to explore emergent themes and concepts that required further development (Strauss and Corbin, 1998). The researcher aimed to provide a setting and atmosphere where participants felt comfortable to discuss issues in detail. The interviewer made use of verbal and non-verbal cues and prompts to guide the participant and enable detailed data to be obtained (Creswell, 2003, McCracken, 1988, Patton, 2002). All interviews were recorded with the permission of the participants and transcribed verbatim immediately. Transcribed interviews were immediately entered into the nVivo qualitative data analysis program according to the pre-defined and emergent themes for analysis.

All thirty one interviews were arranged at a mutually convenient time as per the participant's request. Prior to the interview, participants were provided with a detailed description of the test cocreating health framework, together with the graphical depiction of the test framework shown in figure 3.2. The broad data-generating question guiding the study was "tell me what you think about the cocreating health framework". As they arose within the interview, themes from both the framework and its implementation were discussed in detail. At the beginning of the interview, the researcher recorded a set of demographic questions. These questions included the participant's clinical specialty, level in the organisation, place of work and team. These demographic questions were not part of the audio taped interviews. This was done to ensure participant anonymity. Each interview lasted from thirty minutes to approximately one hour and was recorded on a digital recorder. During data collection, the researcher listened attentively to the participant and discretely recorded field notes only when necessary. The interview audio tapes were transcribed verbatim by the researcher with contemporaneous notes made of emerging insights.

Field notes were collected to support the recollection of important information and ideas that occurred during the interviews (Glaser, 1978). Memoing was conducted throughout as according to Glaser (1978), it is core in generating theory and had four basic goals : 1) to develop ideas (codes), 2) to record these ideas with freedom, 3) to create a rich memo fund, and 4) to sort out these memos with ease. (Glaser, 1978). Memos created during this process varied from a bullet point to a sentence, a paragraph and a few pages. The ideas developed from the memo raised the data collected to a conceptual level. The memos were usually descriptive of the recorded data, but they helped to raise the description to a theoretical level and to draw out the theoretical properties of the coding process. The memos helped to saturate each code by defining boundaries and by establishing the conditions, connections and significance of the major theoretical themes in the data (Glaser, 1978). During analysis the memos were sorted, considered and written into the thesis. A rich memo fund was used to establish the emerging substantive and conceptual framework of the study.

To validate these findings, views were sought from peer experts and from interview participants and they were discussed in the context of two workshops for practitioners

around cocreating health. These views were used to further refine the narrative description of the framework and to develop implementation issues.

3.7 Validity of the Qualitative Methodology

The view of Hammersley and Atkinson (1983) was that data in themselves cannot be valid or invalid, what is at issue is the inferences drawn from them. Hirschi and Selvin (1968) suggested that we need to ask what we wish to learn from data to answer questions about validity. The inference from this is that validity is not an inherent property of a particular method, but pertains to the data, accounts, or conclusions reached by using that method in a particular context for a particular purpose. In the words of Mischler (1990), validity is always relative to and dependent on some community of inquirers on whose perspective the account is based

In qualitative research, saturation is said to occur when further data from interviews provides no new information. However, Strauss and Corbin (1998) suggested that saturation is a "matter of degree" and that the longer a researcher examines, familiarises themselves and analyses their data there will always be the potential for "the new to emerge". They concluded that saturation should be concerned with reaching the point where further data becomes "counter-productive" and that "the new" that is discovered may not add to the analysis, model, theory or framework. The view of Strauss and Corbin (1998) was followed in that developing a conclusion to this work was not necessarily hampered by a lack of data but rather by an excess of it. As the analysis began to take shape the researcher was required to become more disciplined and cut data where necessary. Charmaz (2006, p.114) suggested that "25 (participants are) adequate for smaller projects"; according to Ritchie et al. (2003, p.84) qualitative samples often "lie under 50"; while Green and Thoroughgood (2009 [2004], p.120) state that "the experience of *most qualitative researchers* is that in interview studies little that is 'new' comes out of transcripts after you have interviewed 20 or so people". Guest, Bunce, & Johnson (2006) investigated saturation in a quantifiable way, by examining the point in data collection at which codes were created and the point at which the distribution of code frequency stabilized. In their study, no new codes emerged after 12 interviews; in fact, basic codes were present as early as six interviews. In this study, the first phase data collection had shown rich insights from

participants at policy, leadership and clinician levels and between different clinical groups of doctor, nurse and allied health professional. This gave a total of nine different groups and so three or four participants were interviewed from each group to increase the validity of the research findings. In carrying out the research it was considered important to obtain insights from clinicians working in primary and secondary care. This was facilitated by the integrated nature of Welsh Health Boards meaning that most policy makers, leaders and clinicians had expertise in clinical interaction in both primary and secondary care contexts and others were selected for their experience mainly in either primary or secondary care settings.

In this study using the principles of grounded theory, theoretical saturation determined the criterion for sample size (Strauss and Corbin, 1998). To gain appropriate richness and depth of data on the emerging elements of a grounded theory model, it was initially anticipated that at least 20 interviews would be required. Since there were different perspectives at the levels of policy, leadership and clinician, and from different clinical professions of therapy, nursing and medical, 31 interviews were conducted before each theme was considered to be saturated with data. In particular, it was important to achieve saturation in different contexts of primary and secondary care. Saturation was considered to have occurred based on the depth of the data provided by the 31 participants, cross-correlation with workshop data and quantitative data from the questionnaires and the relative scarcity of new information emerging from the final five of the thirty one interviews. . It was also considered that further quantities of data would prevent the in depth analysis of the detailed and rich experiences of the 31 participants who had been interviewed. The total of thirty one participants interviewed gave significant challenges in time spent in interviewing, transcribing, coding, analysing and considering such a large amount of data. These insights were synthesised and are described in chapter six of this thesis.

This research methodology attempted to demonstrate rigour by addressing the four criteria of credibility, transferability, dependability and confirmability (Lincoln & Guba, 1985). Credibility refers to establishing confidence in the truth of research findings. Great care was taken to document the human experiences of the participants as they were lived and perceived. No assumptions of a single reality, was made, rather that multiple “realities” exist which are created by each individual. The perspectives of each

participant were documented verbatim, faithfully, to ensure that these would be recognisable to the participants (Lincoln & Guba, 1985). Lincoln and Guba propose several techniques for achieving the credibility of qualitative research namely prolonged engagement, persistent observation, triangulation, negative case analysis, referential adequacy, member checks and peer debriefing. Of these techniques, prolonged engagement, persistent observation, peer debriefing and triangulation were used in this research to assure credibility of the research findings.

Prolonged engagement is the investment of sufficient time to achieve certain purposes, such as learning the culture in the substantive area under study, testing for misinformation introduced by distortions either of the self or of the respondents, and building trust (Lincoln & Guba, 1985, p. 301).” According to Lincoln & Guba (1985), building trust is not demonstrated by the personal characteristics of the researcher, but is a developmental and time-consuming process requiring constant engagement, to demonstrate to the participants that their perspectives will not be used against them, that anonymity will be guaranteed, that hidden agendas are not being served, and that the interests of the participants will be honoured as much as those of the researcher. In this research, prolonged engagement provided scope while persistent observation provided depth. However, trust and rapport from prolonged engagement were important in gaining the candid perspectives of participants (Lincoln & Guba, 1985).

In order to achieve prolonged engagement and to build trust, the researcher has over the past five years and continues to be a source of advice and support to clinicians, leaders and policy makers in developing cocreating health approaches. A number of peer-reviewed and other publications were written by the researcher, and are located in an addendum to this thesis. In addition, many workshops, learning events and training sessions were delivered and attended to develop a credible background in cocreating health.

Another technique used for enhancing credibility of these research findings was peer debriefing. Peer debriefing is a process of exposing oneself to a disinterested peer for the purpose of exploring aspects of an inquiry which may otherwise remain implicit in the researcher’s mind (Lincoln and Guba, 1985). This process helped to keep this researcher ‘honest’ by exposure to searching questions by experienced protagonists.

In this way, the researcher's perspectives and understandings were probed, meanings explored and the basis for interpretation of this research data were clarified. Peer debriefers consulted had expertise in both cocreating health and the methodologies used (Lincoln & Guba, 1985).

Transferability is defined as the extent to which the research findings from this study would have applicability to other contexts with other participants. Within a quantitative, positivist paradigm, this would be equated with external validity or the generalisability of the research findings and how they meet the criterion of "fit" into another context outside the study, such as development of the cocreating health framework and its implementation within the context of health services outside NHS Wales. It is acknowledged that this research cannot produce generalisations, but contains 'thick descriptions' which support the validity of the framework and its implementation into another similar context with preservation of its perspectives, interpretations, and inferences (Lincoln & Guba, 1985; Leininger, 1994). Transferability is shown in this study by the rich and thick descriptions which present detail, context, and relationships between clinicians and patients. Specifically, transferability was demonstrated in the validity of cocreating health in both primary and secondary care settings, dependent on context. A rich or thick description was ensured by using participant's words used to support interpretations. This was accomplished by digitally recording interviews and transcribing these verbatim to ensure that each participant's views were captured in detail. Data saturation previously described contributed to thick description.

Dependability was demonstrated by producing a coherent description of a cocreating health framework and its implementation from detailed study. Lincoln & Guba (1985) propose that auditability rather than reliability is the criterion of rigor relating consistency in qualitative findings. Auditability of this project was ensured by maintaining detailed documentation to allow another researcher to follow the audit trail and the audit process of this research. In this study, the audit trail includes raw data, written field notes, questionnaire data, nVivo records and codes available for evaluation. Lincoln & Guba (1985) propose that a single audit can be used to determine dependability and confirmability simultaneously. Confirmability would address whether the findings of this study are grounded in the data by enabling

checking for logical inferences, quality of interpretations and the possibility of alternatives.

Triangulation in this study involved the combination of different interpretations of different types of both quantitative and qualitative data towards interpretation. Triangulation is demonstrated in this study by the three phases of data collection over three years, using quantitative and qualitative methods, by data collection in different geographical contexts, across levels of policy maker, leader and clinician and by different clinician groups of doctor, nurse and allied health professional. In addition, theoretical triangulation (Kushner and Morrow (2003 : 38)) was demonstrated by a constant grounding process at the level of data gathering and analysis, coupled with internal checks through constant comparison of potential theoretical arguments.

3.8 Challenges Inherent in the Research

This research was conducted using the principles of grounded theory with a social constructionist epistemology. Social constructionism, argues that the authority of knowledge ultimately derives from a "knowledge community" of people who agree about the truth. Thomas Kuhn (1970) is quoted as saying that "knowledge is intrinsically the common property of a group or else nothing at all". Within this study, the researcher was engaged in co creating knowledge that was intended subsequently to become part of the internal model of behaviour of the community as a cocreating health framework embedded in routine clinical practise. This gave particular challenges in the context of a doctoral thesis since the research design and methodology evolved within the study as knowledge was gained from the information, attitudes, beliefs and behaviours of participants. Care was taken to avoid bias from the knowledge and understanding of the researcher in collecting data, analysing this and forming theoretical insights. The natural inclination would be for the researcher to place greater reliance on qualitative and quantitative data that support the framework whilst placing less significance on findings that challenge the framework's validity or point to difficulties in implementation. This potential bias was addressed by triangulation of quantitative and qualitative methodologies together with the transparency of data engendered by the use of NVivo. In addition, this research was grounded in the practice of participants and applying the principles of grounded theory

with integrity was intended to ensure that it is the views and insights from participants that guided development of the research questions and ensured that conclusions were minimally biased by the views of the researcher.

A number of practical challenges were faced. Some were general features of research such as gaining engagement from a sufficiently large and diverse range of participants. There were specific issues in gaining unbiased data from clinicians given the researcher's organisational position as an Executive Director with professional responsibilities. There were the usual time challenges associated with gaining Research Ethics approval and competing time pressures arising from work and personal commitments. There were some very significant intellectual challenges in gaining new skills in qualitative methodology and competent application of this and learning to use nVivo.

A further challenge was in obtaining an appropriate sample for semi-structured interview. The first research phase had shown different perspectives from different clinical professions at different levels. It was also important to gain perspectives from primary and secondary care contexts. In selecting individuals to approach for interview, there were a limited number of possible contributors at the policy level. The researcher considered it important to find potential contributors at leadership and clinician level from across Wales to gain as wide a view as possible. A number of the clinician contributors had received training in cocreating health. The participants comprised five hundred and twenty seven workshop participants, one hundred and sixty four clinicians providing questionnaire data and thirty one interviewees providing in depth insights. It is a potential criticism of this research that there were only four general practitioners interviewed. However, the need for larger sample size for a particular group needed to be balanced with the overall research aims, preventing bias towards one particular group and the need to maintain a manageable sample size.

Care was taken to ensure that the scope of the research did not exceed that required of a doctoral thesis. The scope of the research was reviewed after the pilot phase and the first phase study and with supervisory input the study was focused on development of the cocreating health framework and its potential implementation.

3.9 Ethical Considerations

Great care was taken to avoid participants feeling pressured by a senior member of staff to take part in the research. The confidentiality and anonymity of all participants were maintained throughout the process of data collection and analysis. Participant confidentiality was protected by not recording identifiable information either on the recordings or on transcripts and by identifying each person only by a numerical code on questionnaires.

This research involved approaching staff employed within the NHS and Welsh Government. Application was made to the Research Ethics committees of both ABM University Health board and the University of South Wales. Approval to proceed was granted by both committees, demonstrated in Appendix 2.

Two specific ethical issues were addressed, namely gaining informed consent and confidentiality. Each interviewee was asked to acknowledge that: they were sufficiently informed about the research and the nature of the interview specifically; they consent to audio-recording; and that they understand that they could withdraw from the study at any time. Secondly, the confidentiality of research material was protected. Each transcript was given a code giving the profession, place of work, researcher, transcript number and date of interview. Digital recordings and files were password protected, and transcripts and paper forms were stored in a locked filing cabinet at ABMU Health Board Head Quarters. Questionnaires were given individual codes and details of participants entered into a password protected spread sheet. Field notes of direct observation of meetings and discussions were taken by the researcher.

3.10 Conclusion

This chapter has described a research methodology and strategy designed to both develop a cocreating health framework and to determine the issues in its implementation. Both quantitative and qualitative methods were required to answer the research questions. Quantitative methodology is discussed and choice of statistical tests explained. The rationale for using the principles of grounded theory is set out in detail. Within the research design there were three phases of data collection

and analysis. The first phase was a broad dialogue with a wide variety of stakeholders across Wales to discuss principles of cocreation of health. Analysis of data from this first phase suggested a number of elements of cocreating health, allowed the construction of a test framework and suggested issues for exploration in the second phase. In the second phase, semi-structured interviews were held with thirty one participants from professional backgrounds of doctor, nurse, and therapist and with different responsibilities of policy maker, leader and clinician. The research design was developed to gain maximal validity and ownership of the results through triangulation of mixed qualitative and quantitative methodology, the three different phases of data collection, and participation of a large number of stakeholders in cocreating the framework.

Chapter Four : Results and Analysis of Workshops and Questionnaire Data-Exploring Elements of Cocreating Health to Develop a First Iteration of the Cocreating Health Framework

4.1 Introduction

This chapter presents the findings from the first phase of data collection designed to explore widely amongst a broad range of stakeholders in Wales the views of clinicians working in coproduction with patients. Conversations were held in thirty two workshops and focus groups to explore the concepts within cocreating health. The patient's view of concepts within cocreating health was gained through discussion with a Welsh Health Board Community Health Council and representatives of the Expert Patient Programme. Multidisciplinary team perspectives were gained through arranging meetings with a Welsh Health Board Cardiac rehabilitation team and Liaison Psychiatry team. Workshops engaging senior leaders included NHS Wales Executive Directors and Public service leaders from across Wales at PSMW summer school. Additionally, cocreating health and associated principles were discussed at meetings arranged for Health Policy leaders. Questionnaire data was obtained from one hundred and sixty four clinicians training in supporting patient self-management

4.2 Insights from Workshop Participants

4.2.1 Insights from Policy Makers

Policy and clinical leads within Welsh Government expressed the view that currently “systems are structured around linear or simple clinical scenarios” and there was a need for a “transformational change to the way we care”. This would be “Proactive, holistic preventative and patient centred” and would assume “an active role for patients” with a “shift to a partnership model”. This would involve “collaborative, personalised care planning that would agree goals, define support required and give patients the required knowledge, skills, confidence to work in partnership with clinicians to develop treatment plans with appropriate measures that could be reviewed together”.

One policy lead said “As clinicians we need to understand that it's not our life-we have to find a way to support people to be in charge of their own life. Clinicians need to put

the patient first and to focus on the wellness of the patient. The NHS needs to focus on maintaining independent living of patients rather than creating dependence, to work with patients to make them proud of what they can do for themselves. A major challenge in the future will be supporting patients with multiple chronic diseases- this needs a different model than patients accessing very many different appointments for different conditions”.

Policy leads confirmed that, although implementing such a transformational approach such as cocreating health would be challenging, it could be achieved by joint working across professional boundaries and organisations. It would also need all the members within Multi-Disciplinary Teams to have the right skills and competencies with defined roles and responsibilities to provide holistic, co-ordinated care. In particular, for patients with long term conditions it would be necessary to “shift from an episodic approach towards anticipatory and planned care using collaboration at all levels, each clinician taking the opportunity to influence health behaviours. Policy leads acknowledged that this required a review of the existing workload, aligning this with workforce capacity and skills.

4.2.2 Insights from Senior Leaders

In discussing concepts within cocreating health in a workshop organised for this research, a senior leaders group of thirty six Executive Directors from Health Boards across the NHS in Wales gave their views. They said that the NHS in Wales needs to “provide an environment where patients are empowered to engage” and that any model of cocreating health “should not be reliant on patient’s educational level”. They said that patients should feel “part of the team” and that this should give them the perception that “the team is around me”. There was an understanding that the NHS would need to “raise expectations for patients to engage” and to provide “patient centred communication – to the level required”. They said “we can’t assume that we can make decisions for others. Patients need a voice at every step and some will need advocacy. This will need to be done in supportive environments to promote health and healthy behaviours”. There was support for the principles of cocreating health, that “health services need to be individualised”, that “many would want to do this” but expressed concern that people “might not recognise, or would react against the term

co-production” might mix up coaching and co-production. They considered that the cocreating health approach “would lead to a long term ongoing relationship, rather than the current model of see, treat, discharge”. They also said that “it may be easier for clinicians to understand shared decision-making but not co-production”. Some of the challenges identified were that “clinicians currently have different practice than the proposed framework and the professional register frameworks don’t recognise the term co-production”.

In a workshop on ‘overcoming the barriers to coproduction, senior leaders and policy leader participants affirmed the need for changed conversation between patients and clinicians since “the old model was to ask the client ‘what’s wrong ?’ and the new way is to ask ‘what matters to you?’ The feeling was that this approach would “Stop negative conversations and reframe the job of clinicians as connecting people to what matters to them, to stop reinforcing negatives and work to give the life people choose”. They considered that the biggest challenge in embedding coproduction is in “changing cultures and behaviour of staff and citizens. For staff there are currently expectations of form filling, taking away the professional responsibility from staff”.

In a series of three workshops at the Academi Wales Summer School in July 2013, the principles of cocreating health were shared with senior public service leaders from across Wales. The following views were elicited using a free writing exercise: “cocreating health should include elements of an ideal GP consultation a la Pendleton or Neighbour.” Another said “co-creating health is a really good idea as it involves the service user in the decision making and will hopefully help them to take more responsibility for their treatment.” A further view was ““Cocreating health gives the control back to the patient for their own care but must ensure that sufficient education is provided for the patient to aid informed options on their future”. Another said “I do see the value of the concept from a whole systems view”. However, the approach may prove challenging to some clinicians as according to one participant of the summer school “There seem to be the matter of ‘I am a doctor therefore cleverer than you so just do as I tell you” whilst another said “empathy and listening seem to be skills that are not taught or untaught at medical college.”

4.2.3 Insights from Clinicians

Clinicians spoke of “health care professionals increasingly moving from deliverer to enabler with therapists in particular speaking of “a shift from the medical model and from medicalisation” towards the “promotion of an understanding of the social model of disability and its complementarity to the medical model”. Other reactions to cocreating health were “putting the end user at the heart of all decision making has to be the way forward and asking who else can I work with to make this person’s life the best quality it can be needs to be common practice”.

4.2.4 Insights from other Stakeholders

Specific support for implementing cocreating health was gained from a wide variety of stakeholders. Representatives of ‘Expert Patient Programmes’ “approved of cocreating health” since it was consistent with their four stage formula.

On talking to a mental health liaison psychiatry team the doctors explained that they now have less emphasis on the traditional medical model and spend more time discussing behaviour and consequences with individuals and care home staff. They said that psychiatrists no longer work using the same medical model. For example, they used to have a medical solution to a mental health issue, mostly prescribing medication. However the psychiatrists now work in multidisciplinary teams and have changed their practice by working alongside occupational therapists and social workers who have a different clinical model.

4.3 Insights on Specific Elements of Cocreating Health

4.3.1 Preparation

Preparation for the interaction was the first step element identified by workshop participants in cocreating health and a number of different aspects to preparation were identified during the literature review and early discussions. The suggestion of a preparation element arose both from policy leads, leaders and individual clinician participants in a cocreating health workshop. It was acknowledged that preparation is important although clinicians do not currently have adequate time to prepare for an interaction with patients mentally or to fully evaluating information available to them from previous interactions. Feedback from leaders was that in cocreating health,

“some will be concerned also that it will take much longer to do consultations and will require them to be much better prepared in terms of information patient will want to have access to for example around options” Another comment was that “In implementing a preparation period, from clinician perspective it will be important that this is part of their basic training”. One individual with responsibility for implementing coproduction said “Before the consultation, both patients and clinicians need time to prepare – this is a big challenge. There is significant pre-consultation work needed by clinicians to understand a patient’s notes. The same would be true of patients if they had access.”. They acknowledged that “Preparation for interaction is one of the biggest challenges for both clinicians and patients. Bringing patients and clinicians together with knowledge, time is outside the immediate control of people other than patients and clinicians themselves”. However, this individual did signpost that some clinicians already build preparation into their interaction with patients “Some clinical areas for example haematology in Cardiff encourage people to come with written questions and prompts”.

4.3.1.1 Availability of Information

In discussing preparation that patients would need to do prior to the interaction, access to shared electronic clinical record and authoritative information appeared key to cocreating health. A further issue was described by a policy lead who said that “To work in Wales, co-production requires information for the public and we don’t have this yet.” However, since this has been recognised as an issue in Wales, a number of organisations are “developing a strategic approach to health information” for Welsh residents. There were a number of comments from an NHS Wales Executive Director workshop about the need for patient access to information including “I want my health record” ; “We need a consistent message from all staff and services related to condition and to provide wider public health and lifestyle messages” ; “Patient centred communication, to the level I want” ; “Easier access to patient record” ; A range of resources, accredited by the NHS” ; “Patient electronic record shared between health and social care accessible to all with levels of access” ; “There is a potential widening of gap if no access to IT/mobile network” ; “Requires working in coproduction with IT providers for solutions” ; “We need portable devices for information sharing between

clinicians and patients on valid sites that could be kite marked” ; “Sharing with patients and carers enough of the correct information to allow them to make informed decisions – websites; patient information leaflets etc”. One issue for resolution was around “Information governance” with consideration needing to be given to security and levels of access” One clinician said “there is currently an absence of shared resources. Patients can’t access their own information. They need to be empowered with sources of good information and need to be able to use the internet. Although there has been an information revolution in the past 10 years, many people are technophobic and can’t use the internet.”

In terms of best use of resources, one senior leader said “providing information and advice on self-management to people in primary care settings could mean that onward referral is not needed”. Whilst another said “Providing data to communities can change their priorities” and that “we need a shared understanding of data” between clinicians and patients.

Workshop participants spoke of the “Information revolution that had happened in the past 10 years” but that “the public are technophobic and can’t use the internet”. There was a strong acknowledgement that “People need to be empowered with sources of good information” but that currently there is an “Absence of shared resources and patients can’t access those that do exist”. Participants at coproduction workshops also considered that it was important to “have an electronic patient record covering health and social care that is accessible to all with varying levels of access”. Another spoke of the “potential widening of the gap if patients don’t have access to IT/mobile network”. Another spoke of the need for “portable devices for information sharing between clinicians and patients that are linked to valid sites on the internet that have been quality assured or ‘kite marked’.”

4.3.1.2 Patient Education

For people to understand both their own clinical information and sources of electronic information, it was acknowledged that they need appropriate health literacy. One policy lead said that “collaborative, personalised care planning requires the agreement of goals, and meeting patients’ support needs including knowledge, skills and confidence”. Whilst a clinician said that patients “Need more support to access

information and to understand medical jargon within medical reports” and that they “need better understanding of statistics and interpretation skills to help them read data”. He described the Expert Patient Programme working with patients with long term conditions to “empower them to participate in their own health care”. A core skill in this programme is working with patients to give them an “awareness of the interdependence of their symptoms and attitude and other conditions. Most patients can’t access medical information or interpret it”. Another issue was that patients weren’t signposted to the programme “it’s as if clinicians don’t want to know that there is education programme for patients”. This issue in health literacy “leads patients to get frustrated as they can’t communicate with clinicians”. The issue of information for patients was picked up by a policy lead who said “good information is needed for each patient, not just information from GP. Currently there is no single authoritative source, instead there is a random collection of information that patients access. We need the ability for both patients and clinicians to engage around shared information where currently there is an asymmetry of information. We need to treat co-production and co-design differently from prudent health care”. At the workshop on coproduction organised for Executive Directors from the NHS in Wales, one senior leader said “better health literacy is needed for all as individuals and communities with easily access relevant, high quality information and support available to help them to understand their care and make confident, informed decisions about their health and wellbeing”. Another said “we need to develop a strategic approach to health information” and a third said “we need to promote health literacy and high quality information and support”. Other comments were around the need for “jargon-free communication, related to patient’s and clinician’s agenda” ; “provision of healthcare should not be reliant on patient’s educational level” ; “as a patient I want clinicians to talk to me in a way I understand so that I have the opportunity to learn about my condition” ; “Patients expect to be able to have a discussion with clinicians” ; “I want the opportunity to learn about my condition” ; “I want to know about and understand possible outcomes including benefits and harms” ; “we need consistent messages from all staff and services related to patient’s condition and wider public health and lifestyle messages” ; “We need to use expert patient more effectively” and to provide “ Education for patients through ‘my health online’ and use of standardised pathways” One senior leader considered that “patients without good health literacy can fall behind systems” that the “challenge is what suits individual patients if one level of literacy is

different from those at other end of scale” and that “the cocreating health approach will need to be tailored to the health literacy level of patients”. Commenting on cocreating health framework, a senior leader participating in summer school said “This concept gives the control back to the patient for their own care but we must ensure that sufficient education is provided for the patient to aid informed options on their future”.

However, even with good levels of health literacy, there were views expressed in a coproduction workshop of senior leaders that there is a “need to put information in context” since “Information isn’t Yes/No” and that patients “need awareness of inter dependence of symptoms and attitude and other conditions”. Another said “If we are to get person-centred and centred on the individual in clinical care, then the individual has to be ready for that for example ‘yes the drug works but is unlikely to do so in your case’ or ‘yes, knee replacement is available but you would be better off losing weight’. A shift is required on both sides of the conversation”. A further challenge was that “some information may be judged by doctors not to be in the best interest of patients to understand” whilst a practising clinician said “patients can be confused with too much information and can be given conflicting information. We need to keep the message simple. We need to develop information across Wales that is shared by all.”

The theme was picked up by senior leaders at coproduction workshops with comments such as “Coproduction needs better health literacy for all as individuals and communities. People need easily accessible relevant, high quality information and support to help them understand their care and make confident, informed decisions about their health and wellbeing” and “coproduction requires promotion of health literacy and high quality information and support “. In the coproduction workshop, Executive Directors of NHS Wales considered that patients could be supported to better understand their condition by “using the expert patient programme more effectively” and by “sharing with patients and carers enough of the correct information to allow them to make informed decisions. This could be done using websites, patient information leaflets etc”.

4.3.2 Agenda Setting

The second element identified by workshop participants in cocreating health was the face to face interaction where the agenda is set jointly by the patient and clinician. In

a workshop on coproduction for executive directors from across the NHS in Wales, one senior leader said “we need jargon-free communication, related to the patient’s and the clinician’s agenda” a third said “we need to ensure that care is set within the patient’s lifestyle, situation, and ambitions”.

Clearly, some clinicians already work with a joint agenda. For example in Mental Health teams, liaison psychiatrists ask patients “how are you feeling on a scale of 1-10?” and “consider what is meaningful for an individual”. At the coproduction workshop arranged for executive directors from across the NHS in Wales, there were a number of comments around agenda setting : “We need jargon-free communication, related to both the patient’s and clinician’s agenda” ; “My care is set within my lifestyle, situation, and ambitions” ; “I want to know what I can do/changes I can make to improve my health and the impact of my conditions” ; The interaction should be a real partnership of two experts – the patient with understanding of their own life and the clinician with medical expertise”.

In a workshop on coproduction organised by the chief medical officer for Wales with a wide range of policy and senior leader stakeholders, people said “From the Michael Marmot work, there is growing evidence of the need to ensure that people are in charge of their lives” ; “The vision is that in 10 years’ time everyone has :A contract with clinicians ; Is In charge of their choices ; Is Satisfied with their contract with public services” ; There is a need to develop a person centred outcome approach and a need to develop a common understanding of how to live a good life” ; “We need a personal outcomes framework rather than results based accountability” ; “we need to define outcomes as what matters to me. If we all share this it’s about what matters to us.” Another participant pointed out that clinicians assert their authority over setting the agenda by sitting behind a desk, and by the way they dressed “How we dress in having conversations shows power. If clinicians wear suits, then normal people won’t engage due to the class divide”.

At another workshop on coproduction, policy and leadership participants spoke of their practical experience on introducing coproduction within Adult Social Care “We have changed the conversation. The old model was to ask the client – what’s wrong? The new way is to ask what matters to you? There has been a move away from a

transactional model to shift to what matters to someone as an individual. There has been a move away from solving a problem which creates dependencies and leads to social isolation to an integrated model. We have built a new integrated assessment around people's assets and capabilities”

In a workshop on coproduction arranged for a broad range of clinicians within a Welsh Health Board, participants spoke of : “Conflicting agendas between patient and clinician” ; “I will have to try hard not to influence a patient's thoughts and decisions but it will be interesting to see what they come up with for themselves”. Another indicated that “I must now think about wording with specific issues eg weight loss, starting an exercise programme. I will consider what stage a patient is at when they come into clinic for first time e.g. beginner, travelling etc.”; “Keeping quiet is hard.; “The patient should identify the priorities”.; “I need to engage more with patients. Take things with patient perspective. Each patient is an individual” ; “I really learnt lots about how I don't really ask the patient what they want. It's important to ask them what's important to them or they won't change. ; “I have realised throughout the 3 workshops how much I try and impart my ideas and solutions onto patients instead of listening to their point of view.”. Another spoke of changing their clinical model of interaction with the patient to: “What would you like to change/goal? What will stop you doing? What will improve your confidence? What are you going to do next? What times are you going to do? Problem solving. How often?”. One more spoke of finding out “What is important to the patient? What do they want to change? How can we support them to effectively make the change? Explore the barriers, find solutions. Ask before you offer advice. Remember little things may be having a big effect on the patient's journey. Time at beginning is important.” And lastly, one participant said “I now feel motivated to change things on our structured assessment. I will change my agenda for patients. What do they want, not what is my aim.”

4.3.3 Information Gathering

The third element of cocreating health derived from workshop participant's views is that once the agenda is understood, there may need to be further information gathered to inform both the clinician and patient. For the clinician, this might include asking for diagnostic tests on the patient. For the patient, this might include evaluating some information signposted by the clinician or considering their attitudes to risk. This is

such an embedded part of clinical practise that all interviewees and participants considered this important to cocreating health. Aspects of information sharing were discussed at the Welsh Medical Committee. The principle of sharing correspondence with patients and involving them in the philosophical as well as the practical aspects of care was supported. However, reservations were expressed that ‘Consultants may need to change the way in which they write letters for it to be meaningful for the patient not requiring a GP to interpret every section’

4.3.4 Discussing Options

The fourth element identified by workshop participants for cocreating health is for the patient and clinician to discuss their shared knowledge and come to a mutual agreement about the nature and extent of the physical, emotional and social issues impacting on the patient and discuss the available options.

One policy lead said “the idea that outcomes are determined by the patient from what they want is a very healthy starting point, although this is different from where clinician may be”. He went on to say that “GPs need to manage chronic conditions separately, to do this they will need longer appointments for better communication. This will give them a chance to share information, listen to the patient, and to engage in shared decision making. At heart of coproduction is an individual clinical discussion ” Speaking at the Welsh Medical Committee he encapsulated this approach as clinicians asking patients three questions “What do you (as a patient) want to do differently?” ; “What do you want your life to be?” ; And “How can friends/family/community help you to get there”.

In a coproduction seminar organised by Welsh Government, participants drew attention to an approach already being used in Wales “See Wales Council for Voluntary Action and Health Board work on outcomes based on asking people what they want: we have a good sense of what ‘a good life’ means for people. We should use that as a performance framework”. This was echoed by another participant who said “person-centred planning and planning for real are already in existence – use them”. Yet another said “care plans that are owned are likely to be successful”.

Senior leaders at the coproduction workshops at summer school pointed out some other challenges in patients discussing options with clinicians “I think some clinicians will be concerned also that it will take much longer to do consultations and will require them to be much better prepared in terms of information patient will want to have access to for example around options.” Whilst another said “what seems like common sense practice does not even come to mind, such as a surgeon breaking facts about their surgery.” Another said “there seem to be the matter of ‘I am a doctor therefore cleverer than you so just do as I tell you’” whereas another was more upbeat saying “putting the end user at the heart of all decision has to be the way forward and asking who else can I work with to make this person’s life the best quality it can be needs to be common practice.” Specifically in relation to cocreating health, participants at the summer school workshop said “It is good for patients if they are treated holistically and can fairly understand their condition(s) and the range of options open to them to manage them.” ;

Executive directors within NHS Wales participating in a workshop on cocreating health said that it was important for patients to “have the opportunity to learn about their condition” ; that “their care is set within their lifestyle, situation, and ambitions” ; that patients “want to know about and understand benefits and harms, possible outcomes” and “want to know what they can do, changes they can make to improve their health and the impact of their conditions”. To do this they need “data on the procedure and information relating to their condition, treatment options, success rates and side effects”. In the workshop one senior leader spoke of “a real partnership of two experts, the patient with an understanding of their own life and the clinician with medical expertise. These two come together to discuss the options”. Whilst in the coproduction workshop organised by the chief medical officer, one participant spoke of the “need to develop a person centred outcome approach and to develop a common understanding of how to live a good life with a personal outcomes framework rather than results based accountability”.

4.3.5 Agreeing the Way Forward

The fifth element identified by workshop participants was the need for patient and clinician to jointly agree the actions that they would each take. One policy lead said “As clinicians we need to understand that it’s not our life-we have to find a way to

support people to be in charge of their own life. We may need to introduce the idea of a cooling off period to allow people to reflect on the way forward chosen within a consultation with a clinician. We know that if we do this, thirty per cent of patients will choose not to have treatment they had agreed to in the consultation.” She illustrated this with the example of prostate cancer where “surgery can lead to impotence and other disabling side effects, when it might be better to leave alone”. She also signalled that “clinicians need to focus on the wellness of the patient”.

Senior leaders at a coproduction workshop at summer school spoke of the need for “joint ownership by participants of any agreed actions” ; of the “health care professional increasingly moving from deliverer to enabler, agreeing right up front with patients what outcome you are trying to achieve through a co-pro approach”. Another said “putting the end user at the heart of all decision has to be the way forward and asking who else can I work with to make this person’s life the best quality it can be needs to be common practice.” However, the challenges in delivering this were acknowledged “There seem to be the matter of ‘I am a doctor therefore cleverer than you so just do as I tell you’”, whilst another said “Empathy and listening seem to be skills that are not taught at medical college.;

4.3.6 Implementation

The sixth element of cocreating health identified by workshop participants was the need for both clinician and patient to act on the agreed way forward. The clinician would provide treatment, refer to another service, obtain further diagnostic tests. The patient would make health behavioural changes such as increasing physical activity, losing weight, stopping smoking. It was understood that without the patient making changes in the way they lived their life, treatment provided by the clinician might not provide the outcomes desired by the patient.

4.3.7 Review and Further Actions

The seventh element identified by workshop participants was review to determine if the agreed, desired outcomes had been achieved. Senior leaders participating in a

cocreating health workshop pointed to the need for “appropriate measures to monitor progress” ; that this was a “continuous process, not a one-off event”. They considered that this required “robust metrics, shared across organisations with the use of analysis and feedback to drive improvement” and “common goals and outcome measures supported by analysis and feedback”. Another senior leader spoke of the need for “whole system measures that would drive high impact changes” achieved by “agreeing a set of measures for use across the whole system including patient reported experience measures, patient reported outcome measures, metrics for: patient engagement in decision-making ; personalised care plans. This would be delivered by co-ordinated services supporting patient self-management”. Another clinician noted that “Welsh Ambulance staff have concerns that they never know the outcomes of the patient journey.”

4.4 Exploration of Clinician Attitudes towards Cocreating Health

Discussion in the workshops and stakeholder group meetings had determined that for clinicians, working collaboratively with a joint agenda was the most unfamiliar and potentially transformative element of cocreating health. The initial clinical professional training for many different clinical professions is to interact with patients in the traditional medical consultation model. A detailed investigation was designed to determine whether staff from a variety of professional backgrounds with initial training in the traditional medical consultation model could be successfully trained in working with a joint agenda. In particular this aspect studied whether there are differences between professions in their responses to training and whether they could become ‘activated’ towards engaging in partnership with patients in cocreating health.

The Health Foundation had established and published an independent evaluation (Wallace et al, 2012) of ‘the advanced development programme’ to train clinicians to support patients in self-management. One of the trainers involved in this programme, with a supporting actor, was commissioned by this researcher to deliver this training to seven cohorts of volunteer clinicians. This training was delivered to 196 clinicians over three half day sessions spaced a month apart to allow consolidation of skills. Of these, 164 clinicians attended at least two out of three training sessions. Each of these 164 clinicians completed the ‘longitudinal questionnaire’ (Appendix 1) that had been

validated and used by the Health Foundation to evaluate this training. Of these, 129 completed the longitudinal questionnaire before and after training.

In addition, a questionnaire was developed by this researcher (Appendix 1) to investigate whether respondents were using elements of cocreating health identified by workshop participants in their clinical practice. 83 clinicians completed this questionnaire.

An anglicised version of the Clinician Activation Measure (CS-PAM) questionnaire of Hibbard et al (2008) was developed by this researcher (Appendix 1) and used to determine attitudes of clinicians towards engaging with patients in self-management. A licence was obtained to deliver 75 CS-PAM questionnaires and respondents were randomly selected from the 164 clinicians who had attended at least two out of three training sessions. The anglicised CS-PAM was delivered alongside a questionnaire developed by this researcher to determine which elements of cocreating health were in place within the respondent's clinical practice.

Finally, it was intended that responses to the questionnaires were used to elicit themes that could be explored further in the later qualitative phases.

4.4.1 Results from the Health Foundation Longitudinal Questionnaire

This questionnaire asks clinicians a number of questions with either a scale from 1 (strongly agree), 2 (disagree), 3 (not sure), 4 (agree), 5 (strongly agree) 'when working with patients to what extent do you agree with the following statements' or uses a scale of 0 to 10 (0=no importance, 10=extremely important)

Using a paired samples t-test, the data were examined to investigate whether the changes were statistically significant at the $p < 0.05$ level. To account for the Bonferroni effect of making multiple pairwise comparisons, a simple post-hoc modification was used to adjust the level at which a comparison of means was considered significantly different. The α level was computed by dividing the 'p' value by the number of pairwise comparisons, in this case 14. Using this post-hoc adjustment, a statistically significant difference between means would be accepted at

0.05/14, or where the 'p' value was $p < 0.0036$. There was insufficient data to analyse the results by professional group to investigate whether the positive effect of training was different for different professions.

Examining the contention that the patient and the healthcare professional are equals and experts before training, on a scale from 0 to 5, this scored a mean of 3.72, whilst after training this increased to 4.31, demonstrating a statistically significant change with training towards the clinician agreeing that the patient's expertise should be acknowledged.

In terms of the contention that the patient and the health care professional share responsibility for decisions made, on a scale from 0 to 5 before training this scored a mean of 4.25, whilst after training this increased to 4.47, which using the adjusted ' α ' level did not demonstrate a statistically significant change with training. This may be a 'ceiling effect' due to strong agreement with the proposition prior to training.

The next proposition explored 'on a scale from 1 (none) to 5 (expert), how much knowledge the clinician had about supporting self-management? This showed a statistically significant increase with training from a mean of 2.5 to 3.88

When asked 'How important is it to you to do self-management support on a scale of 0 to 10 (0=no importance, 10=extremely important), prior to training, clinicians scored a mean of 9.09, whilst after training this increased to 9.17 This did not change significantly with training, again reflecting a ceiling effect.

The questionnaire then asked a further series of questions were asked on a scale of 0 to 10. The changes following training are shown below in rank order of biggest change first in Table 4.1

Table 4.1 Changes in Clinician Scores with training for Health Foundation Longitudinal Questionnaire

| Question | Mean Before Training | Mean After Training | Mean Change | Standard Deviation of Mean Change | Range of change | t-test | 'p' level | Significant at α | Rank Order |
|---|----------------------|---------------------|-------------|-----------------------------------|-----------------|--------|-----------|-------------------------|------------|
| Sign post to local self management programmes | 5.45 | 7.59 | 2.13 | 2.59 | -6 to 8 | -8.99 | 0.000 | Yes | 1 |
| Confidence in self management support | 5.82 | 7.64 | 1.81 | 2.23 | -4 to 7 | -9.23 | 0.000 | Yes | 2 |
| Help patients to develop skills needed for effective self management | 6.07 | 7.74 | 1.67 | 1.87 | -2 to 9 | -9.88 | 0.000 | Yes | 3 |
| Adopt a culture of continuous service improvement | 6.67 | 8.11 | 1.44 | 2.11 | -3 to 9 | -7.57 | 0.000 | Yes | 4 |
| Knowledge of supporting self-management ? | 2.5 | 3.88 | 1.38 | 1.00 | -1 to 7 | -15.46 | 0.000 | Yes | 5 |
| Jointly agree how and when progress will be monitored | 6.9 | 7.98 | 1.08 | 1.87 | -2 to 7 | -9.88 | 0.000 | Yes | 6 |
| Undertake joint problem solving to support patients to meet their goals | 7.03 | 7.95 | 0.92 | 1.76 | -2 to 7 | -5.83 | 0.000 | Yes | 7 |
| Collaborate in setting personal health goals | 7.16 | 8.05 | 0.89 | 1.77 | -2 to 8 | -5.57 | 0.000 | Yes | 8 |
| Explore with the person how their condition affects their life | 7.74 | 8.42 | 0.68 | 1.87 | -3 to 7 | -4.15 | 0.000 | Yes | 9 |
| The person and the clinician are equals and experts | 3.72 | 4.31 | 0.59 | 1.08 | -2 to 4 | -6.20 | 0.000 | Yes | 10 |
| The person and the clinician share responsibility for decisions made in the consulting room | 4.25 | 4.47 | 0.22 | -0.98 | -3 to 4 | -2.51 | 0.013 | No | 11 |
| Importance of providing self management support | 9.09 | 9.17 | 0.09 | 1.35 | -3 to 5 | -0.72 | 0.473 | No | 12 |

This data showed that training produced a large change in clinicians understanding of the need to signpost patients to self-management support programmes.

4.4.2 Results from the Cocreating Health Questionnaire

Respondents were asked to indicate an answer to the question ‘How much do you agree that in your everyday work you regularly...’, on a scale where 1 indicated strong agreement, 2 indicated agreement, 3 was ‘not sure’, 4 was disagree and 5 demonstrated strong disagreement with the proposition. Answers are rank-ordered by score in Table 4.2 below :

Table 4.2 Results from Cocreating Health Questionnaire of Rank Order of Clinician Answers to the question ‘In my everyday work, I regularly’ :

| Question | Rank Order | Mean | S.D | Min | Max |
|--|------------|------|------|-----|-----|
| Ensure that patients understand their condition and the options available to them | 1 | 1.6 | 0.69 | 1 | 4 |
| Agree an individual management plan with my patients | 2 | 1.61 | 0.75 | 1 | 4 |
| Measure clinical outcomes from individual patients | 3 | 1.76 | 0.73 | 1 | 4 |
| Ensure that patients have the knowledge and understanding to be able to engage in discussion as an equal partner | 4 | 1.85 | 0.75 | 1 | 4 |
| Contribute to service development or research | 5 | 1.89 | 0.8 | 1 | 4 |
| Contribute to audit of my own practice | 6 | 1.93 | 0.75 | 1 | 4 |
| Use the results of individual patient outcomes to inform discussion with individual patients about their treatment | 7 | 1.98 | 0.93 | 1 | 5 |
| Use the results of my own service development or research in discussions with patients | 8 | 2.01 | 0.67 | 1 | 4 |
| Use the results of other people’s service development or the evidence base in discussions with patients | 9 | 2.09 | 0.71 | 1 | 4 |
| Use the results of audit of my own practice in discussions with patients | 10 | 2.44 | 1.0 | 1 | 5 |
| Give my patients written copies of information held about them | 11 | 3.26 | 1.08 | 1 | 5 |
| Find that my patients are well informed about their condition before they arrive for their appointment | 12 | 3.29 | 0.88 | 1 | 5 |

These results suggest that these clinicians have a number of the cocreating health elements identified by workshop participants in place within their practise including working to the patient’s agenda, discussions of options, measuring clinical outcomes, agreeing the way forward in partnership with patients, contributing to audits of practice, both carrying out service improvement and using this in discussion with patients. The cocreating health elements that were not so strongly embedded in practice included supporting the preparation of the patient before the first appointment, providing the patient with written information about the chosen options or using the results of clinical audit to inform discussion with patients.

4.4.3 Results from Clinician Activation Measure Questionnaire

Results from the anglicised Clinician activation measure questionnaire (Hibbard et al, 2010) by clinician profession are given in Table 4.3 below

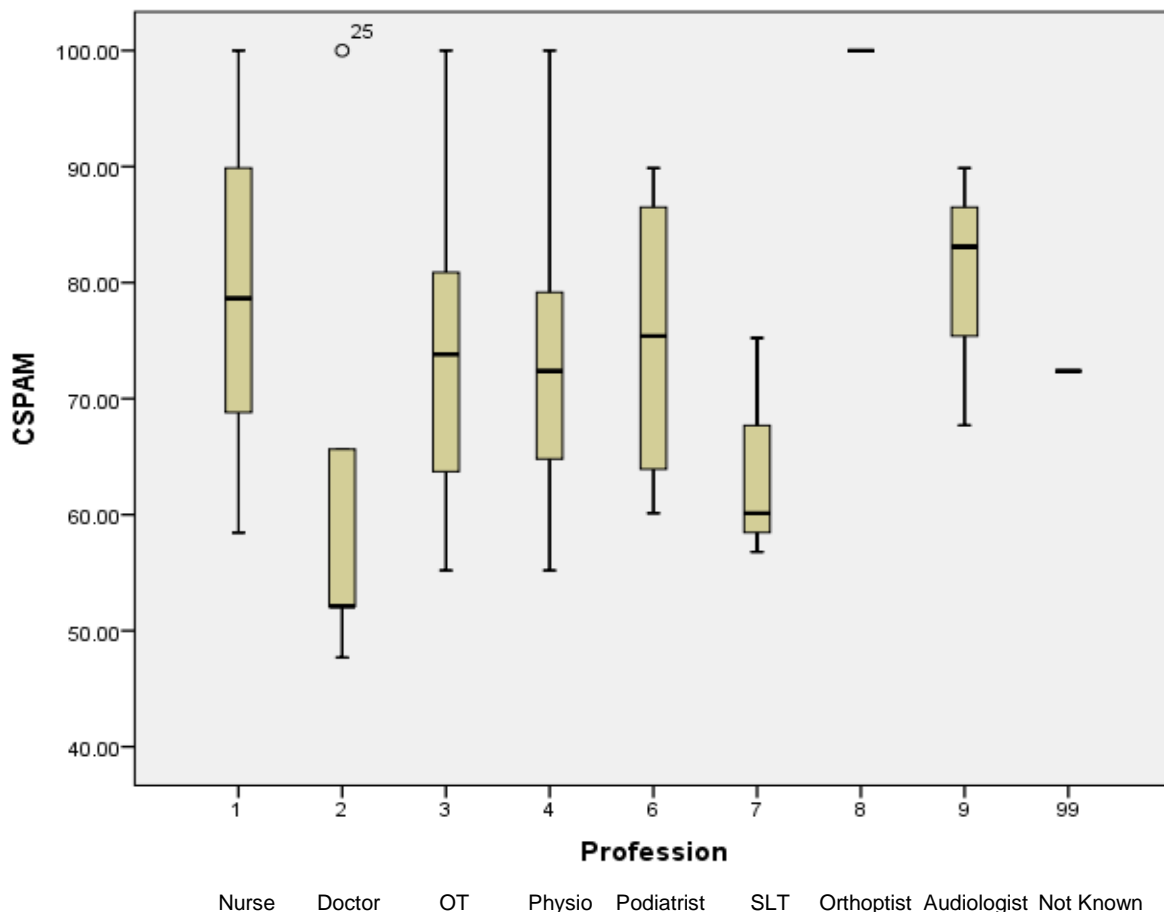
Table 4.3 Results from the Anglicised Clinician Activation Measure Questionnaire by Profession

| Profession | Number of Respondents | CS-PAM Mean | Standard Deviation | Minimum | Maximum | CS-PAM Level 1 | CS-PAM Level 2 | CS-PAM Level 3 |
|-------------------------------|-----------------------|-------------|--------------------|---------|---------|----------------|----------------|----------------|
| Nurse | 20 | 79 | 13.5 | 58 | 100 | 0 % | 15 % | 85 % |
| Doctor | 5 | 64 | 21.5 | 48 | 100 | 0 % | 60 % | 40 % |
| OT | 24 | 75 | 13 | 55 | 100 | 0 % | 4 % | 96 % |
| Physio | 15 | 73 | 13.8 | 55 | 100 | 0 % | 13 % | 87 % |
| Podiatrist | 4 | 75 | 13.7 | 60 | 89 | 0 % | 0 % | 100 % |
| Speech and Language Therapist | 3 | 64 | 9.8 | 57 | 75 | 0 % | 33 % | 67 % |
| Orthoptist | 1 | (100) | xx | xx | xx | 0 % | 0 % | 100 % |
| Audiologist | 3 | 80 | 11.4 | 68 | 90 | 0 % | 0 % | 100 % |
| TOTAL | 75 | 75 | | | | 0 % | 13 % | 87 % |

Hibbard and colleagues (2010) established boundary scores for clinician activation as measured by the CS-PAM by level. They considered that the attitudes of clinicians with activation scores of 37.81 or lower would be that the patient’s role is to follow clinician’s advice (level 1) ; having an activation score of 39.23 to 58.44 signified an attitude that patients can make independent judgments and actions (level 2) ; and where the activation score was 60.13 or above this suggests clinicians believe that patient’s role is to function as a member of the care team (level 3).

Although these are small samples, nurses have similar activation scores to the therapy professions. A strong finding is that doctors are less activated than other professionals and those surveyed are less activated than doctors in the Hibbard study. This is shown graphically on the box plot in Figure 4.4 below where profession 2 are doctors. Within professions, these data show strong inter-subject variances and non-parametric analysis confirmed that the differences in median CS-PAM scores between professions are not significant at the $p < 0.05$ level.

Table 4.4 Box Plot of Clinician Activation Scores by Profession



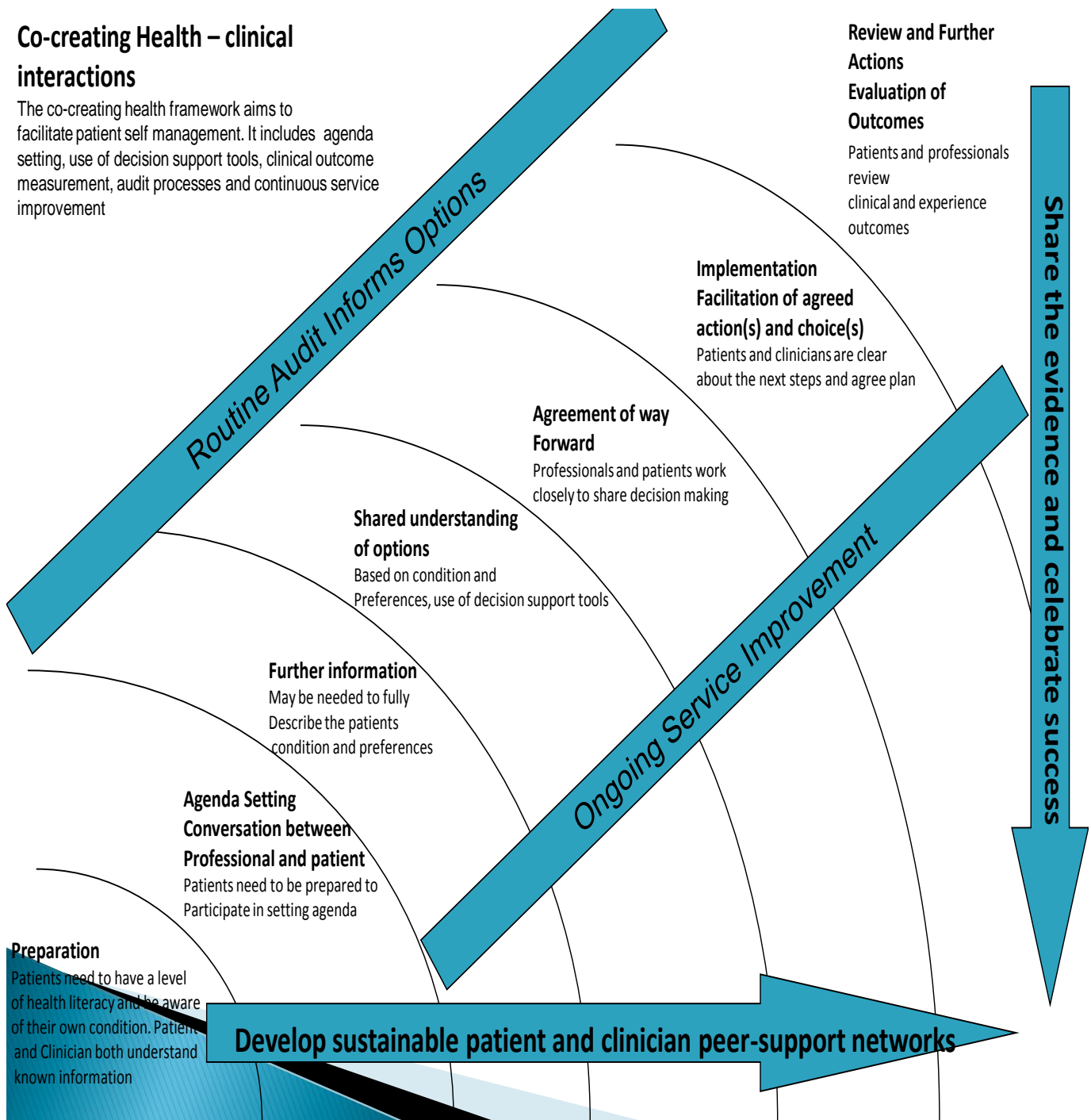
In this study, the average CS-PAM score for doctors was 64, compared with 69 in the research of Hibbard and colleagues. The average difference in activation scores for doctors in this study compared with those in the Hibbard et al research may result from differences in activation of doctors in primary and those in secondary care. The Hibbard et al data was collected mainly from primary care doctors who might be expected to have higher levels of activation than the secondary care doctors surveyed in this research. This data confirms the views of workshop participants that doctors, and in particular, secondary care doctors may be challenged to engage in cocreating health with patients. In terms of level of activation, one hundred per cent of clinicians studied were at level two or better, suggesting an attitude that patients can at least make independent judgments and actions. In addition, the overwhelming majority of nurses and therapists had activation level three suggesting they considered patients as a member of the care team. In this study, the average CS-PAM score for nurses was 79 and was 75 for Allied Health Professionals. Both of these scores are higher than the primary care doctors of the Hibbard et al study, again suggesting higher levels of activation for nurses and therapists, and that these clinicians might be more comfortable with a cocreating health style of interaction with patients.

4.5 Conclusion - Creating a Test Cocreating Health Framework

Findings from the quantitative data from questionnaires demonstrated a positive change in clinician's perception of their ability to support patient self-management following training. The largest beneficial effects were to improve aspects that clinicians generally found most difficult prior to training, such as sign posting people to local self-management programmes, improving their confidence in providing self-management support and helping patients to develop the skills needed for effective self-management. The separate questionnaire examining initial cocreating health constructs showed that in clinicians' current practise, the elements that they least engaged in were preparing patients prior to the appointment and using results of their own audit or research to inform discussion with patients. Results from the clinician activation measure questionnaire showed doctors to be less activated than nurses and therapists.

The literature review of patient clinician interaction models, particularly those of Paget et al (2011), the biopsychosocial model of Engel (1980), human needs set out by Max-Neef (1989) showed the increasing relevance and importance of relational models of clinician-patient interaction. These had supplanted the original 'scientific' bio-physical models based on the work of Maslow and increasingly pointed towards a partnership approach with clinicians supporting patients to manage their own health. The initial concept of cocreating health had been developed by Conway and White (2006) from the work of Max-Neef (1989) but had not given a practical method of implementing the philosophy. A synthesis of this evidence from the literature review gave this researcher the philosophical concepts of cocreating health to explore with a wide range of stakeholders within Wales. Initial discussion of the concepts elicited a number of potential elements that were considered by participants to be relevant in cocreating health. Amongst these participants were a number who had been exposed to literature on the concepts of coproduction, codesign and the Health Foundations' cocreating health programme. The researcher's own reflections from twenty two years clinical practise were combined with insights from the participants of the workshops and questionnaire data providing a synthesis of the elements that were used to develop a first iteration of a cocreating health framework for testing. In addition to the clinical interaction, elements were included from the literature review to describe the supporting effect of both clinical audit and service improvement to clinician understanding of the options and outcomes that they might discuss with patients. The findings from the workshops and questionnaire data were also used to determine themes for semi structured interviews and to set out an initial 'open' coding structure. Given the differences found in clinician activation level between doctors and other professional groups, it was considered important to gain detailed insights from different professional groups. The findings also demonstrated that views of people at different levels of policy, leaders and clinicians gave different insights and so it was decided to seek the views of participants about cocreating health from different professional groups at each of these levels. The test cocreating health framework is shown below in Figure 4.1.

Figure 4.1 Initial Cocreating Health Framework for Testing in the Second Phase



Chapter Five : Results and Analysis from Evaluation of the Test Cocreating Health Framework

5.1 Introduction

Data from the workshops and questionnaires demonstrated the need to explore in depth the views of participants from three different professional groups of doctor, nurse and therapist and from levels of policy, leader and clinician. Accordingly, this chapter describes themes and insights from semi structured interviews carried out with thirty one participants. Interviews from thirty one participants gave a great deal of information, and this is shown in Appendix 4. Selective coding of the data was performed as it was collected against the structure of the cocreating health framework, and against emergent themes arising from the interviews. The outcome of this work was to define a final version of the cocreating health framework with seven elements and supporting factors of reflective practise and service improvement.

5.2 Views on the Test Framework

Although there were caveats, positive support was expressed for the test cocreating health framework across all levels and all professional groups. One policy leader considered that “the cocreating health framework resonates with prudent healthcare” and that the principles of prudent healthcare were “similar to the elements within the cocreating health framework”. He said that “Conceptually the cocreating health framework is a great idea. Now might be a good time to implement the cocreating health framework given ministerial support for coproduction and prudent healthcare”. He said further that “the cocreating health framework is encouraging and describes a negotiation between the healthcare provider and the consumer”. He considered that the first five elements of the cocreating health framework could be readily implemented within the NHS in Wales but the sixth element, ‘implementation’ “will be difficult for patients and clinicians to comprehend”. He also drew attention to the potential for the clinician working within a cocreating health framework to act as the ‘agent’ of the patient and described a “perfect agency relationships where the professional would act solely in the interest of the patient”. He went on to say “however there are constraints on this in current health and social care services such as professional

body, organisational constraints and because of this the clinician as agent is compromised in acting for the patient". He considered that the concept of agency needed to be considered within the cocreating health framework "the cocreating health framework is working towards a better agency relationship between patients and clinicians. Since the consumer is unable to acquire all the required knowledge to make informed decision, the job of the agent is to provide information on which the patient can make an informed decision" but acknowledged that "this will be difficult for some professionals". He further explained that agency is useful where consumers are not well informed "there is the notion that consumers are now better informed via internet. This means that the professional is not the sole source of information to guide the patient in their decision making "

The same policy leader further considered that different professionals will engage differently "some clinicians want to engage patients in the decision making process. When Glyn Elwyn was working on shared decision making in Wales he did not get much buy in with doctors and so went to Holland, where healthcare professionals engaged better in shared decision making". He further explained that cocreating health "could be seen by some in Wales as de-professionalising". However, he echoed Glyn Elwyn's view that "the role of the professional is to ensure that a patient is engaged in their own healthcare and well-being". He further said that "the cocreating health framework helps clinicians and people to move towards different relationships. Some interventions will stop at an early step in the cocreating health framework"

This policy leader said that "the cocreating health framework has mileage" and that "the cocreating health framework fits". He further explained that "because there are many pressures and demands on the healthcare system in Wales, until last October it was difficult to view the cocreating health framework as becoming part of normal practice in health and Social Care. However, there is now much Ministerial support for coproduction and prudent healthcare".

A second policy leader within Welsh Government had been tasked with implementing 'Prudent Healthcare'. He said his reaction to the cocreating health framework was "100 per cent positive" and the "idea that outcomes are determined by a patient from what they want is very healthy starting point which is different from where clinician may

be". He explained that "Prudent healthcare is over and above the current medical model where Doctors interrupt patients because they have got X minutes for the consultation and have to get to the point quickly". The Welsh Government policy lead for implementing coproduction acknowledged that the cocreating health framework "showed people how to embed coproduction" but signified that there has to be the correct environment in place for people to implement coproduction.

A senior leader, a GP by background, considered that the cocreating health framework "is a good idea" and "very comprehensive". She felt that "coproduction should be at the heart of how we manage patients since managing co-morbidities is challenging". She further said that we "need to teach clinicians about the stages in the cocreating health framework" but that "it needs to be acceptable by all those who will use it". She expressed a concern that "because of the financial context, there is a risk that people will think that we are changing to the cocreating health framework to save money". She also felt that there was a "need to understand how to do coproduction on a National scale, so that it becomes an accepted part of the NHS".

A second senior leader has professional accountability for the clinical practise of over a thousand therapists, health scientists and psychologists. She felt that "the co-creating framework reads well, is easy to read and makes good sense". She considered that "the co-creating health framework should be published and used". She reflected that the framework had been "synthesised on 3 sides of paper with a stepped approach, like a recipe". However, she considered that "the framework is not the way that physiotherapists work. They don't like being told what to do. Physiotherapists are more tailored to individual practises". She did go on to acknowledge that "the co-creating framework would fit comfortably with existing processes" and that "if clinicians use the co-creating health framework in their clinical practice they will get better at it".

A third senior leader considered that in urgent care contexts there is a need to be didactic but that even in this situation the cocreating health framework can be used to help people understand the steps needed. She said that to operate the cocreating health framework "clinicians will need to feel they have the permission to be able to suggest that patients go away, understand some of the issues before coming back to

discuss options". She considered that embedding the cocreating health framework would give "challenges in terms of new to follow up ratio, time, and resources". In her view, the framework would be easier to embed in outpatient consultations, rather than inpatients. In inpatient settings she considered that "the plan may be imposed rather than agreed." She said that "the sicker patients are, the more likely it is that clinicians will do things to people, that is a medical approach, with people being told what to do." There would be a need to document appropriately, to describe what patients and clinicians are trying to do that needed to be linked to outcomes which are clear and measurable. She said that there was a "need to structure consultations for more negotiation". In terms of the behavioural change aspect of the framework, she said that "the temptation is to assess someone as not ready for change, but give change information anyway". In support of the framework, she said "we are there for the patient. As long as they fully understand and we clearly document the discussion, that this is patient choice, patients are free to ignore advice. This has to be the patient's decision. They may wish to choose a behaviour that is harmful to them. In this situation we still have a duty of care to guide them". Further in support of the framework she said that the "paternalistic approach is now becoming more difficult. For example in patients with obesity, dietitians used to say that there was only one way to lose weight. Now there is National Guidance is to support weight loss by any mechanism that's working for the patient. When they have lost their weight the dietitian will aim to get them back to a long term healthy diet. She added the caveat that clarity of approach will be needed, with good documentation that options chosen by the patient might be harmful. In terms of embedding the cocreating health framework within multi-disciplinary team working she reflected on her recent experience in trying to embed enhanced recovery after pancreatic surgery meeting where it took a long time to get all professionals around the table to agree even simple procedures such as pain control.

A fourth senior leader was "familiar with cocreating health and supportive of its principles". He said that he "didn't feel that any important steps or factors have been left out of the framework". He liked the flow within the framework, the quality improvement aspect and the elements of Shared Decision Making. He reflected that "getting service users engaged in cocreating health is a systematic challenge. It is even difficult to get people to wash their hands". He felt that "conditioning of patients

to engage starts at the start of consultation process. Clinicians need to make it immediately clear to patients that they're being asked to be active in the consultation". He also said that "academics have tried to promote shared decision making as a single entity. But this needs to be implemented as part of the co-creating health framework". He went on to say that "co-creating health should be seen as a continuum rather than a series of isolated entities". He reflected that "the cocreating health framework links back to a relationship centred approach". He described some implementation challenges in embedding the framework as "the expectation of both patients and clinicians is that clinicians will talk, and patients listen. If there is silence in the consultation, this uncomfortable for both".

One clinician, a practising GP, said that the cocreating health framework "has lots of information, is well structured and with some organisational change "could be implemented within current resources". He considered the cocreating health framework as "the manual to implementing coproduction". He said that "doctors need to understand why to do coproduction" to buy into the principle before applying the cocreating health framework. Also that "the cocreating health framework describes a better overview, a strategic view on how to deliver coproduction". In his view, although the implementation of co-production will take time, "there are quick wins in applying this. For example in patients with long term conditions". He described the cocreating health framework as "a good way forward" that would work well in consultations in primary care as "General Practice is about co-operation, consent and understanding the patient". However, he did see that there may be "issues in translating the agreed way forward into a message that goes forward with different doctors and nurses in the practice". This would need the whole practice to sign up to the concept so that working within the cocreating health framework is "everybody's job". He said that, although "most patients want to work with clinicians", many have a lack of even daily planning in their lives and are reactive. He considered that "unless patient expectations can be lifted there will be difficulties in applying the cocreating health framework universally".

After providing their views of the cocreating health framework, interviewees were asked to comment specifically on the elements that comprise the framework

5.3 Preparation

The preparation element had been found from questionnaire answers reported earlier to be the least well developed in current practise.

A policy lead commented on difficulties in preparation “unless you work in a hospital at the moment it’s very difficult to access patient records. There are ways around that, there are quite easy ways around that but not necessarily ones that we’ve cracked because there are issues about general practice and access to their notes and who gets it”.

This was corroborated by a clinician who pointed to the difficulties in getting patient information “in terms of preparation, because I’m working in a community setting at the moment we’re not always given much information at all in terms of medical notes and things.

Variability in preparation was discussed by another clinician who said “the information I have about the patient before I meet them includes demographics, I have diagnosis, depending on the referral I may have past medical history, I may also have the treatment regime. Before I see the patient I sometimes spend 5 minutes reading the information. It depends, if I get my referrals from the MDT then I’m party to a full discussion about them, and I know what exactly it is that’s expected of me from the MDT. If it’s a referral that comes in randomly then I have whatever, and sometimes I have a name and phone number because sometimes I accept self referrals, so I know nothing about a person until I make that first contact”.

A second policy lead pointed out further issues in preparation for patients with cognitive impairment “at the preparation stage, there will need to be a working out of whether it’s suitable to have that patient engage in that way. So, for example, if someone has a moderate degree of learning disability, would they fully understand and be able to be the equal partner. There’s a little bit of me thinking that the model would work for some people, with a little bit of help, but some people would never be able to step up to the plate to engage in that way. The biggest difference that struck me when we were looking at the cocreating health model, was preparation. Now if I’m

going to see my GP then I will think very carefully about what I want to say to him because it usually takes me weeks on end to get an appointment so I have plenty of time to think about it. Now he may or may not even glance at his notes before I even walk through the door so in some circumstances I will have thought through what I need and I have gone to see some doctors who will say 'you're here why?' and I will say well if you look at my notes I can tell you blah blah, and I'm having to tell the story for them, so the preparation thing I think is probably the biggest difference in the model". .

One leader pointed to assistance for patients to prepare "by using option grids, this would steer or focus the consultation with the patient coming out with a better understanding of their own condition and treatment options".

A second leader described a further challenge "There is significant pre-consultation work needed by clinicians to understand a patient's notes. The same would be true of patients if they had access. This is a big challenge. Some clinical areas, for example haematology in Cardiff encourage people to come with written questions and prompts".

A third leader said "some of the pre-work may mean coming into a conversation with a different lens on, so this isn't a 'come and tell me how bad your breathing is and I will give you a prescription', it's what are the important things to you, so it might be going to the newsagents, popping in to the hairdressers, her friend, so the framing is set from outside, almost outside of the consultation, I think that's quite useful as well".

A fourth leader pointed to "the type of information we give to the patient, we'd have to work them up prior to a clinical appointment in a different way and we could do that by paper, on their appointment slip".

A fifth leader said "the preparation stage is probably one of the bigger challenges in the model in bringing clinicians, patients together with the right level of understanding, skills, readiness, time. Once the consultation or an encounter starts, there's more that's taking place, a more controlled environment to a certain extent. But before people come to that as patients or clinicians, they're influenced by so many other things that. From a clinician's perspective, we need to introduce the need for

preparation starting at the training, at the education level and being able ideally to put people in student environments where these things are practised almost overtly, people soon pick up the habits of people who are training them. So there's an immediate signposting of patients to their need to be active and engage in their consultation. Because doing that preparation before is challenging, there is the aspect of people might not fully understand why they've got to secondary care. One of the small pieces of work around the 'ask three questions' in Australia suggested that the timing of the consultation could be shortened or the time used more effectively if people were using some sort of structure, and intuitively it's a reasonable approach that if there is a focus around questions or around work / preparation that's been done previously, that the time in the consultation is used more productively rather than going round the houses."

A clinician said that they prepare fully in their current practise "I will have read the notes, so I'll have had a big picture because they'll have been referred, either from the ward, or re-ablement or something, so I have quite a bit of information, and will often ask the relative to come at least to the first one. It's only on the first meeting that you find out how much a patient understands their condition. People cope with their conditions in different ways don't they. I've got a couple of patients with MS that would never go on an MS website because it would just really upset them. They cope by dismissing it. And others will get absolutely immersed in it and want to know absolutely everything about it. And that's the hard bit, you're dealing with that mix the whole time". A third clinician said "I would take a telephone handover, so you've got time to think about who's coming on to the ward, what their pressure relief needs are, their seating arrangements, and how they transfer, and so you've got a bit of information there. But when the patients come to the ward, you're going to spend about thirty minutes going through the medical notes".

Another clinician said ". We would probably see something like six or seven patients a day and because of what we're doing with them, rehab, and discharge planning it's pretty important that you get to know each patient in quite a lot of detail".

However, preparation time was an issue for another clinician who said "perhaps what we don't do is the sending out of information, the preparation. The challenge at the

preparation stage is having access to medical notes, time to read through the medical notes and the time to get the medical notes”.

Team work in preparation was described by a sixth clinician who said “In our service we read through the summary which has come through the chronic pain team. So we get an idea of their background, their condition, and it also includes something on their social situation. And we do that together as a team. So we try to anticipate how the persons going to be without trying to pre-judge too much”.

In addition to clinician preparation, a number of interviewees spoke of the need for patients to prepare. Most interviewees agreed that to support preparation there needed to be appropriate, quality assured information available electronically to both Clinicians and Patients and relevant to the Welsh context. This was echoed by policy leads who said “The issue is in patients taking responsibility. The co-production model requires information for public and we don’t have this yet. We need to resolve the asymmetry of power and information. We need to get good information into the hands of the public to enable them to have an equal discussion with clinicians. To support this we are developing a strategic approach to health information”. This theme was picked up by a senior leader who spoke of the need to develop “information sources that can advise people and support them to self manage their condition where referral to a clinician is not warranted”

In preparing for their interaction with the clinician, it was recognised that patients would need to understand specific information held about them and their individual circumstances. A policy lead pointed to some of the difficulties in patients understanding their own condition “There is a notion that consumers are now better informed via the internet. The concept of Agency is useful where a consumer is not well informed. But it must be pointed out that the professional is not the sole source of information to guide the patient in their decision making”. Another policy lead pointed out that “we need good information for the patient. Not just information from their GP as there is no single authoritative source. Instead we have to recognise that there is a random collection of information that patients access. We need the ability for both patients and clinicians to engage around shared information where currently there is an asymmetry of information.”

Some of the issues in patients reading their own records were pointed out by a senior leader who said that “In terms of joint record keeping there is an issue about how much we share against how much clinicians retain, particularly with vulnerable patients. Some information may be judged by doctors not to be in the best interest of patients to understand”. This was echoed by a second senior leader who said “Patients can be confused with too much information and they can be given conflicting information by different clinicians. We need to keep the message simple. We need to develop information across Wales that is shared by all.” A clinician pointed towards the need for more support for patients to “Access information, understand medical jargon and to read medical reports written about them. To do this, patients need the interpretation skills to read their own data, the information needs to be put in context. It is important to realise that information on patients isn’t usually yes/no. For the patient, endurance is important”.

A number of interviewees pointed out that making information available to patients will be unhelpful if they do not have adequate health literacy to understand it. A senior leader said “patients without health literacy can fall behind in our systems. The challenge is that what suits a patient with one level of literacy is different from those at other end of scale. The coproduction approach will need to be tailored to the health literacy level of patients”. A clinician commented that patients “need a better understanding of statistics and interpretation skills to help them to read data”. He went on to talk about patients needing “awareness of the inter dependence of their symptoms and their attitude and their other health conditions”. He further said that “Most patients can’t access their medical information or interpret it” and because of this, “people get frustrated as they can’t communicate with clinicians”.

One clinician further described issues in health literacy “It makes life easier if the patient has basic health literacy and understanding of the anatomy and physiology of the body. However, a lot of our patients are illiterate, they have no idea of their body concepts as well as anatomy and physiology so then you have to bring it back to practical terms and you might miss some elements of why the swelling is there but more practical elements of what can you do now to help yourself. What fits in your lifestyle that you can make subtle changes that will make a big difference?”

A third clinician described issues in health literacy “I think one of the things you need to be mindful of, is that the patients who haven’t got health literacy are the very ones most at risk of health inequalities” But I think the challenge will be what suits a patient of one social class or level of intellect and literacy, will be very different from those who are at the other end of the scale and I think that’s something we need to recognise, that perhaps there will be different approaches, depending on experience of health literacy for patients”.

A second clinician said “You’re going to have to have the method of educating the patients. At this minute in time, we haven’t got the systems in place than can influence all of that community stuff, so unfortunately we can’t start that out there just yet. And then when you’ve got the education of the patients on board, that’s your first stepping stone. Because they then come in with a different expectation. They think I know about my new knee, I know about my new hip, I’m more informed, I know how I’ve got to prepare myself for going in, I know that if I do this well, they way they’re telling me, I’m likely to be out in a short space of time, therefore I need to ensure that the environment I’m coming out into is suitable. What support do I need, they’ve set up the support because they know they need it in a week’s time. Do I need to ask my family to take some time off work to help me, I need somebody to collect me, I’d better fill my fridge with some easy food. If we educated the patients when they come in to have a discussion, say with a doctor, that might influence the way the doctor dealt with them, interacted with them. And that’s about letting the patients know in the community before they even need to access healthcare. A way of taking responsibility for their own healthcare.

Improving health literacy is one objective of the Expert Patient Programme. One leader associated with this said “the Introduction to self-Management is a new initiative It’s not about making the person an expert in their condition, the courses that we deliver are all about showing them how they can manage on a daily basis. So the patient looking after themselves in conjunction with the health professional, in partnership. Maintaining who they are as a person, if they are working, if they’re not and also the emotional changes that come around. So as well as taking the symptom cycle that I mentioned earlier the six weeks are all about managing the symptoms, which can

make a huge difference”. He did express some frustration himself with his perception of clinicians failing to understand the health literacy needs of patients “It is as if clinicians don’t want to know that there is an education programme for patients”.

One leader, involved in the Expert Patient Programme said “one of the things about co-creating health, one of the major things that you’ve got is that information pool that’s only been accessible. And that isn’t available yet, and creating that is going to be a huge challenge. One of the important aspects we also cover with this, is information, which is awareness of the internet, of the dangers of the internet. Yes, it’s a great source of information but it’s also a great source of misinformation, disinformation and outright fraud.

A second clinician spoke of the challenge of educational attainment “I suspect the printed information that is given is standard. Someone with a lower educational attainment who just comes in will normally just accept information given to them by the clinician at face value”.

A fourth clinician spoke of the benefit of patients being well informed “you’d have to have a really strong way of ensuring how the patients learn about their own condition. Because what you want are patients that are well informed. And that could be that they are well informed prior to hitting a hospital setting. But you need to have good, robust systems of that happening and you need to have governance of those systems, not set it up, pay lip service to it and hope that somewhere in the distance that it’s happening. So you need that can we call it community education, because it’s when they’re outside of the hospital that you need to have robust ways of teaching patients about responsibility for their own health so that they have a different expectation, a different view on health care, of how they look after themselves in the community and whether they need to step across the threshold of a hospital. I’m not saying that it can’t be done but it’s a big big undertaking, it’s the cultural change of a community, of an area”.

A sixth clinician said “cancer patients are medically, fairly well informed actually. Most people have a very good understanding about what their treatments are. They know what their regimes are, they know as well as is possible for some of the long surgical

patients, often because they're waiting for various scans and other bits and pieces, they know the vague plan, they know they've been asked to see me to try and improve their general performance before they're considered for surgery".

Another theme was providing patients with literature before the appointment. One clinician used prompts to ask patients "what are you hoping to get out of it, what are you hoping to discuss. This was handed out before their appointment. The clinician said "a lot of patients might not be able to do it. We make them do it in order, so what were you hoping to discuss today, and then what is your goal, and then what steps".

A policy lead made the point that patients will independently seek information "the whole notion now that the consumers via the internet have become more informed".

One leader said "This is taking it to the next level and the intelligent patient, using intelligent in the right way, around their condition, probably, is the next level of intervention we need to have with our public and the populations we serve. Because there is a health gain in this clearly, because they would be a more knowledgeable patient through their condition".

These views shaped the description of the preparation element of the cocreating health framework described in figure 5.1 below :

Figure 5.1 : Preparation Element of the Cocreating Health Framework

Preparation Element

Preparation requires both patient and clinician to evaluate information known prior to their interaction. The clinician will need to consider the patients preparedness for a cocreating health interaction from the knowledge they have from clinical records and any referral. The clinician may need to consider whether the patient has an appropriate standard of health literacy, their level of understanding about their condition and their level of 'activation'. To support the patient to be prepared for the cocreating health interaction, the clinician may need to send written information or links to electronic information. In addition, the clinician may send questionnaires to the patient to gain basic clinical and patient-centred information and to understand their level of activation. The clinician may also need to consider whether to refer the patient for self-management education, such as delivered through the Expert Patient Programme. The clinician would also consider any referral to determine whether, with their scope of practice, experience and clinical skill, they would have the ability to support the patient to achieve a specific, measurable outcome. If this is not the case, the clinician may decide not to

accept the referral. Immediately prior to interaction with the patient, the clinician will thoroughly evaluate the patient's clinical record, answers to questionnaires including activation, and their person-centred information to become fully informed and emotionally prepared for the interaction, separating themselves from the consequences of their previous patient. This step would be supported by both patient and clinician having access to the patient's clinical record and to a shared source of information about their specific clinical condition(s). Additionally, the clinician would prepare the environment for the interaction with consideration to reinforcing a discussion between equals. In this way, the clinician would give consideration to the way they are dressed, the seating arrangements for patients and family, how they might access electronic information during the interaction and how they will record information shared during the session

5.4 Agenda Setting

The second element of the test framework concerns the initial face to face interaction and collaborative agenda setting to meet both the patient and clinician's agenda. From the workshops, this was considered to be the potentially most transformative aspect of cocreating health for clinicians.

One policy leader pointed to practice changes in recent years "the consultation where you start saying so what can I do for you, I've heard that said and whereas in the past I think a lot of doctors would have perhaps leapt in to say well this is what I can do for you, we'll send you for this test etc, rather than what would you actually like to achieve as an outcome. It might not be that you want to be fast tracked into surgery, you might just want painkillers thanks very much. So I do see a bit of a shift in recent years to having a bit more of a 'let's see what you hope to get out of this before me leaping in to tell you what I'm going to do for you. I think the cocreating health framework would lend itself very well to either one or multiple interactions around something that isn't life threatening that you have to make immediate decisions around. That you have time to think about what does it mean for me, what do I want to get out of this. I think chronic conditions particularly if you've got diabetes, you're going to have constant interactions with say are you going to take your insulin. You're not, so let's talk about your diet, you're not, let's start chopping your toes off, you're not, let's talk about your eyesight loss".

A senior leader said “The cocreating health framework requires the clinician to have an honest discussion with the patient.” A second senior leader said “Doctors should use a counselling/coaching approach but it is difficult for doctors to put themselves in the place of someone without medical training. It is difficult for older doctors trained in a paternalistic role to adopt a different way of working. Patients say ‘what would you do doctor’ and it is tempting in the limited time available to maintain the current medical model. It is easier for doctors to say what they think rather than working in partnership with patients. There are simple ways change the culture of the consultation. Doctors could ask patients why have they come, what are they looking for, that they think that is the right place to go”. This theme was picked up by a third senior leader who said “We say we need to listen to patients, but we don’t do much around sharing, agreeing goals. We need this in addition to improving the environment of care but this is left to chance amongst clinical teams Clinicians need to encourage patients to engage at the start of consultation”.

A second leader acknowledged “some of the pre-work may mean coming into a conversation with a different lens on, so this isn’t a ‘come and tell me how bad your breathing is and I will give you a prescription’. It’s what are the important things to you, so it might be going to the newsagents, popping in to the hairdressers, her friend, so the framing is set from outside, almost outside of the consultation, The continuity of the contact I think is essential. The framing pretty early on may be helpful in getting people to think differently before they even enter the room. The patient’s own goals may not be anything that would prevent a pressure ulcer, yet we are very much focused on reducing pressure ulcers. So what degree does the professional override the patients express wants and needs for fear that they may be ignorant to some of the risks”.

A third leader spoke of the current interaction “at the moment it’s about me the clinician, and I’m being a bit loose with my language but you the patient, are a bit of an interruption and I’ve only got ten minutes, and you go up there and have a few minutes”.

Another senior leader spoke of the current process “All our pathways and our guidance and our finances and our systems of recording and information are all around single

conditions. And this approach around care planning and self-management and co-production, with co-production being the sort of common denominator throughout, is what will enable us to manage them in a truly different way. And actually make it sustainable.“

A fourth leader spoke of an implicit contract “I think it might differ between different specialties. but actually any treatment, any touching of a patient has to be part of the informed consent process so that has to be part of your contract with the patient. And what it is that you’ll be agreeing, goals around the patient have to be based in evidence. So you’re required to keep up to date with the evidence base of whatever specialty. Which would then form part of your discussion, your contract if you like with the patient about options and within the options will be the benefits and disbenefits”,

A fifth leader spoke of an entirely different philosophy “I’ve been looking at Gadamer’s idea that understanding the patient is a process of what he called ‘coming to an understanding’, so it’s a joint consultation. So it isn’t a technical thing about a practitioner trying to understand the patient. It’s a therapeutic conversation where they come to a joint agreement. He says the scientific, rational approach, where you apply scientific knowledge to a specific situation is less than helpful, mostly, and we should be trying to understand, getting knowledge from our patients, rather than applying knowledge to our patients.” This senior leader added a caveat around working with the patient’s agenda “how far do you take it, though ? Because the extreme case in that would be the patient saying ‘ok, I’m having treatment for cancer, its terminal phase, whatever you do, I’m not going to get better, if you do nothing, I’d like to die now please’.

A sixth leader pointed to the difficulties that some clinicians may have in working with the patient’s agenda “it’s a stereotypical view that surgeons enjoy the operating session and they don’t enjoy the discussion with patients. I think in primary care, doctors engage in discussion about health behaviours relatively often. But ultimately they think they can best treat the patient with a tablet. They might say to a patient ‘you should eat less salt’ and the patient says ‘but I like salt’, and then they say-well, here’s a blood pressure tablet, because otherwise they aren’t fixing the blood pressure”.

A seventh senior leader considered that some practise is already consistent with the framework “. So one of the biggest issues for me is getting patients involved in their care and they have to be hand in hand with us, we can only facilitate. That is a problem we are facing whereby patients with this chronic illness have had their condition for such a long time they want somebody to come in and wave this magic wand and there is no such thing. We are actually upfront with patients about that. But I think where we're at is that patients have to take responsibility. So something that we looked at was patients setting their own agenda, and the reason we chose this was, sometimes, as professions, we think we know best as to what the patient now needs. And doing a lot more work over the years dealing more with patients goals and settings and so on, we've felt that ok let's see, lets tip it on its head. A patient comes in on an appointment, we give them a sheet of paper and we say what would you want to talk about in your half an hour appointment today? So it's all about setting their own agenda for appointment. So included on this piece of paper is 'list three things you want to discuss, but also of the following tick if there's anything you would like us to chat about today'. So it's things like weight management, scars, anxiety, depression, movement and exercise, your garments, your skin, there's numerous things they can tick. It then says, what is your weight, do you know what your BMI is, and they have to write it. How important is your appointment today from nought to ten. How important is it for you to manage your weight nought to ten, and then when would you like to be seen again. One month, six months, nine months, twelve months. And then they fill that in and then they come into the appointment. So after they'd been engaged, they were much more 'yes, this appointment is really important to me'. For us as clinicians, I felt that some things they wanted to discuss wasn't what I wanted to discuss. But I went along with what they wanted to discuss. I think based on what we've done with 'setting my agenda' it's made us think more about what the patient wants rather than what we want them to want. And I think that's the difference. It's still the eighty per cent that are taking it on, it's still the twenty per cent that are still not engaging straight away. The setting my agenda is not right for first time appointments. It's also not right for people who are coming in every other day for intensive treatments”.

A ninth senior leader made the point that clinicians who expertly carry out treatment may not have the skills to engage in cooperative agenda setting “my daughter had a complex hole in the heart, and she was operated on in Brompton and she had a lovely

cardiologist, and the cardiologist gave us all the information we wanted. The surgeon did the operations that she needed, and he had very poor communication skills, we got very little out of him, he was rather rude to be honest, and perfunctory. But I didn't mind because he did the surgery and he did it well. And my relationship was with the paediatric cardiologist who I had complete faith in. And I did know I was told all the potential outcomes of surgery. We had all the information we needed before the operation but we just put our faith in the cardiologist. And we knew that they were giving us the best service they could give us and the outcome was ok. But you don't always want the best communication skills. You want people to be really good at what they do, and to know that they're part of a system that is a safe system".

A second clinician spoke of the need to "ask for a person's priority, about things that have meaning for them. If someone identifies a personal need, I negotiate goals with the patient. I tend to set the borders of what would be considered, guide the patient's questions starting broad, and funnelling down. The patient can set the agenda but I also present my preferred agenda to avoid complaints. I document the agendas set."

A third clinician pointed to current practice "very often clinicians of all types have a conversation around the clinician's agenda, or the system's agenda, rather than the patient's agenda."

A fourth clinician described the contextual issues "the idea of working to a patient's agenda doesn't quite fit so well in the inpatient context. If the patient is unable to speak for example then it's rather difficult to establish what their agenda is. Sometimes we're dealing with people who are extremely elderly and the agenda isn't just their agenda it's their family's agenda as well. So I think we do have to lead the conversations in the direction it's needed to go in. to a certain extent, give people a bit more guidance than Petrea was advocating I would say. One example I gave was to use the difficult conversations that we have often, this business about people saying they want to walk again, people are often cognitively impaired they may say that every day, and you'll go through explaining to them the same thing every day.. That isn't going to happen because and you may be having that conversation with their relatives as well. Who are grieving, the relatives are grieving, the patient is cognitively impaired and you're

having a two way conversation But I do think it's difficult and it's a skilled thing to do, have those kinds of difficult conversations with people".

A fifth clinician spoke of the challenge of incorporating the clinical and patient's agenda, particularly when options were limited and clinical risks high "for me, I try to narrow everything down to the experience of the person I'm seeing at the time. I understand how the framework works in terms of there being a flow, the development of a policy side of it. If I can set the agenda with the patient, I try to achieve that. So as well as them learning how to dialyse themselves, they can also choose something that they want to do for themselves. And I try to help them, in my small way, to achieve it. I haven't had lots of patients where I've set the agenda with, but the patients I have set the agenda with I have had success with them. Can I give you an example ? I had a young lady. She was about twenty five when I first met her and she was very concerned about weight, very concerned. And I thought this problem that she had, and we set the agenda together, that problem might have overshadowed her ability to be able to dialyse herself. Her weight had become the biggest problem. She knew she was headed for transplant and I knew that her weight would probably exclude her from transplant. So I thought this is a lady I can work with, we can see what her confidence is, her importance is, and scale it. I was able to engage with other people in the department. Obviously the physio was able to help with the weight loss through exercise. Some of my nurse peers said that because the patients have so much to do when they're learning to dialyse themselves, actually we don't think this setting the agenda can be an option. Because their agenda has already been set".

A sixth clinician spoke of needing practice in collaborative agenda setting "We ask the patient 'can you just tell us what your expectations are from your physiotherapy sessions. But the manner in which you ask it, and also the manner in which you receive the information that's given back to you, shapes what you do with that patient next. And even though I might hear somebody say to me I'd like to reduce the pain in my knee, that's what I've come for, I'd like the pain to go'. In my head I'm already formulating I've got three, four, five different options of treatment and for this patient. Option A would be the best because... And I'm already going through that in my subconscious brain, rather than having that discussion out loud with the patient. The trouble with the way it's done at present is that because maybe we don't engage as

fully with the patients as we could, and that's because of our own inexperience with this new method of interviewing the patients. I need to spend time phrasing my questions, to recognise it's going to take me longer and I might not see all those patients today however, given time this is an invest to save policy. As I get better at this I'm going to have more patients responsible for their own health and therefore I am going to be able to see more patients because I'm going to have less contact with the patients. But it's that time at the beginning, and I think that you almost feel guilty taking that time. Even though I can say to you it's an invest to save policy there's still an element of guilt because of the pressures of the health service”.

A seventh clinician spoke of some of the challenges and benefits of collaborative agenda setting in relation to their own practise “i've always asked patients if they know why they're here. But I've never asked them what they want from it. I tend to say to them what would you like, what's important to you when you leave here today to have done? Sometimes, it's not anything I would do, and I can explain to them well, look we can't do that today it's not really within my remit. But what we could do about that is refer you here or there or whatever. I've started to prioritise and say well how important is that to you. It varies on the patient, if the patient has an understanding of what you're doing. Some patients don't seem to be able to take that on board they just want you to be able to fix it. I tend to gauge it by the individual patient. Previously I thought I was working quite well with patients with regards to their agenda, but a lot of the way I might have termed things to the patients, I think it's improved the way I work with the patients. If I feel that they are keen to be involved I've worked with them and I've found they definitely leave enthusiastic. And although I've thought they've left enthusiastic before I can see that they've been putting up barriers as to why they couldn't do things, and when I've changed the way I've worked with them they are more enthusiastic about working with them. I'm keen to go forward with it, because I think we need to be responsible for our own health and patients need to take it on board. I think within the NHS a lot of people come in and want you to give them something. I think the whole culture needs to change to 'what can I do to help me' and can you participate in helping me'. I think even financially that will save us a lot of money but I think it's going to be a long haul to change, because it's quite embedded. ”.

An eighth clinician spoke of steps they had taken to facilitate collaborative agenda setting following cocreating health training “we now send out an additional form which is a self-supporting agenda setting form and that asks questions such as what the persons already doing to manage their condition, what their goals are, so questions like that. So hopefully the patient comes in to us having completed that. And I have a look at that before we actually start the interview. And I think it’s important for the clinicians to get rid of their own agenda, and think less about how well their outcome measures will look. The patient’s agenda can differ from the clinician’s agenda because a clinician would want the patient to make healthy changes.

A ninth clinician spoke of modifying her practise around collaborative agenda setting “Because you’ll find that people will move away from the patient agenda if they think that there’s going to be some kind of criticism for the fact that they’ve not been thorough enough. So you’ll find that you can teach junior therapists to set a patient’s agenda but you’ve then got other members of the MDT demanding that they be able to provide certain amounts of information that weren’t part of that agenda setting. Then you’ll find that they immediately default back to ‘well, what if I don’t know this, then I’ll get in trouble so I’ll just do what I do’. To give you an example, somebody may present with functional difficulties. If you were to ask that individual what their concern is, perhaps their concern wasn’t purely one specific element of their function performance, it might have been something else. If that something else wasn’t, in the grand scheme of the world, as important as what we’d identified as being the key component, then often people would, and I’m not saying all OTs but I’m saying the health service would in general, often we overlook that and say well it’s insignificant that you can’t walk your dog but we need to make sure that you can get to the toilet and eat and drink. So if that lady said to me, well I’m worried about who’s going to walk my dog, well that leads the conversation through, would you normally do it, how would you do it, why can’t you do it now, how can we get you back to doing it. That opens up the opportunity to say well if you can’t do that, what else can’t you do. But often people will go, well don’t worry about your dog, let’s focus on you, and they kind of ignore that. Now that’s not just an OT thing, that’s the whole of the NHS thing.

These insights from clinicians informed the second element of the pathway, agenda setting, described in figure 5.2 below :

Figure 5.2 : Agenda Setting Element of the Cocreating Health Framework

Agenda Setting Element

When the patient and clinician begin their interaction this might be face to face, conducted over the telephone or through a telemedicine discussion. The clinician will begin the interaction using appropriate language to indicate that the agenda setting is collaborative by acknowledging that the patient will have an agenda that brought them to the appointment, that equally the clinician has their agenda. It is helpful for the clinician to clarify the length of the appointment. Within the interaction, the clinician indicates that there is mutual recognition of three sources of expertise. The clinician will affirm that the patient brings expert knowledge of their own health, social circumstances, attitude to risk and social circumstances. The clinician understands what they bring is expert knowledge of human function, interventions, their own limitations to resolve issues including knowledge from audit and service improvement as well as understanding of navigating through complex health services. The clinician will ensure that the patient is supported to access the third expert within the interaction comprising a source of information, and knowledge base held electronically, such as clinical outcomes, patient reported outcome measures, patient reported experience measures, evidence based research and appropriate literature describing the patient's conditions. In this step, patient and clinician build a relationship around their mutual need to impact positively on the patient's health and wellbeing within the context of a continuous, consistent and possibly long term relationship. This relationship is built on mutual respect, consistent with Nolan's 'enriched environment' where each experience the five senses and supports the 'cocreating health contract' of Smith. In this phase, there is exchange of information, opinion and the parameters of the patient's issue established. The clinician is required to engage empathically with the patient, to consider their emotional and social circumstances in addition to their physical concerns and to understand their own emotions and prior considerations that might impact on their interaction with the patient. The clinician acts as coach in supporting the patient to set the agenda and discuss their goals. Questions asked of the patient should be open, using appropriate language to build rapport, with clinician demonstrating reflection and affirmation of the patient's perspective. The clinician will use reflective listening, using the patient's own words to let them know that they have heard what they have said or to check facts, using appropriate non-verbal body language. The clinician will be focussed on what's important **to** the patient using open ended questions, reflection and empathy to explore everything that the person wishes to cover in the consultation, to find out their priority and what they are hoping will happen, allowing time for their response. This includes understanding the patient's activation, confidence & problem solving skills, their capability, capacity, and health literacy. The clinician will be supported in gaining an understanding of patient centred factors by using tools such as scaling of importance and confidence. In coproducing the agenda, the clinician will identify and share clinical agenda, clarify the boundaries and agree or negotiate the scope of their engagement. Using this information, supported by questionnaire results of patient activation, the clinician can determine the patient activation level and start to consider the possible scope of any intervention. At the end of this phase, patient and clinician will jointly agree further steps in terms of any further information required to inform an agreed management plan.

5.5 Information Gathering

The third element of the test framework is that once the agenda is understood, there may need to be further information gathered to inform both the clinician and patient. For the clinician, this might include asking for diagnostic tests on the patient. For the patient, this might include evaluating some information signposted by the clinician or considering their attitudes to risk. This is such an embedded part of clinical practise that all interviewees and participants considered this important to clinical practise generally, including the cocreating health framework.

A policy lead spoke of the difficulties for patients in obtaining information “the danger is the only source of information for the patient is the GP, random collection of bits and pieces some of which the GP may think of value and some of which they don’t. But it seems to me the whole idea of co-production is two sets of people who can at least engage around a shared topic, but the volume of information is too great. You’ve still got a master / serf relationship”.

A second policy lead spoke of the limited time for information gathering within the clinical encounter “the step in the model where the patient is able to go away and start thinking about the discussion they’ve had. And I don’t necessarily know whether or not that lends itself to every encounter because often you don’t have very long to think about things. To go back to the GP example, you could go in and say well I’ve got this pain, and they could say well I’ll stick an injection in it now or give you some pills. I can’t go away and spend some time thinking, well do I really want steroids stuck in my tennis elbow and what does that mean? No, he’s got ten minutes and there is a bit of pace behind some of our consultations but I think we almost railroad people into making decisions so the model that you’ve got is one that allows reflection and consideration. Now for big surgery yes, of course, people are usually told by their consultant, yes we’re going to whip your bowel out. Go away and think about do you want to have your bowel whipped out or not”.

This was echoed by a third policy lead who said “I don’t think the time for reflection is necessarily available to you because if it’s minor then you’ve just got to get on with it. It’s something about the magnitude of the intervention and the immediacy of your

health status will be factors that will play into whether or not there is any breathing space to allow the person to reflect on the decision making”.

The issue of patients having time to reflect was picked up by a leader who said “There needs to be a bit more recognition that I’m not quite there yet, I’m not quite ready to change. That temptation is they’re not ready to change but I’m going to forge ahead and give them the information and tell them what to do anyway, regardless. We’ve got to try to make sure that people understand that it’s ok to say I think you maybe need to go away and think about this and why don’t we come back another time”.

A clinician pointed out that information gathering may not always need to be a discrete step “with older frail patients, the part about going away, doing your investigations, asking them to do likewise at the same time and coming back together, that’s a step in that process that almost merges into your initial assessment”.

A third clinician pointed out that patients may not understand why they’ve arrived at an appointment and further information gathering will be necessary “You might not get a lot of information in on the referral. Sometimes people are quite knowledgeable and they’ll know why they’re there, other times they’ll have no idea why they’ve come to see me.”.

A fourth clinician pointed to the difficulties that patients may have in information gathering “we do balance assessment which gives people a score which translates into their risk of falling. I would routinely explain that to a patient if I feel they would have a chance of understanding it. I wouldn’t explain it if I felt that they were cognitively impaired to the extent that it would confuse them or not be appropriate.

These views informed the third element of the cocreating health framework, information gathering, described in figure 5.3 below :

Figure 5.3 : Information Gathering Element of the Cocreating Health Framework

Information Gathering Element

Where additional information is required, this may be from the results of diagnostic tests, review of knowledge by either patient or clinician or the patient having discussed issues with friends, family or the wider community or merely to spend some time considering their own attitudes to risk or possible interventions. The purpose of this is to ensure that both clinical and patient-centred knowledge is available to fully characterise the patient's physical, emotional and social circumstances. The clinician needs to gain an understanding of the functional impact or future impact of the patient's circumstances. This will support the clinician to decide if they have the appropriate scope of practice, clinical skill, experience to interact with the patient or if the patient needs further investigation or referral to other clinician(s). Typically, the clinician would review this information in a further preparatory phase prior to further patient interaction.

5.6 Discussion of Options

In the fourth element of the test framework, the patient and clinician discuss their shared knowledge and come to a mutual agreement about the nature and extent of the physical, emotional and social issues impacting on the patient and agree the options available.

A policy lead outlined that not all options that a patient would wish to choose are open to them “preferences are not always open to the patient. For example, in podiatry my first survey asked what patients wanted. But ninety nine percent of patients wanted their toe nails cut. But this was not a service we offered I struggle with co-production if a patient is given choices which are not always fully there.”.

A second policy lead signposted the ‘agency’ function of clinicians when discussing options with patients “the Agency notion is predicted on the perspective that the agent will indicate quality of service and make a recommendation and the consumer makes choices. Since the consumer is unable to acquire all the required knowledge to make informed decision, the job of the agent is to provide information on which the patient can make an informed decision. But this will be difficult for some professionals.” However, he pointed out one of the issues in patients deciding on options “where there

is no agreement on the way forward those who shout loudest are likely to get their way". He also spoke of limitations in options that might be presented to patients in that clinicians "tend to offer those services that are available rather than what a person requires". Further challenge came from the Welsh Government policy advisor on coproduction who outlined that the current approach of clinicians is not to discuss options but to "give instruction and lifestyle advice". But that the "idea that outcomes should be determined by patients from what they want is a very healthy starting point, different from where clinicians may be. We need to ensure that there is mutual discussion to form a view, a chance to share information, listen to the patient and engage in shared decision making ". Although regulatory structures have been perceived by some clinicians as a barrier to coproduction, he said that "at heart of coproduction is an individual clinical discussion."

A third policy lead spoke of the need for patients to have clear, unbiased information on risks and benefits when discussing options "the idea of sharing information very honestly, and that should be local information that's very relevant to the immediate circumstance. I think that's right. Where we know twenty five percent or thirty percent will say no the second time around having reflected on it the first time. And that's something the minister wants us to pilot in clinical practice".

A sixth senior leader spoke of clinicians having the skills needed to discuss options with patients not necessarily being the clinician providing treatment "my daughter had a complex hole in the heart, and she was operated on and she had a lovely cardiologist, and the cardiologist gave us all the information we wanted. The surgeon did the operations that she needed, and he had very poor communication skills, we got very little out of him, he was rather rude to be honest, and perfunctory, but I didn't mind because he did the surgery and he did it well, and my relationship was with the paediatric cardiologist who I had complete faith in. And I did know I was told all the potential outcomes of surgery. We had all the information we needed before the operation but we just put our faith in the cardiologist. And we knew that they were giving us the best service they could give us and the outcome was ok. But you don't always want the best communication skills. You want people to be really good at what they do, and to know that they're part of a system that is a safe system".

A senior Leader, a Physiotherapist by profession spoke of tailoring supported decision making to individual patients “physiotherapists use different processes with different individuals. There are no particular challenges to using decision support tools such as MAGIC in discussing options with patients. Clinicians in Cardiff like decision support tools and are using them”. However, she did point to one issue that “not all staff do all treatments, for example not all physiotherapists do acupuncture” meaning that some options might be constrained by the particular clinician seeing the patient.

A second senior leader, a GP by profession spoke of some of the challenges within the cocreating health model of asking doctors to discuss options with patients. “there is a culture of paternalism within the medical profession and formal health services have taken aspects of patients’ responsibility for self-care into it. This has resulted in a reluctance to let go from patients and clinicians. It is difficult for older doctors trained in a paternalistic role to adopt a different way of working. Patients say ‘what would you do doctor’? And it is tempting in the limited time available for the consultation to maintain the current medical model. Although it is recognised that doctors should use a counselling or coaching approach. Sometimes it is right for doctors to tell patients that there are options, some safer than others but we need to help doctors convey information about risk. Doctors need to bring in messages of prevention and health promotion. Doctors need to be able to combine discussion of preference with ensuring that patients understand their risk and benefits where they don’t have the training. It is difficult for doctors to put themselves in the place of someone without medical training. Doctors need to be able to convey information and knowledge and ensure that patients have understood this. But it is easier for doctors to say what they think rather than working in partnership with patients”

These tensions are also understood by other professional groups. Another senior leader, a dietitian said “Most of our work is in agreeing options with patients as they won’t make changes if told to do so but sometimes in dietetics there are not many options. In terms of the time available it is easier to tell people what to do, but I realise that then the outcome may not be effective. This means that we will need to structure consultations for more negotiation with the patients. More junior staff will need to believe that they have permission to interact with patients in a different way. Most of our work is talking to people about changing their behaviour so we need to give

patients permission also. In terms of the Prochaska change model, the temptation is to assess someone as not ready for change, but to give them the change information anyway. Clinicians need permission to be able to suggest that patients go away, understand some of the issues before coming back to discuss options. But this will be challenging in terms of new to follow up ratio, time, and resources. Discussing options is easier in outpatients than inpatients. In inpatients there may be an imposed plan rather than agreed with patients. The sicker the patients are the more likely it is that we will do things to people, using the medical approach and telling them what to do. As long as they fully understand the options and we clearly document the discussion, that this is patient choice, the patient is free to ignore our advice. This has to be a patient decision. If we see a patient who wishes to choose a behaviour that is harmful to them we still have a duty of care to guide them. The paternalistic approach is now becoming more difficult. For example in treating obesity, there used to be one way to lose weight now. Now National Guidance is to support weight loss by a mechanism that's working for patient and when they've lost the weight we'll support them to get back to a long term healthy diet. The HCPC are with us as long as we have fully advised the patient. Sometimes we need to be clear with the patient and have good documentation that we have discussed with them that their behaviours might be harmful".

Another senior leader pointed out the importance of clinician engagement in discussing options and the utility of tools to aid 'shared decision making' "I like the elements of shared decision making within the cocreating health framework. In the implementation of shared decision making within Cardiff and Vales Health Board there was the sense that by using option grids, this would steer or focus the consultation with the patient coming out with a better understanding of their own condition and treatment options. For example, the breast cancer team are using the techniques consistently, particularly to discuss options. This is mostly done by the clinical nurse specialists who take patients through the option grids and shared decision making process. Clinical nurse specialists were fundamental to the success of shared decision making as they do a lot of the patient discussions around choices. They then evaluate people's knowledge before and after they have made their choices. Clinical nurse specialists implemented shared decision making more readily than doctors as they felt their jobs were more at risk. Clinical Nurse Specialists were able to move

people from being uncertain about which option to take. In patients with major Head and Neck cancer, after diagnosis, their decision making was supported by a nurse. Although the option grid approach was not helpful due to the variety and complexity of the clinical presentation. There is a perception that surgeons are more 'gung ho' and interested in the technical and clinical outcomes of surgery and not so interested in issues affecting patients' quality of life. On the other hand, clinical nurse specialists look after patients in the long term, and organise the processes of treatment and care. The risk is that surgeons will see shared decision making as a 'nurse project', and see their involvement more as letting it happen rather than actively engaging in the programme. Shared decision making in Paediatric tonsillectomy has also been sustainable. In making decisions about tonsillectomy it came down to the options of tonsil removal or not. Use of option grids raised the awareness of the small risk of death under general anaesthetic and consideration of the age at which children are able to make their own decisions about healthcare interventions. In the renal service the choice of dialysis is informed by an option grid which includes no treatment as an option. This is used in practice a lot which changed from giving lots of information. This change was made independently by the nursing team. Other areas in which option grids to support shared decision making have been used include cataract surgery in ophthalmology, mental health areas, paediatric diabetes, and independent prescribers. In Primary care, there was a lot of activity in shared decision making in phase one of the programme. This included statin prescribing, antibiotics, these were driven by practice nurses". He further suggested that "a link should be made between shared decision making and the co-creating health framework. This would be more sustainable than trying to just implement shared decision making alone. We need to see the co-creating health framework as a continuum rather than isolated entities. Academics have tried to promote Shared Decision Making as a single entity, but this needs to be implemented as part of the co-creating health framework". He went on to say "We need to make it easy for patients to follow the process of cocreating health. This needs an infrastructure that supplies option grids and ask 3 question cards and practice managers will be important in delivering this". He further explained "we now have an awareness of shared decision making in Cardiff and Vale Health Board, but delivery only in pockets. Now funding for the programme has finished we are working with service improvement teams to embed shared decision making in pathways, but this may stop as improvement resource is targeted at improving unscheduled care".

He further explained some of the tensions “what if patients choose what clinicians consider to be the wrong option? This is not a regulatory concern, but it is an issue that clinicians are concerned about. We need to ensure patients are fully aware of the options and risks and that these decisions and conversations are well documented. We could use option grids to document patient decisions store these in notes with a copy held by the patient”. He further explained some of the issues outlined by clinicians who say “we don’t have the right materials’, but option grids are easy to create. They provide a structure that can be quickly put in place. We often assume that clinicians have the knowledge base to describe the option they’re offering. But if they don’t, they shouldn’t be offering these interventions. Option grids are really helpful and using them is straight forward. If patients asked to read through the option grid within the consultation, then people can get uncomfortable because there is silence whilst the patient is reading. Because consultation is supposed to be full of dialogue and clinicians get twitchy and feel that silence means that time is being wasted”. One thing that did surprise me though is that we had some discussions with physiotherapy as part of this, and with podiatry. Interestingly, and in both areas they came up with things they felt they probably didn’t offer a full, shared decision with the patient. So even amongst therapists, although they still have time they are still conditioned to a certain extent. Same with physios, options for treatment. I think a lot of them still fell into ‘this is what we’re going to do for your bad knee’. So I think whilst they have got the time, I think the way they practice gives them more time, it makes it sound as if they still need taking down a path which says patient preferences, lifestyle choices, what are the goals and how can we work with you to best deliver them”.

A fourth senior leader spoke of the benefits of engaging clinicians and patients in discussion of options “we need patients to understand their condition more so there’s a huge public health agenda when you’re looping this back in to the front door, whatever that front door, it’s a preventative strategy for GP practice. Again what you’re talking about is the patient owning their condition. So therefore from a long term condition management, you’re creating discussions.

A fifth senior leader described the importance of discussion of options in properly informing consent “I think it might differ between different specialties. But actually any

treatment, any touching of a patient has to be part of the informed consent process so that has to be part of your contract with the patient. And within the options will be the benefits and disbenefits, I can perhaps give you an example. If you have back pain, with the evidence there's three different things that work quite well; you can have a 6 week course of acupuncture, you can have an offer of some manipulation or you can do exercise. You would have to discuss with the patient the options, and pros and cons of those. In a decision support tool approach you would list all the benefits and disbenefits on a bit of paper for the three different treatments. For example, a disbenefit of acupuncture is you need a six week course, so you have to attend the department for six weeks over however many attendances per week were required. So it may not be possible for an individual to say this would be my primary choice, because I don't want to attend the department that frequently. Whereas if you're teaching me the exercise and I can do some of them at home and incorporate those in my life, actually they're more likely to comply with that.

A sixth senior leader spoke of the challenges in discussion with patients and was particularly supportive of option grids in discussing options with patients "one of the things that seems attractive about the option grid approach is that you narrow down the discussion. From my own clinical practice in reality the large majority of NHS patients have a single consultation. We endeavour to get round the discussion of options by providing the patient in advance with some information and by following up the consultation in a virtual way or with another member of the team. None the less, we essentially use a single decision point. What's interesting is that in private practice, particularly in cosmetic private practice, it would nearly always be the other way, nearly always two consultations. And from my experience of that, in the days I used to do it, where that worked really well was when the second consultation was focussed on an area of critical decision points, or the patient needed greater clarity. What was interesting in that area was that quite often I would start the first consultation saying 'I'm not expecting us to reach a decision today. I've got a lot of information to give you, you've got lots of stuff to ask me and I think you need to go away and think about it and then we need to meet again'. And the response would nearly always be 'but I knew you were going to tell me lots of stuff, doctor but actually i've already decided I want to have an operation'. To which my response would be 'Yeah sure, I'm not suggesting the outcome of this would be that you decide you don't want an operation necessarily, although you might, but I just think it's important that I know you

understand what you're letting yourself in for. And you'll have read lots of stuff, not all of which will be right and we need to discuss that. I need to give you some information that I know is correct. You need to think about it and you might need to talk about it with your friend or your partner, your husband or whatever. And although many people were initially unhappy with that because they just wanted to get on with it, and they thought it was just a set of obstacles being put in their path. But they would normally welcome at the end of it. I'd give them an information leaflet, ask them to take it away and read it. I didn't realise I was doing a sort of option grid thing. It highlighted the bits that people were concerned about, or didn't understand, or needed some more information-it was important that people really understand. Then when they came back you could talk about things. And actually, that resulted in a reasonable proportion of patients choosing not to proceed with surgery. Or, the ones that did proceed normally were clearly better informed and probably having better expectations because the problem with cosmetic surgery is that people have unreasonable expectations. People become dissatisfied because they had unrealistic expectations. Their expectations hadn't been set well for them. I think we need to get better at discussing options. An example is that I know several friends who've had consultations for painful arthritis of the knee who have been told by an orthopaedic surgeon that until it's so bad they want to kill themselves they shouldn't have a knee replacement. But put in those terms, not really in a self-management, positive, there's lots you can do for yourself, the operation has quite a lot of complication. To say 'if I were you I wouldn't have this done until you want to kill yourself because it's so painful is not really a very engaging conversation. And interestingly, I know three friends who've had separate conversations with different orthopaedic surgeons and they said exactly the same thing. So it's not an engaged, cocreation discussion. Either surgery or radiotherapy might be equally valid choices in basal cell cancer. So designing an option grid for that situation would be quite straight forward because there is equipoise about the treatment, although no one has quantified the cost either to the patient or the state and arguably there isn't equipoise if we do that. I think in primary care, they have a discussion about health behavioural choices relatively often. But ultimately they think they can best treat the patient with a tablet. They might say to a patient 'you should eat less salt' and the patient says 'but I like salt', and then they say-well, here's a blood pressure tablet, because otherwise they aren't fixing the blood pressure. If the GP had an option grid that they could share with the patient which described the options in secondary care,

the advantage is that you're then left with possibly only having one consultation in secondary care and GPs would no doubt say that many of these patients have many consultations in primary care and they are only referring the ones where things have been going on for months. But, for that to be meaningful, the GP would have to have a proper conversation to allow all the options to be meaningful. And the debate is, are they well placed to do that and for some things they would be. And in other situations, they might not. And the danger is that the patient would be making decisions based on poor information. The support we provide to help people stop smoking, lose weight, take more exercise is very patchy. I think we have some good examples where there are focused and targeted programmes, particularly where it's de-medicalised, referral to exercise programmes. There are an awful lot of people who are overweight that we're going to end up operating on, waiting to have their hips and knees done. So we need more support to make health behaviour choices and that needs to be seen as equally as likely an outcome from seeing the doctor, who may send you off down to the gym, the gardening club".

A seventh senior leader had observed discussion of options in a visit to America "and at the end of the consultation, the bit I remember and almost getting quite tearful about was now tell me Mrs Jones, was that a good use of your time', and it was just so clever that it was all about you. You've come, you've made the commitment, I've supported you, I'm your coach, I'm not in charge of you. It was beautifully done, it was really powerful",

An eighth senior leader raised the issue of discussing patient health behaviours when considering options "so in terms of the health behavioural changes, clearly the model suggests that the clinicians should routinely engage with in discussion about health behavioural changes. It says first that you have to assess what stage the patient is as in the behavioural change cycle, from not having thought about it, to thinking about it. It's a helpful way to be thinking about it in terms of the health service, clinical work, clinician's practice".

A fifth clinician pointed to the difficulties in having conversations with patients about their health behaviours "getting patients to engage in healthy behaviours is extremely

taxing to all of us. In fact it's such a heart sink, the idea of getting people to lose weight, or stop smoking even when they're pregnant and they have a lot of extra impetus to make changes, it's very difficult indeed. I've made a mess of it only lately, I've got a lady who rang up and didn't want to come and see me again and was very peeved because there isn't anyone else who does it and she would have to travel. She was very cross because I described her unborn baby as fat. She was displeased because the word was 'disgusting'. But she and her husband could model for what not to do in terms of responsibility for one's wellbeing. And when you look at them you can see it. I wasn't, after that point, really in a position to be able to discuss her health behaviours. Most pregnant women are very open to the idea that change will help the baby but it's still very difficult, I make people cry all the time. I understand why people don't quit smoking. I would never finish a course of antibiotics, I smoke and I expect to die of various problems, or cancer and I would rather do that than quit quite frankly I talk all the blooming time about behavioural changes but I try my best to let it come from them of course. People know damn well. Big fat women with polycystic ovaries are not unaware and if I sit there and say it's because of your weight they say 'oh, everybody says everything's because of my weight. So I wouldn't introduce these subjects because it's so unhelpful. There's an extent to which people understand that their behaviours are causing their unborn baby or themselves to be unwell but it's an unwillingness to do something about it. And I think I have tremendous success with weight loss and healthy behaviours in diabetes clinics, and I can't replicate that in gynae with the polycystic ovaries girls for nearly the same proportion of people, because pregnancy is highly motivating. I've got cards I can show you. 'I can't believe I've lived my life feeling so crap, and now me and the baby are doing really well, and thanks everybody' it's lovely. It makes it worth bashing on".

An eighth clinician spoke of the importance of understanding where patients are in the behavioural change cycle "the pre-contemplation, contemplation phases, the health behavioural change model is probably something that with experience we've been doing it, but it's only now I recognise. I've been doing it all along, because you just adapt your approach, to people. And you can tell if they're resistant and don't even want to change just about thinking about changing. Some people are more entrenched in their behaviours and that could be for any number of reasons. It's the patients that have low mood, that's gone under the radar, particularly and they're just not ready yet.

You need to come back and you need to give them time, and you need to keep exploring when they're going to be ready and not just ignore them and think oh well they're not engaging. That's it. It's just keep going until you find a level where there's some kind of carry over, some kind of change happening that you can make your move".

Some of the challenges in discussing options with patients were outlined by a clinician "patients have the perception that the clinician has all the answers and that there are simple solutions to all of their problems. This is a farce, but it is a consistent mindset. Some clinicians rely on that and don't set aside time to explain the options to patients. However, we know that time spent by the patients in talking with their GP puts the options in context."

A second clinician, a practicing GP agreed that patients needed clear information on benefits and disbenefits "patients need to be told when they may not survive a particular operation. That an intervention may not work, that it may give better outcomes for them to change their health behaviours rather than have an operation or medication. But in general, doctors don't have this discussion with patients. Instead they rush to treatment. Patients may not want to have open conversations about the risks of treatments. Like gamblers they don't want to hear who's lost, that is died during an operation or for whom treatment wasn't successful. Instead they want to know about the patients for whom intervention by the doctor was successful, that is the ones who won".

A third clinician spoke of challenges in having conversations with patients about their options and that there is a cultural expectation that options will be discussed with doctors and then other clinicians will carry out treatments "i've got a gentleman who's quite resistant because he's just given up with his MS, and I could tell there was a lot of disuse weakness rather than neurological weakness. And I was basing this on my clinical assessment, but he trusted me and we've basically found it hard to motivate, so if I couldn't draw on that kind of data, I would say I know that if you do this and this, I can guarantee that you will more or less be. Because I can tell it's disuse weakness from sitting all day rather than. The gentleman with MS, I knew he didn't want to be

referred back, he agreed to come. The MS nurse referred him back, and we spent the whole session just talking. And perhaps we don't spend enough time ensuring that the patients who do want to understand their illness have that information. We're contextually informed aren't we when we find out what we want, make the decisions, the options with the doctor".

These views informed the fourth element of the cocreating health framework, discussion of options, described in figure 5.4 below :

Figure 5.4 : Discussion of Options Element of the Cocreating Health Framework

Discussion of Options Element

Having gained appropriate information, patient and clinician interact to discuss their shared knowledge and come to a mutual agreement about the nature and extent of the physical, emotional and social issues impacting on the patient. At this stage, the clinician would consider the aims of any intervention in consideration of the level of the activation of the patient. These aims might include : Prevention, to decrease the risk of future harm, and/or preventing any anticipated difficulties, complications or impacts ; Stabilisation, to stabilise functional ability or slow down the deterioration or loss of function ; Participation, to support the patient to participate more in their activities of daily living ; Resolution, to support the patient in developing well-being, problem solving skills to become curative ; Improvement, to support the patient to increase their skills and improve their condition towards rehabilitation ; Adjustment, to support the patient to gain acceptance of their condition and the impact of this on their life as a result of a change in feelings, attitudes or insight ; Comfort, to support the patient in achieving reduced pain or discomfort whilst acknowledging that their condition or overall impact of these hasn't changed. In considering the aims of interaction, the clinician will be mindful that patients at low activation, in the pre-contemplation stage would often benefit from the biggest change in their health behaviours but at the lowest levels of activation will face the biggest challenges in self-efficacy. The clinician will be mindful that patients interacting with them will already have made the health behaviour changes that are easiest, prior to their interaction, the importance of small improvements in reinforcing patient's self-efficacy. The clinician will be aware of their role not only to consider the patient's human needs for sustenance and safety, but also their needs for empathy/understanding, love, creativity, community, recreation, autonomy and meaning/purpose. In a cocreating health interaction, the primary role of the clinician is to support the patient to increase their resilience to improve their own health and well-being, rather than either to quickly focus on the treatment they can provide which may disempower the patient. In enacting this role, clinicians will be mindful that patients may not wish to be active participants, being more comfortable in passively receiving expert care or fighting for treatment that they believe the clinician has power to provide. In discussing potential options, clinicians may choose to use tools such as paper based option grids or electronic decision support tools. Clinicians will be mindful that patients need adequate time to consider their options. Options presented to patients will be informed by the National evidence base,

by outcomes achieved by patients in the care of the clinician involved and the characteristics of the patient including their level of activation. Patient's preference-sensitive choices of active interventions might otherwise include referral to a specialist clinician, additional diagnostic tests, or interventions such as prescribed medication, surgical treatment or the provision of aids to daily living, therapy, support for maintaining healthy behaviours. In discussing these options, both patient and clinician are guided by accessible clinical outcomes, patient reported outcomes and patient reported experience measures, possibly from a number of potential service providers or individual clinicians. In addition, the clinician would be informed by review of incidents, complaints, claims, harm review, by audit and service improvement of their own practice and by recent literature on research and development. Clinicians will not present options where outcomes are not achievable by the patient.

5.7 Agreeing the Way Forward

The fifth element describes the patient and clinician agreeing the way forward. For the clinician this could mean agreeing to personally carry out an intervention, agreeing another time for this to be carried out, making the appropriate referral, or informing the patient of the mechanism that would allow the patient to interact with them as required. For the patient, this could mean health behaviour change such as stopping smoking, increasing physical activity, eating healthily or reducing alcohol consumption. This aspect of people making health behaviour changes was clearly considered challenging for both patients and clinicians in terms of their current expectations. One policy lead said "Step five of the cocreating health framework needs a change of culture to do. If we are all about treating sick people then the current culture will be difficult to get out of". Another policy lead said "it's really step five agreeing the way forward, is the most difficult a. to predict, b. to get in place given the pressures I was just referring to. And it may require not just a behaviour change but a culture change as well". A senior leader pointed out the need for clinicians to give patients consistent information about health behaviour "I'm bothered that the slogan, make every contact count might give the impression that giving a complex message in the early interaction with patients is important. But the quality of the interaction is important. Patients can be confused with too much information and can be given conflicting information by different professionals. We need to keep the message simple. We need to develop information across Wales relating to choosing health behaviours that is shared by all." There are also clear challenges for clinicians working with patients, constrained by resource in not being able to provide the standard of treatment or care that they consider

appropriate. For example, a fourth senior leader said “OTs currently only give 6 week Reablement treatment. This isn’t enough for people to resume independent living”. A sixth senior leader said “given that most healthcare interventions take a team approach, rather than an individual I’m wondering how this is communicated to other members of the team, whether other team members might be involved in this. Does an individual conduct a consultation and then feedback to colleagues ? There would need to be some sort of communication within the healthcare team. Someone would need to make a clinical judgement about this and pass on to their colleagues””

The views of interviewees were used to set out the fifth element, agreeing the way forward, as described in figure 5.5 below :

Figure 5.5 : Agreeing the Way Forward Element of the Cocreating Health Framework

Agreeing the Way Forward Element

Having discussed appropriate options, patient and clinician agree the way forward including any goals that the patient wishes to achieve within a specific timeframe. It may be that the patient is reassured, having become fully informed, and autonomously chooses not to take up any further intervention, a situation which the clinician accepts despite their own views. Alternatively, the clinician having had training in supporting patient self-management would be able to support the patient in effectively managing their own condition outside of formal health services. In supporting the patient to adopt or maintain healthy behaviours, the clinician is guided by an understanding of the patient’s level of activation and phase of behavioural change that assists them to determine the readiness and motivation of the patient to make a change in their health behaviour and to set their support appropriately. In their interaction, the clinician looks for trigger words from the patient to signify that they are potentially ready engage in ‘brief intervention’ around health behaviours such as referral to smoking cessation, national exercise referral scheme, weight reduction programmes, alcohol reduction programmes. The patient and clinician agree a management plan with appropriate SMART goals that are ; Specific, quantifiable, and related to the aim of intervention ; Achievable and Realistic ; have an agreed Timescale ; and meaningful and person centred, relating to the patient’s life plan Pre-intervention patient defined and clinical outcome measures are obtained to set the planned outcome. The clinician will support the patient to move from a goal to an agreed plan by supporting the patient to identify their first action, the importance of this, the timescale for carrying this out, the frequency of action, the potential barriers to acting, the potential ways around the barriers and the confidence that the patient has in achieving the plan. The clinician will acknowledge that supporting patients to develop problem solving skills is key to achieving the plan. The role of the clinician is to support patients to find solutions that will work for them in the context of their lives, rather than suggesting solutions. The agreed plan including the option(s) chosen, rationale and both clinician and patient responsibilities is documented by the clinician in the clinical notes and a copy provided to the patient.

5.8 Implementation

The implementation element had very few comments from clinicians since essentially this concerns their everyday work and is non-controversial. Clearly, clinicians are concerned that patients having agreed to health behaviour changes may find these difficult to carry out. The implementation element was primarily informed by the researcher's knowledge and experience as a reflective practitioner and by the review of the literature described earlier.

The implementation element is described in figure 5.6 below :

Figure 5.6 : Implementation Element of the Cocreating Health Framework

Implementation Element

Once the way forward is decided and a plan jointly agreed to meet the patient's needs, the next step is for the patient to make the required health behaviour changes and for the clinician to facilitate the agreed way forward, either by personally carrying out an intervention, agreeing another time for this to be carried out, making the appropriate referral, or informing the patient of the mechanism that would allow the patient to interact with them as required. When the clinician carries out an intervention, they must be assured that this is not dis-empowering the patient or reinforcing psychological dependency by achieving a goal that the patient may have been capable of reaching themselves. Any intervention carried out by a clinician must have an evidence base that is grounded not only in literature but knowledge of their own practise. In discussing health behavioural change or providing an intervention with the aim of health behaviour change, the clinician should acknowledge that ambivalence is a normal part of change, that ambivalence can occur at any stage and that motivation is particularly difficult after illness, exacerbation or difficult life events. The role of the clinician is to provide sensitive support to help the patient explore and reflect on their ambivalence to support their autonomy and help them move forward in their contemplation of change. The clinician will acknowledge that there are costs and benefits to any change and will not attempt to persuade the patient of the health benefits in making change or of the dangers of staying the same. By reflecting back to the patient using their words and phrases the reflections that the patient has made on their health behaviours, the clinician will establish a common understanding.

5.9 Review and Further Actions

In this element, the patient and clinician meet to review the outcomes of the actions they have both taken and take further action as required. These outcomes would include those defined by the patient as important to them as well as the outcomes of interest to the clinician.

A policy lead set out the policy perspective “co-production outcomes have to be agreed by each individual and not by the system. We need Patient Reported Outcome Measures and Outcomes to be co-produced. We can’t continue to have system outcomes as these force a machine approach. For example, health visitors already use specific outcomes. If clinicians can identify outcomes to develop with clients this will give a stronger sense of satisfaction and provide evidence of benefit for managers. Individualised outcome monitoring and collection is at the core of cocreating health. The ultimate test is whether coproduction provides outcomes valued by patients and clinician”. A second policy lead explained “there is a need for providers to know how they are performing by measuring patient outcomes and experience rather than think it’s doing well without undertaking measurement. The Agency notion is predicted on the perspective that the agent will indicate quality of service and make a recommendation and the consumer makes choices.”

A senior leader spoke of the need to define outcomes in terms of patient benefit “when I say, we would expect this to give improved clinical outcomes, how are we going to define that in this model ? Because there would be a percentage of people that we wouldn’t help. You know, if they’re informed, and understand their disease, we wouldn’t be affecting their outcome. So is there something softer around a good clinical outcome could be a patient understanding their disease process better. That is a clinical outcome. It may be a psychological slash mental health outcome, but it’s an important outcome because then they act in a different way in which to manage their disease. How do you balance that ?” An eighth clinician confirmed that she was using individual outcome measures to inform patient options “the type of service we’re offering now, yes we do use some outcome measures. We’re using timed up and go, and group strength. And also subjective ratings with breathlessness. At each initial assessment, the relevant outcome measure is used for presenting condition. We’re right on the cusp of changing the service so from now everybody who is seen will have a nine week review where those outcomes will be repeated because I want to start gathering this data more coherently. That will then guide whether they will stay on the existing treatment plan, if there is further gains to be made. Whether they could be escalated to a slightly more challenging plan, whether they perhaps need to be de-

escalated because their condition has changed but we will be looking to slow down that decline”.

A second senior leader described the patient defined outcomes already in use “for physio practice reviewing individual achievement of goals should be a consistent part of each and every patient that you treat. But once you’ve done your diagnosis and assessment you’re then required to have a discussion with the patient around agreed goals and agreed outcomes so you’re both clear about what it is that you’re working towards. I don’t see that this is different in that respect. You’re talking about proms and prems and further actions, you might want to agree what the clinical outcome is that you’re wishing to get from this, what outcome from this process”.

It was clear from participants insights that the routine use of outcome measures is already embedded in the practice of Therapy staff. One senior leader said “Physiotherapists consistently discuss agreed goals and use outcome measures. Physiotherapists do need to use proms and prems more with agreed clinical outcomes and this should be mandated.” These thoughts were corroborated by a second senior leader who said that “we need to review assessment tools used in practice placements to ensure the co-production approach is being used. We need to ensure this is embedded in practice for junior staff. Dietitians set goals in each consultation and measure against these for individual patients, but don’t collate outcomes across their caseload. This is better in group education programmes such as in diabetes which encourages an individual goal setting approach and usually a database is set up to audit outcomes. Similar review also occurs in the practice of occupational therapists. A third senior leader said “OTs set goals with an intervention plan based on desired outcome goals. On review, they see if these goals were achieved and this is particularly true in patients with long term conditions. OT’s normally agree activities or exercises with patients and if these are not achieved they look at further intervention. Frail, older people will be coming back through the systems because their condition has changed. Much prevention could be done by OTs if they could work with people before they become frail. However, another clinician working with cancer

patients commented that “Outcome measures are on the agenda but are not routinely used in my practise since it is difficult to find an appropriate outcome measure.”

One clinician described the challenges in standardising approaches to outcome measures “I do find our patients are so different and the treatment is so individual and the goals evolve as we’re treating them, and change, that I feel I find it quite difficult. Well I think all the therapies have a problem with trying to evaluate don’t they really. Clinically they’re affected because of time constraints and we don’t want standard outcome measures because everybody’s different. This was echoed by a seventh clinician who said “We’ve tried several outcome measures. We’re in the process of looking. We’re re-structuring the admission department so my colleague and I have started looking at outcome measures. Because the way the outpatient department works at the moment we do GP referrals, general referrals through rheumatology, it’s difficult to find an outcome measure that meets the needs of all the areas. We do review them but they’re not standardised outcome measures. We review them, and if there’s problems we change the practice, we change the intervention, but it’s not a standardised outcome that we use at the moment in outpatients”.

A second clinician was supportive of routine use of outcome measures “I definitely agree with giving clinical outcome measures at the beginning, and the end of treatment. That’s what we do at the moment. But again it could be very physio based in terms of objective markers, with I don’t know, patients levels of mobility, their quality of life. So I think maybe changes in that, trying to suit this framework would help. I don’t know whether having access to a wider database that’s got some proven outcome measures that we could use, focused on this topic. So we’re using the right things”. This was corroborated by a third clinician who said “we don’t audit, we just check improvement. Individual improvement in certain aspects. And we tend to use sort of old faithful. Like if we’re looking at balance, we’ll stick to balance measures, or stroke outcomes or strength, things like that”.

A fifth clinician raised the challenges in using outcome measures for clinical audit to improve practise “we’re not very good at collating outcomes for a caseload. We’ve got

to get to grips with doing that. We're better at it with certain group education. And actually it's much better at measuring outcomes because there's usually a database or a method set up to do that. So that's quite positive. This was echoed by a fourth clinician who described the challenges in the use of standard outcome measures for audit and improvement "we use two outcome measures routinely, MAS and TCT which are initiated on admission by the guys on F. And obviously we also work to goals, so goal attainment is a good measure of achievement. But I must admit I don't find any of the outcome measures particularly satisfying. They don't really measure performance very accurately. And the inter rater reliability is poor. I think more in terms of functional carer burden, so I would see them and think right this person is likely to be discharged using hoist transfers four times a day package of care, or nursing home. Or this person is likely to achieve walking to the toilet with supervision. Which is the significant bit. It's not how well they are at the end of their admission, it's how they cope when they go back home. Outcome measures is a good example. You're routinely filling out outcome measures which I don't think reflect patient performance. And we're doing it because they're the best ones we've got. But still, that begs the question, if they're the best ones, they're still rubbish".

A sixth clinician talked of the contextual challenges in reviewing patient outcomes "the patient is more concerned about living. 'I've had a cancer diagnosis, I'm going to die'. So they really don't care about the secondary consequences of treatment, they just want that cancer gone. So it's the timing of when they're given this information. And that's why we see them four weeks post-op to go back through things when things are slightly more clearer in their head, and when the cancer has been removed.

The review element of the cocreating health framework informed by interviewee's views is described in figure 5.7 below :

Figure 5.7 : Review Element of the Cocreating Health Framework

Review Element

On review the patient and clinician review the outcomes of their interaction to evaluate whether the action plan has achieved the agreed person-centred and clinical goals. Where the goals have been achieved there is a further discussion centred around the actions required by both patient and clinician to ensure that desired outcomes are maintained and the mechanism for the patient to seek further support as appropriate. If goals have not been achieved and it is jointly agreed that further improvement is possible, then the patient and clinician would discuss further iterations of similar or different interventions or health behaviour changes. Where the patient has not made the agreed health behaviour changes the role of the clinician is further to explore the reasons for this and discuss alternative ways to support the patient. At this point, the clinician will undertake measurement of both patient-centred and clinical outcomes against the baseline measurement. Review and evaluation may be repeated until there is agreement between patient and clinician not to pursue further interaction. In this event, the patient is either discharged or the purpose of referral is agreed to another source of support.

5.10 Reflective Learning

Underpinning each of the first seven elements is a requirement for the clinician to reflect on and adapt their interaction with patients from information gained from clinical audit, complaints, incidents, claims and sentinel events such as harm review. This aspect was informed by views of participants and the literature review reported earlier.

One policy lead said “within the later parts of the framework, reflective learning and quality improvement aspects are missing currently in many professions practice as they don’t have the time to do it”. She also said “There are areas in the framework that are already being done by certain groups but steps eight and nine are not addressed at all”. Another policy lead said that we need “robust metrics shared across organisations, analysis and feedback to drive improvement”. A senior leader said “physiotherapists should audit their own outcomes. But it is more likely that a practitioner would gain learning from the service outcomes rather than their individual outcomes”. This approach within therapies was corroborated by a second senior leader who said that “the desire to improve services is embedded in the culture of dietitians. We work with colleagues across Health Board boundaries to devise common pathways and establish common policies.” A third senior leader said “clinical audit is not routinely done by OT’s due to time constraints. They do selective

retrospective audits for example on the orthopaedic pathway to look at what staff do with patients and why they do it. Prospective audit has been carried out by an OT into fibromyalgia. Also, the multidisciplinary cardiac rehab team review information then modify their practise as a result. In general, Occupational Therapists and other therapists rely on information from national projects rather than carrying out local prospective audits”.

A senior leader said “I quite like the reflective learning, and the quality improvement because there’s a learning element with this which I think gives you permission not to always get it right first time. But actually second time you’d be better. You should understand the outcomes that patients are getting from your service and my word is ‘should’. It depends whether this is done at individual practitioner level. It is more likely that a service will look at the outcomes of acupuncture as a service, not necessarily as the individual practitioner doing it”.

A second senior leader spoke of the importance of reflective learning in changing practise of the multi-disciplinary team “and I think also for that particular caseload, the dietician to be fair to her, she went to the audit meeting with the MDT and she presented her work. And a year later she was able to go back with a draft pathway, and went back to them with the pathway actually in process. I think the value of that was gaining approval from the medical clinicians to treat patients in that particular way”.

However, despite the known advantages of reflective learning, it was clear that clinicians find it challenging to make time in their busy clinical schedules to carry this out and that there are issues in auditing specific aspects of the cocreating health framework. A clinician said “It would be lovely to spend time reflecting on what has happened. I’m struggling now to do an audit that dates back two years. I’ve got colleagues off sick that I’m going to have to pick up their roles. There’s loads of stuff I would love to do, that I heartily agree would be of benefit to the system. But you can’t tell people who are already horribly overloaded with keeping their heads above water, to also reflect on what’s dragging them down. If they did, it would pay dividends. But when ? You’ve got to keep swimming. You can’t stop or you’ll sink I’m presently

auditing the outcomes of pregnancies among ladies with diabetes because I look after them. So yes I do, but I don't audit every area of my work, this is probably the only one that gets a very detailed audit. Choosing to audit the most important aspects of my work is hugely valuable and I do it every year except I didn't last year because I got snowed under. But every year I audit everybody I see in minute detail. I do it all myself because I know it will have a knock-on for next year".

These themes were picked up by a second clinician who said "There's pressure to do an audit I think, because everyone has an outcome measure. We're conscious that we're not auditing enough, and small research studies, we're not doing. And yet we've got very good client groups to do studies on. We've got them all here and they would all consent. We don't have any protected time for doing that. If you were perhaps doing a masters you would get the odd afternoon, so if you've signed up to something you might. Our audit representative is trying to have something going but it slips because as soon as the clinical pressure builds up that's what goes." A third clinician agreed "No audit is done on that at the moment, Audits are focused on waiting list times.

As a direct challenge to the local production of knowledge described in the cocreating health framework, a fourth clinician said "information and understanding is derived from national information rather than local information. We don't have local information to hand as I would have assumed it was broadly the same. Am I wrong? Is it not broadly the same? We're taking part in the sentinel, royal college of physicians huge audit thing that's going on at the moment. We don't look at the results of that to inform our practice because I don't think it's finished yet. I might look when it's finished".

A fifth clinician said "We do review our outcomes but they're not standardised outcome measures. We review them, and if there's problems we change the practice, we change the intervention. We do look at changing the system at lot, how we can make it more accessible".

The underpinning reflective learning requirement, refined from the views of participants is described in figure 5.8 below :

Figure 5.8 : Reflective Learning Element of the Cocreating Health Framework

Reflective Learning

Clinicians will routinely complete a reflective learning cycle by reflecting on information gained from clinical audit, complaints, incidents, claims and sentinel events such as harm review. The clinician will routinely audit clinical and patient-centred outcomes to determine whether interventions are resulting in appropriate improvement for the population of patients served. The outcome of reflective learning is used in discussion with patients about potential harm and benefit arising from interactions with the clinician. Outcomes from reflective learning are routinely shared within the multidisciplinary team, discussed with colleagues, compared with benchmarks and used to improve the service delivered and inform prospective preference-sensitive choices of patients. Outcomes are also shared with service planners and commissioners to ensure that appropriate resource allocations can be made with the aim of shifting resources down from specialist services into prevention and enhancing both individual self-efficacy and community resilience.

5.11 Service Improvement

Informed by the views of participants, and by the literature review reported earlier, a second aspect underpinning practice was found to be service improvement. One policy lead said “The AHP improvement quality guide that we published recently showed the importance of small scale change. In working towards an end result you need a vision. I would argue that a barrier to implementing the framework is a lack of buy in to the vision. This will include patients and staff”. A second policy lead said “So continuous improvement is part of the cocreating health framework. And I know from looking at colleagues over the years that the better clinicians practice this already. But that is a challenge because we’re trying to make all clinicians better. Which is great, but not easy”.

A senior leader said “I like the quality improvement aspect of the cocreating health framework”. A second senior leader said “formal quality improvement projects are not frequently done by occupational therapists. But OT’s do frequently reflect on their practice. Systems and processes change as a result of discussion about how they can make things better for patients Quality Improvement is done by Occupational Therapists but not formally. They all want to do things right the first time, but may not recognise that they are involved in quality improvement”. An occupational therapist

working with cancer patients said “time to do research is an issue”. A second clinician pointed to challenges in service improvement “in terms of the reflective learning parts, again I suppose because at the moment this is something that should be obvious to all clinicians, from my training that I did here with the feedback, it came across that a lot of us aren’t, really. In terms of service improvement at the moment, trying to get appropriate referrals in, getting appropriate referrals, takes a lot of time for the triage staff, to redirect them so there’s been some talk of liaising with GPs a little bit closer to make sure they’re actually referring to the right service. The service improvement focus on this, apart from service training, which we do regularly and obviously the topic I did a few weeks ago was on this”. A fourth clinician pointed to the difficulties in finding time for service improvement “we find it difficult to find time for service improvement work. I would say that this ward has been mired by staffing issues. There’s always something. People are off sick, on annual leave, on maternity leave, or they’ve left and haven’t been replaced so it’s a constant how can we juggle this. Not for want of ideas, and not for want of some of them being put into play. A sixth clinician also pointed to difficulties finding time “We’re going to collect routinely, I’m going to collect this data for a group of patients, and use it to audit the service to influence service delivery. It means we might be able to get a couple more bodies to cope with demand. I think at the moment I want to know because we are the first doing something like this, we need to know if it works. This is action research. Research time is an issue”.

A second senior leader confirmed that service improvement is routinely carried out in her team “I suppose it’s quite embedded in our culture to always want to improve service”. This was acknowledged by a third senior leader who said “all of us in the lymphoedema service have done our bronze improving quality together award, so we knew it was something we wanted to do. A few of us are doing silvers so it’s pushing forward ideas but having time to plan. The problem with our service is we are very much we have an idea and we act, we are reactive, we are not proactive. So cocreating health has made us more aware of lets think about things, let’s think of other things what other impacts are we doing”.

A third clinician spoke of her use of small cycles of change “. And service improvement is very high on my own agenda, for my own practice Even though we’ve got an idea of what’s evidence based good practice, it’s not being embraced fully on all the wards.

So I've had a few meetings and had some funding for a little bit of my clinical time, so that I could observe and report back as to how good work”.

A fifth clinician confirmed that “service improvement is routinely embedded in our practice. We're looking at ways of getting patients in quicker, to give them a better service”.

The service improvement element of the cocreating health framework, informed by these insights is described in figure 5.9 below :

Figure 5.9 : Service Improvement Element of the Cocreating Health Framework

Service Improvement

Service Improvement and Action Research using small size PDSA cycles, at introducing novel aspects of service provision are key to success and sustainability. This creates knowledge to inform and change practise for both teams and individuals within their local service context. The aim of this is to continuously refresh clinical practise with current evidence to provide improved clinical and patient-centred outcomes.

5.12 Conclusions on Development of the Cocreating Health Framework

Having taken account of participant's views, a further iteration of the cocreating health framework was produced and fed back to participants to investigate whether this had captured their insights. Following the further input from interviewees regarding the tested cocreating health framework, a final version of the cocreating health framework was developed. This is set out in detail in the discussion chapter. The developed cocreating health framework contains each of the original elements of the test framework, but they are described slightly differently and have a revised content. For example, the use of option grids in both the preparation and option discussion phase was considered important and has been added to the narrative description. Since no other such framework for clinicians to engage patients in cocreating health exists in the literature, this is the first example. The cocreating health framework is different, both in concept and design to the current 'medical model' of consultation. It contains individual elements such as shared decision making, self-management support and behavioural change that have previously been implemented singly within the context of the medical model of consultation. The framework was informed by synthesis of models in the literature, particularly those of Paget et al (2011), the biopsychosocial

model of Engel (1980), human needs set out by Max-Neef (1989) and the initial concept of cocreating health developed by Conway and White (2006) with findings from the workshops and questionnaire data and the insights gained from in depth interview of participants.

Chapter Six : Results and Analysis for Implementation of the Cocreating Health Framework

6.1 Introduction

This chapter describes the findings on implementation of the cocreating health framework gained from in depth semi-structured interviews. A number of implementation issues were identified in the workshops and questionnaires in the first phase of data collection. To investigate these factors in depth, a total of thirty one interviews were held. Interviews were initially coded against the open codes determined from the workshop findings as shown in Appendix 3. Interviews from thirty one participants gave a great deal of information, which was initially coded against the open coding structure. The interviewee's rich and illustrative knowledge and experience provided insights that were coded as they were collected and immersion in the data gave a modified axial coding structure with a number of interconnected categories. This chapter provides a synthesis of participant's insights, which are shown in full in Appendix 4.

Immersion in the data identified three major themes influencing intent to implement the cocreating health framework, representing both barriers and facilitators. These were categorised as System Factors, Patient Factors and Clinician Factors. System factors included the use of a framework for patient-clinician interaction, pace/complexity, politics, leadership support and infrastructure. Clinician factors were the availability of supporting evidence, communication, current models of practice, risk management, clinician training, peer expectations, policy expectations and context. Patient factors were patient training, patient expectation, patient activation and power relationships.

Consistent with this paradigm, insights from the interviews were re-coded and are described below.

6.2 Clinician Factors

This research demonstrated that if communicated to them clearly, clinicians respond positively to the conceptual Co-Creating Health Framework especially where this is supported with a strong evidence base including case studies and training.

6.2.1 Evidence Base

Participants confirmed that clinicians and particularly, doctors are highly influenced by the academic evidence base, including numbers and statistics, particularly if these are produced locally to their practise. This suggested that an evidence base of effectiveness will be required to engage doctors in cocreating health. However, views were that therapists and nurses are more influenced by practical examples of patient benefit from local team members. To engage doctors in cocreating health will require examination of the literature on what convinces doctors, for example to engage in change programs

6.2.2 Clinician Training

Participants considered that to cocreate health, clinicians need knowledge, skills, confidence, and tools since some concepts are new for clinicians. It will not be possible to implement cocreating health without clinician training. Training for cocreating health would be most effective if this is embedded in pre-registration training. Therapists and nurses were considered easier to train in cocreating health than doctors but some doctors, for example GPs will be easier to train than others such as Surgeons. Facilitating practice in cocreating health within a 'safe' environment is very helpful, both in face to face training as in role playing and practice between training sessions. Some clinicians feel that they are already practising in a cocreating health way, but face to face training including role play can demonstrate to them that they are not. E-learning modules are needed to support face to face training, before training to prepare clinicians and afterwards to support clinicians in embedding the approach and to achieve large scale roll out. Clinicians described the importance of current practitioners teaching cocreating health to students and trainees. Some clinicians may not be suited to cocreating health philosophically, and may not be able to develop the required communication skills, and in this situation their permission should be sought for other team members to engage in cocreating health. Clinicians are able to see

changes in their own practise as a result of cocreating health training, but this requires highly skilled and experienced trainers as cocreating health is challenging clinicians existing practise and way of thinking. Training the whole multi-disciplinary team is the most effective way to embed cocreating health. Training in agenda setting and self-management support are the key and potentially transformative elements requiring training within the cocreating health framework. Clinicians need to practice new cocreating health skills to develop their competencies. Established staff who have many years clinical experience may return to old ways of working when under pressure.

6.2.2.1 Embedding Cocreating Health in basic professional training

In embedding cocreating health within basic professional training the importance of interprofessional training, pre-registration training, training on placement, during foundation years and preceptorship were highlighted. These were seen as the key factor in facilitating a new approach to healthcare delivery with longer term benefits if they can be sustained once new graduates in practice as influence from longer serving clinicians can be very powerful.

Participants considered that clinicians find it difficult to change their model of interaction once in practise. There is strong support for the cocreating health framework amongst educators involved in basic professional training. Factors evaluating clinician's cocreating health skills should be embedded in clinician skills assessment tools. The cocreating health framework is consistent with the values of the NHS and with the psychological contract of new entrants to the NHS.

6.2.2.3 Training the Multidisciplinary Team

To be most effective the whole MDT should be trained in the cocreating health approach to ensure they have a consistent language and approach. But it is difficult to release the whole MDT for training whilst trying to keep a service going. It is particularly challenging to release doctors for training. Training for cocreating health needs to be different to current models of training that take place in professional 'silos'. Training in cocreating health could drive different ways of MDT working. Training needs to emphasise the importance of the whole team to own the agenda and goals agreed

with the patient. Training one member of the team is not helpful as this leaves them exposed, trying to work in a different way from the rest of the team and they may not influence the team to take a cocreating health approach. Senior medics, particularly consultants in secondary care need to be trained in cocreating health to successfully embed this in practise by influencing their peers and staff in training. It is also important to train whole professions in cocreating health, particularly if they work in uni-professional teams.

6.2.3 Communicating the Cocreating Health Framework

In communicating the cocreating health framework it will be important to carefully define terms, to provide an introduction to explain the concept and its value in plain English. How the cocreating health framework is communicated will be important to its acceptance by clinicians. The language used to communicate the framework is important as cocreating health needs to be understood by different professional groups. In particular, communication should avoid buzz words, neologisms and long words. It will be important for patients to understand that this is about best use of all resources including patient expertise, rather than rationing, otherwise they may react against it. It is important to explain cocreating health as a practical framework that can be applied in practice, rather than just an academic concept. It is important that the concept of cocreating health is understood by and supported by politicians and the media. Adoption of the cocreating health framework will need to be supported with links to other resources and case studies. Cocreating health needs to be embedded in strategic documents. It is important to describe the cocreating health framework as an iterative loop, rather than a linear process. Clinicians, particularly doctors need to understand when they are operating a medical model that they are not currently practising consistent with the cocreating health framework. Engaging clinicians in cocreating the framework will help in developing ways to communicate it. Clinicians need reassurance that implementing the cocreating health won't add to their workload and will release time to work more effectively. The cocreating health framework must be presented with a visual depiction that is easily understandable. The test depiction using the waves diagram was not helpful. A visually attractive depiction is needed to enthuse people with ideas about cocreating health to get them to read the narrative description of the framework. Enthusing clinicians about cocreating health will be a

challenge given perceived time and workload constraints and communication will require strategies and incentives.

6.2.4 Current Models of Clinician Practise

The normative understanding of clinicians was found to be set by their previous training, mostly within the 'medical model'. Clinicians practice was also informed by the expectations of patients to interact with them in a particular way. Clinicians, particularly doctors, feel a pressure from the expectations of peers around what constitutes a 'good clinician' including unwritten ethical and moral codes. Clinician's practise is also dependent on the requirements of the system they work in, including the expectations of policy, organisation, professional body, regulatory body and medico legal aspects including risk management. The same clinician may interact with patients in a different way within private practise than their NHS work due to the different system factors and their greater control over these. The way clinicians practise adapts according to the context in which the interaction with the patient takes place.

6.2.4.1 Conflict between existing clinical practise and the cocreating health framework

Some clinicians, particularly doctors who are in a position of power within the health system say that they don't want to be told how to practise. Certain professional groups would be covert in not engaging with cocreating health. The current medical model gives short consultation times and clinicians may find that negotiating additional time for cocreating health interactions is a barrier. Currently clinicians may feel their services are there to deliver the medical model of assessment, diagnosis, treatment, cure, and discharge. Staff will require support to see cocreating health as an opportunity rather than as a threat to their autonomy. In practising the current 'medical' model, rather than listening to patients, doctors can interrupt patients as they have got only a few minutes for the consultation and they have to get to the point quickly. Many doctors may feel initial discomfort at the re-balancing of the power relationship and must be encouraged to avoid controlling behaviour that could interfere with true cocreation and better outcomes for patients. Doctors and nurses may also consider that offering patients choices that are not supported by the evidence base or are not

the right choice for the patient is ethically and morally wrong. Therapists and other staff groups who implement many elements of the framework don't always have time for reflective learning and quality improvement. Therefore, examples of re-structured interactions must be available to show staff how reflection can be built into their interactions. Staff need support to recognise the value of coaching in the relationship between a clinician and a patient through patient and staff testimony. Cocreating health is moving towards a better agency relationship, where the agent (clinician) acts completely and solely on behalf of the patient. In the current medical model, the agency relationship is constrained because the clinician has to satisfy other stakeholders. Clinicians belong to professions, they belong to other organisations which have agendas, they have constraints, and sometimes the clinician is compromised in meeting the requirements of the other stakeholders and can't act entirely on behalf of the patient as the consumer. The cocreating health framework conflicts with the medical model that defines an expert clinician model for doctors and nurses. Clinicians may face a moral conflict or anxiety when they think they know what's best for patient but the patient chooses a different option. When patients choose a different option than the one the clinician would recommend, clinicians may be unsure of their responsibilities, and concerned that they may need to put aside best practice. Outcomes desired by patients may be in conflict with the legal or moral framework. In the way they are currently constructed for the medical model, systems don't support practise in cocreating health way. Cocreating health is challenging since it is difficult for doctors to put themselves in the place of someone without medical training. It is easier for doctors to say what they think rather than working in partnership with patients. Clinicians and patients need permission to change to a new way of working and doctors are important in granting this permission to both patients and other clinical professions.

Therapists can prioritise talking to patients about the benefits of behavioural change rather than spending time assessing the patient's readiness for change. There are system constraints around setting clinician's role, for example occupational therapists are directed to spend their time in inpatient settings in facilitating discharge rather than engaging in rehabilitation of patients although it is recognised that this is a false economy since quick discharges can result in increased social care resource use, increased equipment use, and repeat admissions. Doctors may feel that working in

cocreating health challenges their professional judgement and competence. Surgeons have spent much time on developing operating skills and want to practise these and would not necessarily prioritise cocreating health conversations with patients around the options for not operating, or operation at the right time such as deferring for a few years. Cocreating health in elective surgery might need a different clinician to have conversations with patient about options than the surgeon doing the operation. In a team, you need clinicians to practise in a cocreating health way, but also need others who can't do this, but who are very competent technically. Cocreating health will require transformational change in the practise of doctors. Cocreating health will work best for clinicians working with patients with chronic conditions. Doctors need training to work with patients who already have self-management skills. Clinicians may not refer patients to patient education programmes as clinicians feel they should have the expert role and patients shouldn't. Cocreating health is transformational for nurses, who find it an uncomfortable way of practising. Nurses are influenced by the medical model and are currently focussed on the clinical agenda based on assessed risk factors rather than the patient's agenda. To practise in a cocreating health way, nurses need support from each other and from other members of the MDT. Clinicians have found it difficult to work with the patient's agenda within the medical model. Sometimes clinicians need to prioritise working to the clinical agenda rather than the patient's agenda, for their safety. Nurses starting to work with patients in cocreating health can grant themselves permission to leave things out of their clinician's agenda. Therapists may feel they have to work to a medical model to avoid criticism by doctors. Patients come to doctors for alleviation of suffering but get treatment of symptoms, which is not the same thing. Clinicians have the experience that many patients are accustomed to being told what to do and lack the confidence to manage their own condition.

6.2.4.2 Clinician Permission

To work in a cocreating health way, clinicians can feel they need permission granting, from their employer, senior doctors, professional bodies to practise differently

6.2.4.3 Clinician Profession

In the way services are currently organised there is symbolic interactionism in that patients respond differently to doctors, nurses, therapists as they perceive their role

differently. Therapists and to a lesser extent, clinical nurse practitioners are more likely to change their practise to work in a cocreating health way. But other professionals will find it difficult to engage patients in cocreating health without support from senior doctors, who are seen as the person in charge by patients and other professions. Cocreating health needs long appointments which patients have with clinical nurse specialists and therapists, but not currently with doctors.

6.2.4.3.1 Doctors

Without training, doctors may not always have the skills or attitudes for cocreating health. Doctors are trained in a paternalistic way of working, and work within a paternalistic culture often under a break-fix medical paradigm. It is difficult for doctors to put themselves in the place of someone without medical training since as they have expert knowledge, they believe they know best what is in the patients' interest. There can be lack of equality in MDT working, with doctor's expertise and opinion and way of working valued more highly than that of nurses or therapists. Doctors like to see themselves as 'a good doctor' and are concerned that if they do not intervene medically to prevent illness they may face criticism from their peers. Doctors are not all the same. Different specialties, for example physician, surgeon, radiologist have different skills in interacting with patients and some such as pathologists may never do so. Since they have a long term relationship with patients, GPs may be more likely to want to work in cocreating health way than surgeons. GPs may need to be financially supported to change to a cocreating health way of working. It is of prime importance that doctors grant permission for cocreating health, and do not actively oppose it. When under pressure from patients or time, doctors tend to prescribe or refer for tests or agree an intervention. Doctors say 'nothing ends a consultation like a prescription, discussion takes longer'. In secondary care, it is very important that consultants are supportive of cocreating health as they have the power to prevent other clinicians working in this way.

6.2.4.3.2 Nurses

It is helpful for nurses to have a framework to support their working with patients. Nurses are currently trained to become expert practitioners and this may discourage them from wanting to work in a cocreating health way. Nurses work within a

'maternalistic culture', are trained to care for people, to do things for them and in their current practise may not prioritise supporting people to do things for themselves. Nurses are very busy in their daily work and may say that its quicker to do things for people but realisation that they're not there for the rest of patient's life may lead them to think of practising in a cocreating health way. Clinical nurse specialists and district nurses may find it easiest to co create health since they have more time with patients. Clinical nurse specialists can be competitive about the number of people they are 'saving', rather than the number they have supported to manage their own condition. Cocreating health would move clinical nurse specialist thinking from 'I've got control over the patient's condition ' to 'the patient now has control over their own condition'. Nurses 'do' for people, whereas therapists teach people how to do it for themselves. . In areas of ongoing, high service demand Nurses may prioritise 'getting people out of hospital' as the principal purpose of their work rather than how they can better teach people to look after themselves.

6.2.4.3.3 Therapists

Many therapists are already practising a number of elements of the cocreating health framework and have that mindset. But some therapy professions such as physiotherapy and podiatry can work in a way similar to medical model. Reflective learning and quality improvement are currently limited in the practise of many therapists due to time constraints although reflection may happen informally. Occupational therapists are trained in the biopsychosocial model but are constrained in their daily practise by the medical model. NHS structures can prevent therapists working in cocreation due to role definition or culture and the dominance of the medical model. Patients respond differently to different clinicians. Patients will complete activities with therapists that they refuse when asked to do so by nurses, partly because of their perception of role and partly because of therapists' practice of cocreating health elements.

6.2.4 Peer Expectations

Currently, needs assessment can be predicated on what the system provides rather than what the patient may need. Peer expectations can be a barrier to cocreating health since the peer expectations of clinicians can be to demonstrate expert,

paternalistic practise. Nurses have peer expectation of caring, working as an expert practitioner. Doctors have a peer expectation of achieving a good result for the patient, being a good doctor, leading the team. There is also a Medico legal expectation that another practitioner seeing the same patient would have practised in a similar way. Peer expectations are set by the professional body, regulator, and employer. There can be a peer expectation to reduce variation, each patient having the same outcome, with the more patients treated in the same way, the greater the certainty of achieving a particular outcome. There are peer expectations of reaching 'moral' judgement or decisions that may not be those that the patient would choose.

6.2.5 Policy Expectations of Clinicians

Clinicians may need an incentive to shift to a cocreating health approach. Commissioning of good system design can be used to support change in practise. Cocreating health is consistent with the prudent healthcare agenda in Wales and collaboration but not with competitive, consumerist health policies in England. There is a need to codesign policies and services with patients to ensure the right support is being offered by clinicians. There is a need to align government policy, performance management of providers and training to support cocreating health. There is a need to ensure that Government is consistently supporting cocreating health by setting out citizen responsibilities for their own health in addition to supporting their rights within health services. Widespread implementation of cocreating health will need consistent policy direction despite elections and changes of minister and for ministers to insist on measures against purpose that inform improvement and provide true assurance of progress rather than static targets that do not.

6.2.6 Requirements of Regulatory Frameworks

In the view of interviewees, professional regulatory bodies will not have an issue if a patient chooses a particular option that a clinician doesn't think is best for them as long as cocreating health decisions and rationale are recorded in patient records. If a patient doesn't want to take responsibility for managing their own condition, then the clinician needs to retain this responsibility. In some clinical situations there is a legal responsibility to complete certain objectives, which clinicians need to complete to protect themselves from risk of regulatory sanction or medico legal consequences.

6.2.7 Context

There are some situations when applying each element of the full cocreating health framework may not be appropriate, such as when patients need acute care to save their life. In this context, however, clinician's practise would still be informed by review of individual outcome, audit, and quality improvement. It will be important for clinicians to decide themselves which elements of the framework to use in a particular context. The sicker people are, the more likely it is that they will have things done to them, but clinicians can also work in cocreating health with families or carers of patient acting as advocates. If a patient can't speak or doesn't have mental capacity, or is a child then cocreating health may require family or carers to act as advocate. Cocreating health is consistent with supporting people to manage their own health at home, rather than being admitted to hospital. This needs secondary care providing better support to GP's, and GPs working in a cocreating health way with patients to prevent exacerbation of chronic conditions. Patients may be more able to co create health when they are more obviously in charge when in their own homes, rather than in the clinician's 'consulting' room. There are challenges in cocreating health in an inpatient setting. Clinicians engaged in cocreating health will need to ensure that patients have the appropriate understanding to be able to manage their own condition. This is difficult to achieve in inpatient setting, but can be done prior to elective procedures. Cocreating health is a challenge in MDT working unless all clinicians in the team are signed up to cocreating health approach and can see the chosen action plan in the patient's record. Cocreating health will need a seamless patient record that primary, community, secondary, social care and the patient has access to. Currently, it can be difficult to maintain a record that all clinicians can see, unless working in hospital. Currently clinicians have more conversations about behavioural choices in primary care than in secondary care. In the context of a system, both primary care, emergency care and inpatient care that is pushed to its limits with demand pressures from people with chronic conditions, it's going to be difficult to implement cocreating health since this needs buy in and some additional time at least initially. When interacting with people in outpatient settings, clinicians understand that the patients have the level of motivation, cognition and support to get them to the appointment, but this can be different in inpatient settings. To implement the cocreating health framework there is a need to ensure that primary care, and other clinicians than doctors have access to diagnostic tests, specialist opinion so they can fully describe the patient's condition

rather than send them into secondary care unnecessarily. Decision support tools are helpful where there are a limited range of presentations and options but not where this is more complex and there are unknowns. The same health condition can have a different effect on different individuals, dependent on the context of their life. People can change their health status day to day and changed circumstances will need a different discussion. Currently, people often don't know why their GP has referred them into secondary care. Cocreating health requires continuity of clinician interacting with a patient, otherwise the interaction will cycle around the elements of the framework. Cocreating health depends on clinicians establishing a long term relationship with patient, and the framework is less helpful if the patient interacts once with the clinician and is then discharged. This goes against existing acute care culture of 'pushing' patients through the system. Cocreating health will work well in paediatrics where clinicians have long term relationships with child and parents. The cocreating health framework will work better with GPs than secondary care clinicians but GPs have 1500 people they are caring for, so will take some time to implement. If people are feeling very ill then they may not have the ability to enter into a discussion on self-managing their condition, in this situation they just want the clinician to take charge. In acute care, patients may be in shock over a traumatic in their health and find it difficult to accept the new reality of the situation. Family members may want to care for their relative or see them being cared for, and may be uncomfortable with clinicians trying to get them to do things for themselves. Cocreating health is applicable to interacting with patients with cancer where clinicians focus on quality of patient's life.

6.2.8 Management of Clinical Risk

According to interviewees, the healthcare system is risk averse and cocreating health carries inherent risks. Cocreating health will need clinicians to be trained to discuss risk issues with patients and to address the change in responsibility and accountability in these new relationships, and option grids can be helpful in this. Patients are currently not used to being told in detail about complications, or possibility of death or that an operation may have a poor outcome. It is very difficult to get patients discharged from hospital due to risk aversion from clinicians with a high threshold to discharge. Systems can burden clinicians with weight of assessments of inpatients that will prevent cocreation. The cocreating health framework has very different risk

management expectations of nurses than they are used to. There is a lack of public debate on risk of medical treatments. Clinicians need to balance clinical risks against working with patient's agenda. Clinicians can feel that risks are being managed by filling out assessment forms, rather than working with patients on managing risks and achieving benefits. Some patients find involvement in managing risks to be difficult and want to delegate this to clinicians. Clinicians can feel that they risk being hung out to dry when things go wrong and will need the support of the system if working in cocreation. Agreements on risk and responsibility need to be overtly stated within the new patient-clinician relationship

6.3 System Factors

6.3.1 Pace-Complexity

Clinicians say that it is easier and quicker to tell people what to do, but this doesn't necessarily lead to good outcomes. Short appointment times make it difficult to implement cocreating health, this needs an appointment of at least thirty minutes, but in primary care and secondary care, doctors have about ten minutes to complete their interaction. Engaging in meaningful conversations about health behavioural change takes at least an hour. An appointment to meaningfully review outcomes and decide on the way forward takes at least thirty minutes. The cocreating health framework suggests multiple interactions between patients and clinicians. A cocreating health interaction between clinicians and patients with multiple chronic conditions will take longer than current appointments. Time in face to face interaction could be reduced by patient preparation beforehand by sending them option grids, questionnaires, information, asking them to think about how they want to live their lives. Because of the pressure in hospitals, secondary care clinicians can prioritise their time to deal with the immediate care priorities. It will be easier for nurses and therapists to implement cocreating health as they have longer interactions with patients. Longer appointment times in private practice means that doctors implement aspects of cocreating health in private practice that they can't in the NHS due to time, so the barrier to cocreating health may be more organisational than cultural. Another time pressure is that some clinicians, such as surgeons must do a certain number of operations each year to be considered competent, so they would have concerns if asked to spend more time interacting with patients and less time operating. If clinicians don't spend time

interacting with people, they can just keep returning to see the clinician because their health issue is unresolved. Time is wasted in the current system with patients being referred from one specialist in secondary care to another, being cycled through clinics, not listened to, without achieving the outcome they want. Clinicians may consider that time spent interacting with the patient is time wasted that could have been used in treating them. Clinicians may rely on patients thinking they have all the solutions, so want to spend only a short time with the clinician being given the answers. In the current system, when under time pressure, GP's refer more to secondary care and prescribe more, just to end the consultation. There is a challenge in getting clinicians to change their interactions with patients as they are currently highly overloaded with work. To resolve this will require clinicians to be given space and time to implement the cocreating health framework and to have some work diverted away from them such as psychological therapies, and walk in clinics for therapies and nurses. Clinicians who work in a cocreating health way found that although the initial appointment took longer, the patient subsequently returned to clinic less frequently, saving time in the long run and significantly increasing the quality of interaction for the patient's perspective. Working with the patient's agenda is a more effective use of time. Initially, whilst learning how to co create health the interaction with patients takes longer, but as clinicians become more comfortable with it, this reduces. But when under time pressure clinicians tend to revert to efficiency over effectiveness mindset and the medical model. There is less time available for cocreating health in inpatient settings than in outpatients. Systems can be currently constructed to give each patient a set number of sessions, rather than the number appropriate for their needs. There is a recognition that current systems don't use clinician time effectively, with much time wasted. If moving to different system then managers may need to plan for fewer patients being seen initially, with longer term gains. This has to be understood and accepted by Health Economies for the implementation of cocreating health.

6.3.2 Political Support for Cocreating Health

Co-creating health requires political and policy support as it challenges the existing culture; both the power of the Medical Profession and also patient expectations of being fixed. There may be suspicions from patients that co-creating health is about saving money, denying them services and this will need to be overtly addressed from the outset. Cocreating health is easier to implement in an integrated health system.

The welfare state has created a culture of entitlement and people may feel that the purpose of cocreating health is to deny them access to a treatment they value. For cocreating health to be implemented it needs to be accepted by politicians across all parties, public services, citizens and the public. People in poorer communities have less experience in planning their lives, in making decisions and have lower expectations of their lives. If implementing cocreating health leads initially to an increase in waiting times, this would need to be considered by politicians and policy makers against the medium term benefits.

6.3.3 Organisational Change

In the view of participants, implementing cocreating health will require organisational change although healthcare systems are very complex and current system conditions have significant inertia, preventing change. In particular, cocreating health needs a continuity of relationships, which is particularly challenging in the way that secondary care is currently organised. Cocreating health will need primary care clinicians to refer to secondary care for assessment, without giving patients expectation of having a particular treatment. Clinicians in private practice have greater ability to influence organisational change including the arrangements to see their patients than they have in NHS practice. NHS managers can consider that clinicians are inefficient if they have multiple interactions with their patients, see them without providing interventions or have long appointment times. To ensure management support for cocreating health there will be a need to collect evidence to demonstrate the improvements in both patient care and cost effectiveness. Cocreating health will require restructure of primary care to reduce the bureaucratic load, to get other clinicians to take on tasks currently performed by GP's, to hold chronic condition clinics that consider multiple physical and mental health conditions within a single interaction, rather than multiple appointments for single conditions.

6.3.4 Infrastructure

All interviewees were clear that implementing the cocreating health framework would require a supporting infrastructure. Part of this concerns the contractual arrangements in primary care. Cocreating health requires an IT infrastructure giving all clinicians and patient access to electronic sources of information. Managers need to be engaged in creating the infrastructure to support cocreating health. Electronic decision support

tools are helpful but paper based option grids are an easy way to start engaging patients in discussion and documenting the outcome of these discussions. An IT infrastructure is needed that is part of the work of clinicians, not extra to it.

6.4 Patient Factors

6.4.1 Patient Expectations of Clinicians

The participants considered that patients can have the expectation that everything will be done for them, that clinicians will fix them and that when they interact with a clinician they need to come away with a prescription, a referral or a treatment. This patient expectation of treatment, of being fixed is driving health service development. People want more, specialised, treatment from expert clinicians. People can have unrealistic expectations of being fixed and this can be set up in primary care before referral to secondary care. People come into hospital with the expectation of being fixed but without an understanding of what that means. Patients can have the expectation that clinicians have all the answers and can apply a treatment that acts as a magic wand to cure them, and can become frustrated if this expectation isn't met. Clinicians having a conversation with patients about what they can do for themselves may be against their expectations. To make health services work effectively, patients must accept that they have responsibilities for managing their own health and wellbeing as well as rights to treatment. Patients have the expectation that doctors are in charge of their health and unless doctors say otherwise, this isn't going to change. There will be a proportion of patients in the current system who are willing to engage in cocreating health, another proportion who are willing to consider it and a small proportion who would not engage, wanting only to be fixed. Cocreating health needs to change the expectations of individuals, their families and community by educating people about how to look after their own health, that of their immediate family and the wider community. Patients don't have an expectation that there are preference sensitive options in their care and don't come prepared to engage in such discussion. Some patients are challenged by the lack of certainty in being presented with options by clinicians. Some patients want to transfer their problem to the clinician, hoping they will provide the 'holy grail' of a cure without behavioural change and when this isn't offered, feel that the clinician is at fault. Patients who have been acutely unwell often

have unrealistic goals and then the clinician has to balance a conversation about realistic expectations with ensuring that their motivation remains high to achieve lesser goals. When patients come into hospital, they expect not to have to do anything for themselves and this is reinforced by hospital rules and the behaviour of staff. Patients expect that all of their healthcare will be free, so they don't expect to pay for things that improve their health such as eating healthily, exercising or paying for treatments. People have the expectation that, having paid their taxes, the NHS will fix them. In poorer areas people have lower expectations of themselves including less ability to manage their own health and poor planning skills, so need to increase people's expectations of themselves whilst reducing their reliance on clinicians 'fixing' them. Patients have the expectation that any treatment will be effective and without risk and don't expect that clinicians will discuss this with them. During the interaction there is the expectation that the patient will listen to what the clinician has to say and not say much themselves. It may be that people feel that when they are in hospital or in health service premises, they should do what they are told but when clinicians are working in people's homes they are more likely to engage in managing their own condition as it is their turf. Patient's expectations can be changed by contact with other patients with the same condition. If they don't gain a cure through medical intervention, patients can come to the realisation that they need to be engaged in managing their own health. Patients can be deferential to doctors, wanting someone with more knowledge to take charge of their health and wellbeing. The cocreating health framework may be easier to implement with some patient groups such as mental health patients as they need to engage or they won't get better and in mental health services there is less pressure to work at the pace of the system rather than at the patient's pace.

6.4.2 Patient Activation

6.4.2.2 Patient Engagement

Interviewees considered that engaging patients in cocreating health requires a transformational change, but patients and clinicians may not welcome this, preferring to maintain the status quo. Patients need training to understand risks, how to consider options and to interact more effectively with clinicians. Patients need to think how they want their lives to be, what support they have to achieve this, and lastly what gaps are

there that the health service can fill, rather than formal health services being the first place they go to.

6.4.2.3 Patient's Ability to Understand Their Condition

Interviewees considered that to interact in cocreating health, clinicians need to be able to assess the patient's ability to understand and manage their own health which is a skill set that is perhaps under-developed in the current paternal/maternal culture.. Patients can be given too much information that they don't understand and conflicting information by different clinicians. Patients need support from clinicians to understand information about them, to understand numerical information and statistics in the context of their own lives. Patients may not want to hear about unsuccessful treatments, thinking that this will never happen to them. Once patients are educated in their condition, they can understand their responsibilities and manage their own health better.

6.4.2.4 Patient's Health Behaviours

Participants concluded that for effective cocreation of health, health services must organise to support people to remain well, rather than just seeing them when they are sick. One challenge to cocreating health is that currently the population has poor health behaviours and these are getting worse. In primary care, clinicians have conversations with patients but they mostly try to fix a problem with medication rather than addressing the health behaviours. Cocreating health will require a change towards patients accepting that following a conversation with clinicians they may have to change their health behaviours. Cocreating health will mean that the organisation of health services will need to change to supporting people to achieve an outcome through changing health behaviours rather than a secondary care intervention. To cocreate health, clinicians will need training to assess a patient's readiness for behavioural change, to understand why they aren't ready to change and to not give up on a patient changing at some point. Patients may have very little awareness of their own bodies and clinicians may wish to promote this understanding. In cocreating health, it is important to use the right language with patients to prevent them disengaging from behavioural change. It can be challenging for clinicians to accept that patients may not want to change their health behaviours despite the bad effect this is having on their health. It can be very challenging for some people to reflect on

their own health behaviours and realise that their health maybe poor because of the life choices they have made, rather than their illness being a fault of the healthcare system. People may well know what is making them unhealthy but lack motivation to change, although pregnancy is highly motivating towards women making health life choices.

6.4.2.5 Patient Self-Efficacy

At the policy level, there is an understanding that the NHS needs to change towards supporting people to better manage their own health and wellbeing. Supporting patient self-efficacy is well established in mental health services. A challenge to cocreating health is that the needs of a patient's family for them to be cared for might be in conflict with the patient's wishes to manage their own health with family support. In chronic conditions, patients go through stages of believing that they can be cured, but when they realise that there is no cure, they may welcome support to help them manage their condition. Nursing originally meant caring for people when they couldn't do so for themselves and when they could, supporting them to do this. In cocreating health, patients with chronic conditions need to be engaged in developing management plans as full, active partners from the first interaction with clinicians. Through consistency of relationship, clinicians can develop the confidence of patients to manage their own conditions. When clinicians have a fully informed discussion with patients this can lead to them choosing not to have interventions that they would have otherwise felt were valuable but denied to them. When clinicians are honest with patients that there is no cure for their chronic condition, eighty per cent of patients will engage in self-management. Of the twenty per cent of patients who are unwilling to engage, about half will become engaged in self management when they've had time to reflect, leaving around ten per cent of people who will continue to believe that there is a cure that doesn't involve them in making health behaviour changes. That ten per cent who refuse to engage might be offered further support in order to help them make evidence based changes but could ultimately be discharged by the service because they are unlikely to gain benefit and very likely to not attend appointments. People in lower socioeconomic groups are less likely to engage in self management or to make health behavioural changes. Some of this may be due to lack of resources or choosing to spend their resources on poor health choices. It important that target these hard-to-reach groups. Patient education programmes such as EPP are important in patient

self-efficacy, but these may need to be bespoke for particular conditions. Patient education programmes such as EPP are important to help people understand how to better live with their condition. Part of this is ensuring that patients understand when they should self-manage and when they need support from a clinician. Another part of patient education is ensuring that patients know how to best interact with clinicians. Patients look to clinicians to alleviate their suffering but the clinician can only facilitate the patient to do this. By giving patients challenging goals, clinicians can support their self-efficacy, particularly if the patient has family support. The ability of patients to manage their own health is highly dependent on the support network they have from family and friends. Older people living on their own with little family support face great challenges in managing their own health. Patients need small, achievable goals in order to manage their own health. Clinicians are important in giving patients the confidence to manage their own health. Patient self efficacy requires knowledge, will and action.

6.4.3 Patient Characteristics

6.4.3.2 Patient Socioeconomic Circumstances

Interviewees considered that the ability of patients to self manage their condition may be related to socioeconomic circumstances. Clinicians often come from higher socioeconomic groups and need to understand that patients with less access to resources may not be so able to engage in cocreating health. Free prescriptions are helpful in providing access to healthcare but move patients away from cocreating health. Patients in better socioeconomic circumstances may be able to contribute to cocreating their own health in managing their condition in non-medical ways. They are also likely to have better health literacy and are better prepared for the cocreating health conversation, feeling more empowered to have cocreating health conversations with clinicians. Cocreating health may need clinicians to engage with people from lower socioeconomic groups differently and in different places. It may be necessary to offer graduated levels of support for patients based on their capabilities as assessed by the clinician

6.4.4 Power Relationships

Some clinicians may see cocreating health as a challenge to their power and autonomy. Some clinicians reinforce their power by choosing to sit behind a desk or in their choice of smart clothes, whilst patients may not even be offered a seat or are in hospital gowns or are partially clothed. Clinicians may also use non-verbal behaviour in reinforcing their power over patients, even before they start their interaction. To cocreate health, clinicians need confidence to equalise the power relationship with patients although clinicians can feel a weight of responsibility from patients to be powerful, to take charge of their health. Clinicians should be aware that the interaction is of greater importance to the patient than to them. Patients start the interaction with clinicians in a position of very little power. Hospital doctors consider themselves as very powerful within healthcare and may consider that the more patients they have coming to see them, the more powerful they are and this might make them less interested in cocreating health as this would reduce the number of times a patient would come to their clinic. Although clinicians consider they have power derived from their expertise, they may not be able to articulate the reasons for their opinion and the cocreating health framework will cause them to reflect on this. The cocreating health framework reduces the power imbalance by acknowledging the expert power of the patient. Deferring to the power of the authority is particularly strong in older people and this may prevent them from cocreating health. Clinicians can reinforce their power by controlling the duration of the interaction and by interrupting patients. Many clinicians may wish to maintain the power imbalance over patients. To cocreate health, patients need access to better sources of information to improve their knowledge, reducing the gap in expert power with clinicians. The power imbalance reduces the ability of patients to co create health. Application of the current medical model reinforces the power imbalance between clinicians and patients whilst the cocreating health framework makes this more equal. The assumed role of clinicians in telling people what to do and the implied role of patients to listen and not contribute reinforces the power imbalance. Clinicians can struggle to interact with empowered articulate patients because they are not trained to do so, because this is unusual and because the system is not organised to facilitate this. Healthcare has developed a paternalistic culture that has taken away many of the responsibilities of patients to manage their own health and changing to cocreating health will be challenging for both patients and clinicians.

What is required is wholesale redesign of the care environment to remove the symbols of power to influence clinical behaviours at a system level. Clinicians will need training in empowering patients to cocreate health. The power is with clinicians because they are the decision makers. Both patients and clinicians may not want to maintain the current imbalance of power, but if patients feel they have had good treatment then they tacitly accept the power imbalance, even if they haven't had good outcomes. Patients with chronic conditions may have more expert power and be more willing to cocreate health. The interaction between patient and clinician can shape the power balance and this includes the rationale for the discussion, which may overtly be a patient seeking an expert clinician opinion. The imbalance in power can be partly addressed by the patient having an advocate with them during the interaction. The reflective element of the cocreating health framework would help clinicians to consider whether there is an unintended imbalance in power. Educating patients and in particular their understanding that a clinician may not be able to offer a cure for a chronic condition will help to address the power imbalance and engage them in cocreating health. The power imbalance can come from learnt roles of 'clinician' and 'patient'. Some therapy professions have changed their interaction with patients to acknowledge the sharing of expertise and power. Clinicians can choose not to refer patients to educated patient programmes because they want to maintain their expert power. Clinicians can feel exposed if the power relationship is more equal, and this may be more of a challenge for some medical professions such as surgeons. The imbalance in power between patients and clinicians can become a co-dependent relationship. The coaching model entails the clinician supporting the patient in achieving their goals.

6.5 Support Factors

The previous factors determined intent to cocreate health, but the actual cocreating health behaviours where intent became action was found to be dependent on :

6.5.1 Patient Training

The educated patient's programme (EPP) prepares patients for cocreating health through providing them with knowledge, empowerment and problem solving skills.

Clinicians are not generally supportive of the EPP programme. Although the benefits of patient education are known by some clinicians, there is a lack of capacity to offer this routinely. Ninety per cent of patients who complete the EPP programme are able to engage with clinicians in cocreating health.

6.5.2 Leadership Support

Leadership provided by senior clinicians will be required to implement the cocreating health framework. Leadership is required to generate enthusiasm for change and to show the way. The cocreating health framework will need champions who are opinion leaders for its implementation. The cocreating health framework requires leadership and passion at every level of management and clinical leadership.

6.5.3 A Clinical Framework to support Cocreating Health

Within the semi-structured interviews, participants were asked to comment on the framework and its implementation. The cocreating health framework was considered by interviewees to be comprehensive but needs to be described in language that demonstrates it is different from current practise and encourages its adoption. Implementation of the framework should be phased and will require tools to embed it in practise. Implementation will require a jointly owned management plan. To cocreate health, clinicians will need training to develop some additional skills such as coaching and self-management support. For clinicians to support the cocreating health framework it will require them to have ownership of it through being involved in its development. Clinicians will also need to be assessed on their ability to support self-care and to coach patients through numbers use of reflective logs and other measures of patient benefit.

An evidence base including case studies is required to demonstrate the efficacy of adopting the cocreating health framework, that it adds value to patient outcomes and can be incorporated into the daily work of clinicians rather than being an 'add on'. Implementation of the cocreating health framework must be carefully planned in the recognition that if this is not done well, it will be some years before we can try again.

Implementation of the cocreating health framework could deliver a better agency relationship which is currently partial due to clinicians having incomplete information. The cocreating health framework is a very different model than that currently practised by doctors and nurses. Improvement resource is directed towards high priority issues and there may not be resource to spend in supporting widespread implementation of the cocreating health framework. The cocreating health framework may be implemented independently by a number of enthusiastic teams. E-learning can be used to spread cocreating health more widely. Cocreating health will fundamentally challenge the innate desire of nurses to care for people. The cocreating health framework presents a very different conceptual model to current thinking. Patients will need to understand the benefits they may realise from engaging in cocreating health. The cocreating health framework will fundamentally change the relationship between patients and clinicians. The cocreating health framework is fundamentally about establishing relationships and trust between patients and clinicians through a consistent interaction over time. The support of leaders for the cocreating health framework will give clinicians permission to be engaged in person centred care.

6.6 Controls

Factors that were seen as barriers to the intention to cocreate health were complacency or contentment with current ways of working and the mistaken perception that this practise is consistent with cocreating health. System factors acting as barriers or controls included the way interactions with patients are currently organised and perceived lack of time to engage in longer interactions. Patient factors acting as barriers or controls included patient's perceived lack of willingness to engage. Infrastructure barriers or controls were particularly centred around the lack of shareable electronic patient records. Clinician factors acting as barriers or controls included the perception of risk to patients of being offered and choosing an option uncomfortable to clinicians, the current power relationships, and most significantly performance targets and short term financial measures that mis-direct clinicians and senior managers attention away from true cocreation.

6.7 Conclusion

Analysis of participant insights demonstrated that clinician intention to engage in a cocreating health interaction with patients was determined by their attitude to cocreating health, their normative behaviours and perceived controls. It was found that turning intent into cocreating health behaviours requires whole system redesign including the engagement of patients, support from leaders across organisations, a framework for this new style of interaction, resources and support of the multidisciplinary team. The resulting framework and implementation issues were subjected to testing by arranging a series of three workshops each attended by clinicians from three different teams. This gave useful information that was used to further refine the framework and explore implementation issues. Specific information was obtained on training issues and a programme and guide for training clinicians in cocreating health was developed. Finally, the framework and implementation issues were provided back to participants for comment with the resulting insights fed into the completed framework and implementation issues described in this thesis.

Chapter Seven : Discussion of Results

7.1 Introduction

This chapter provides a synthesis of the key results gained in this study and places these in the context of the literature. This research set out to determine how to engage clinicians in cocreating health by developing a framework for cocreating health to support the patient-clinician interaction and to identify the factors in its successful implementation in health services. Porter (2010) argues that *“The fundamental goal of healthcare is to increase value. We must define value as the outcomes that matter to patients divided by the cost of achieving those outcomes.”* Since demand is increasing and funding is constrained, Porter contends that ‘a relentless focus on value is the only way to achieve sustainable healthcare’. Porter contends that outcomes that matter are the outcomes that the patient says and that patients should define value. We know that informed, engaged patients make better choices; that people equipped to manage their own health conditions stay healthier and have a better quality of life; that confident patients are well placed to challenge poor practice at the point of care; and that having access to your own health record or your own personal budget can make you feel much more in control. Patients are a larger workforce than all the clinicians employed in health services and can not only define value but create value if supported to do so by clinicians.

The first step to provision of high quality health services is equitable access. However, across communities, there are barriers for people who don't have the cultural expectations, knowledge and language that accessing services requires. These barriers have the consequence that people from disadvantaged, marginalised and excluded communities who often have the greatest need of health services face many challenges in getting the care they need. It is a truism of healthcare that the articulate middle classes who form the ‘worried well’ have disproportionate access to health resources whilst the poorer, less well educated citizens often with chronic conditions have very poor access. For example, De Silva (2011) has shown that clinical outcomes can be improved by clinicians supporting patients with long-term conditions to manage their health and care; that when people play a more collaborative role in managing their health and care, they are less likely to use emergency hospital services and that they are also more likely to stick to their treatment plans. De Silva (2012) also

demonstrated that patients who have the opportunity and support to make decisions about their care and treatment in partnership with clinicians tend to choose less costly treatments and are more satisfied with their care. Importantly O'Connor and colleagues (2004) showed that patients supported by clinicians are more likely to choose treatments based on their values and preferences rather than those of their clinician. Hibbard and Gilbert (2014) demonstrated that patients with greater knowledge, skills and confidence to manage their health and health care are more likely to engage in positive health behaviours and to have better health outcomes. In terms of clinician benefit, a study by the Kings Fund (2012) showed that as patient engagement increases, clinician performance and morale see a corresponding increase. It has been argued that a cocreating health approach should also deliver more effective use of resources because it ensures that services are provided for the needs and preferences of the people who use them, rather than from what providers think they should have. A report by NESTA (2013) suggests that there is robust evidence to predict 7 per cent savings from using a cocreating health approach based on interventions that reduce expenditure on attendances at emergency departments, planned and unplanned admissions and outpatient admissions. For these reasons, the development of a cocreating health framework had broad support from policy makers, senior leaders and clinicians with professional backgrounds as doctor, nurse and therapist.

7.2 Elements of Cocreating Health

7.2.1 Preparation-Supporting the Autonomous Participation of Patients

The first element of the cocreating health framework, determined from this research is preparation. Bodenheimer (2005) described the preparation of patients before their consultation as 'pre-activation', supporting patients to be more assertive during their consultation. This 'pre-activation' suggested that patients should consider their part in the consultation before it began. Consistent with Bodenheimer's work, this research suggests that preparation using training booklets could improve patient information seeking, patient retention of information post-consultation, compliance with medications, and improved health-related behaviour change (Cegala et al, 2000). Middleton et al (2006) had shown that encouraging patients to consider their own agenda before interacting with clinicians improves the patient-clinician relationship

and Little et al (2004) demonstrated that preparation increases both patient satisfaction and communication with clinicians.

This research supports the use of patient education programmes in preparing patients such as those devised by Lorig et al (1999) that comprise short programmes led by lay educators where people learn from others with similar conditions to : set goals and make action plans ; problem solve ; develop their communication skills ; manage their emotions ; pace daily activities ; manage their relationships ; communicate with clinicians ; develop their health literacy ; understand the importance of healthy behaviours and ; manage fatigue, sleep, pain, anger and depression. This education has been shown to significantly improve patient's knowledge, coping behaviour, sustain agreed management plans and self-efficacy and give modest improvement in pain, disability, fatigue and depression (Chodosh et al, 2005 ; Foster et al, 2007).

Specifically, this research supports the routine offering of the expert patients programme (EPP) that was launched by the Department of Health in England in 2001 with the aim of establishing lay-led self-management programmes in the NHS. Although EPP is best known a peer-led self-care support programme adapted from the Chronic Disease Self-management Programme developed by Lorig and colleagues (1999), its principles could be used to prepare patients more broadly for their interaction with clinicians. A Randomised Controlled Trial evaluation of outcomes from the EPP (Rogers et al, 2006) demonstrated increased patient's self-efficacy and improved health status outcome, reduced admission to hospital and less use of day case facilities. A health economics analysis showed one extra week of 'perfect' health per year arising from the EPP course. The EPP was shown to reduce health care costs, though patient out-of-pocket costs were higher for patients suggesting the potential for cost shifting from the NHS. There were small gains in secondary outcomes including psychological wellbeing and partnerships with doctors. There was high satisfaction with the course and particularly the experience of being in a group. Improved self-efficacy was related to people feeling better about their actions because they were able to compare themselves to others in the group and to identify with others who share their experiences. Analysis of written comments people made about the course showed that social support from the group was highly valued and the facilitation skills of the tutors were vital to the success of the group's experience.

Participants in this study agreed with other authors that the key to success in self-care education may lie in encouraging participation from those who can benefit most, those who lack confidence in managing their condition (Coulter, 2011) and those who are finding it particularly hard to cope (Reeves et al, 2008). Self-management education is most effective when integrated into interaction with clinicians (Coulter, 2011). This work corroborates the view of Protheroe et al (2008) that clinicians must change their interactions with patients to engage with the information, recognise their experience of dealing with their condition and engage in reviewing alternative preference-sensitive choices with them.

Another form of patient preparation would be to use health coaches employing motivational interviewing, tailoring their support to individual needs with a blend of listening skills, open and closed questioning, and reflective feedback (Rollnick et al, 2010), It has been demonstrated by Kennedy et al (2002) that such support helps patients to determine options for themselves that are different from those that might have been made on their behalf by clinicians. However, such support for active participation by patients may have limited success without changes in clinician's internal model. Kinnersley et al (2009) demonstrated that where patients had received coaching to ask questions immediately interacting with clinicians using the medical model, there was a small increase in question-asking and improved patient satisfaction but no other significant improvement.

There was broad support in this study that patients should have access and ability to write in their own clinical records to help them understand their own condition and support self-management particularly if this can be accompanied with targeted information and decision support (Royal College of General Practitioners, 2010). Given that this technology is not yet in development within the services studied, a good first step would be to action the Department of Health (2003) recommendation that letters written between clinicians should be shared with patients. It is understood that this would have benefits of ; improved openness and trust between clinicians and patients ; giving patients better understanding of their condition and their preference-sensitive choices ; supporting patients to sustain agreed management options and healthy behaviours ; giving patients the ability to spot and correct errors within the record ; ensuring that patients are better prepared and less anxious within their

interactions with clinicians ; giving improved clarity of communication between clinicians and between clinicians and patients.

However, research in this study showed that this is not routine practice and the Care Quality Commission (2010) has shown that fewer than half of patients discharged from hospital in England in 2009 received copies of letters written about them. The majority of those who had seen them said they were written in a way they could not understand, which argues that clinicians need to write their reports without using jargon, acronyms, Latin or technical language incomprehensible to a lay person

7.2.2 Discussion of Options-Shared Decision Making

The benefits and challenges in supporting patients to make decisions about their health and treatment were raised by nearly all participants. Clinicians considered that given the opportunity, many patients would like to play an active role in making decisions about their health (Martin, 2002 ; Magee et al, 2003; Chamot et al, 2004). This work has also demonstrated that the context of the issue influences the degree of autonomy that patients want in decision making (McKinstry, 2000; McKeown, 2002). Results from the questionnaire analysis and interviews were that currently clinicians do not provide adequate information for patients, either in preparation or to help them make decisions and that this is not satisfactory for patients. Kiesler and Auerbach (2006) have demonstrated that the better the match between the information desired by patients and the information provided by clinicians, the better the patient outcomes. In particular, participants pointed out that when patients with chronic conditions, are well informed, they are far more likely to keep their conditions under control, leading to fewer hospitalisations and emergency department visits (Wennberg et al 2010). Participants at the policy and senior leadership levels considered that in discussing options within the cocreating health framework, patients are very likely to choose fewer interventions than if this is decided by clinician. This is consistent with the International Cochrane Review that included eleven trials involving major elective surgeries and showed that demand declined by twenty per cent after patients became well informed. This systematic review reported consistent evidence that as patients became better informed, they made different decisions and felt more confident (Stacey *et al*, 2011)

Clinicians in this study had a clear view that considerable support is required to ensure that patients are informed and make a choice they feel confident in. There was considerable support from participants for using decision aids although it was acknowledged that their use in clinical practice has been limited to date. Research in this study elicited similar practical barriers to the adoption of decision aids that were found in other studies such as Gravel *et al* (2006), Coulter and Collins (2011) such as time constraints, lack of some clinician's willingness to involve patients in decision-making, lack of trust in the information contained in published decision aids, perception of a patients' lack willingness to take greater responsibility for their own care, patient's limited health literacy, lack of patients' willingness to invest time and energy learning about treatment options and outcomes.

Since the time that patients and clinicians have face-to-face is limited, this research suggests that decision aids used during the interaction must be simple and quick. Option grids were suggested by a number of participants for use in cocreating health. These are one-page tables that compare treatment options and answer questions frequently asked by patients (Option Grid Collaborative, 2012; Lloyd *et al*, 2012, Elwyn *et al*, 2013). They are designed to facilitate conversations that can take place in the constrained period of the patient-clinician interaction. They were considered to at least partially inform patients and point them in the right direction towards further information. In this research the importance was highlighted of clinical teams developing their own option grids based on their reflective practice as well as knowledge of the evidence base.

Engagement of both patients and clinicians as active partners depends on mutual recognition of the expertise that each brings to the interaction. The clinician brings knowledge of health systems, clinical practise, diagnostic techniques, causes of poor health, prognosis, treatment options and prevention. The patient brings expert knowledge of their own attitude to risk, experience of poor health, social circumstances, behaviours, values and preferences. Successful patient-clinician interaction requires sharing of this expertise and engagement of both in a negotiated decision making process (Charles *et al*, 1999) where the clinician acknowledges the legitimacy of the patient's preferences and the patient accepts shared responsibility

for the treatment plan (Coulter, 2011). Successful shared decision making is dependent on an understanding of research knowledge of effectiveness of treatments (Mulley, 2009) and recognition of the importance of providing patients with information and support when making difficult 'preference-sensitive' choices.

In the context of time pressures on clinicians and the need to summarise what is and what is not known about treatment outcomes where the evidence base is conflicting or limited, decision tools have been developed to support patients in making 'preference-sensitive' choices by :

- Providing information about specific diseases and conditions, treatment options and the benefits, risks and uncertainties involved ;
- Estimating outcome probabilities related to an individual patient's risk factors ;
- Assisting patients to evaluate the outcomes that matter most to them ;
- Guiding patients through decision making and communicating their preferences.

Coulter (2011) describes use of decision aids in a number of applications, such as :

- Symptom management and triage to the most appropriate level of care, including self-care ;
- Weighing of risk and benefit in conditions where there are more than one preference-sensitive options ;
- Chronic condition management in determining patient's goals and behaviour change priorities.

The application of appropriate decision aids has been demonstrated to improve patient's knowledge, increase their understanding of treatment options and give them a better understanding of risk (O'Connor et al, 2009). In this way, they have been shown to increase patient's confidence in shared decision making and lead to a better match between patient's preferences and the options chosen (Coulter, 2011). There is also evidence that use of decision aids can improve cost-effectiveness with patients choosing less costly and less invasive options (Kennedy et al, 2002) with reduced demand for elective surgical procedures (O'Connor et al, 2009). Since both clinicians and patients have an imperfect understanding of statistics (Gigerenzer et al, 2008), decision aids are helpful in communicating and presenting information on risk.

In studying the difficulty of introducing decision support tools into routine practice Holmes-Rovner et al. (1996) considered that there were many barriers, that the key obstacle was time pressure and concluded that successful implementation would require system changes. However, a systematic review by Gravel et al (2006) revealed a taxonomy of barriers, including time constraints and lack of applicability to patient

characteristics and to clinical situation suggesting that that the successful adoption of interventions depends on more complex interactions than of overcoming barriers.

7.2.3 Agreeing the Way Forward-Self-Supported Management

Clinicians supporting patients with self-management support skills were considered by participants to be a potentially transformational element of cocreating health. Self-care is the most prevalent form of healthcare with more than 80% provided by people themselves, their families, carers and communities with only 20% through formal interaction with clinicians. The actions that people take to recognise, treat and manage their own health is a key determinant of demand for interaction with clinicians. Interactions between patients and primary care clinicians increased by 40% between 1998 and 2008 (Coulter, 2011) and the Department of Health estimates that 40% of clinician time is spent on formal interaction with patients who could have managed the condition themselves. Around 17 million people in the UK live with at least one chronic condition including 60% of all people over 60 years. The causes of chronic diseases include social determinants, modifiable health behaviours and non-modifiable factors such as age and heredity. Chronic diseases are now the leading cause of mortality in the UK. The primary aim of teaching clinicians to support patients in their own care planning and supported self management is to enable people to have the best quality of life they can and achieve the clinical outcomes they want. Based on the average consultation length of 11.7 minutes and an average of 5.5 consultations per year (Department of Health, 2007), the average person spends about an hour per year in the UK in direct interaction with clinicians, whereas they have many thousand times this opportunity to understand and improve their own health. This also argues for resources to be devoted to improving self-care as more effective than adding to the contribution from formally delivered healthcare.

The Wagner (1998) chronic care model aims to develop an informed and activated patient supported by a well prepared, proactive primary care team with an emphasis on empowering people to manage their own health and healthcare. In this model, the role of the clinician is to provide effective self management support by acknowledging the patient's central role in their own health and enhancing their confidence and skills. This is achieved by clinicians working interacting collaboratively with patients to define

issues, establish goals, create individual management plans and provide support to make necessary lifestyle changes. In this way, clinicians have an emphasis on proactive interactions to support people in their health rather than reacting to their sickness.

The integration of self management support through cocreating health allows interactions with clinicians to be appropriately targeted. A number of analytical tools have been designed to target levels of support to identify patients in need of intensive, regular interactions with clinicians and those who may need less frequent interactions (Kings Fund, 2009). In the US, Kaiser Permanente uses a pyramidal, three level model to represent the levels of support required by different sub-groups. At the bottom of the pyramid are those 80% of people who can manage on their own with self-management support. At the second level are those with more than one chronic condition requiring frequent interaction with clinicians but also benefiting from self-management support. Those at level three, the top of the pyramid, are often elderly, frail and with multiple chronic issues and disabilities who will require intensive interaction and multiple services coordinated by a case manager. The cocreating health framework is consistent with the views of Curry and Ham (2010) who suggested that self-management support should come from a well-managed, integrated health system where care is patient-centred and coordinated effectively to produce good outcomes and patient experience.

Taylor and colleagues (2014) reviewed the existing evidence to determine which forms of self-management support are the most effective for patients with a wide variety of chronic conditions. Consistent with the cocreating health framework, they found that the most effective forms of self-management support were tailored to the individual patient and their condition, and underpinned by support from healthcare professionals and their organisations. Key components of successful interventions included the provision of education about the condition as well as psychological support, strategies to support adherence to treatment and practical support tailored to the specific condition. Taylor and colleagues suggested that self-management should be actively supported and become a normal part of care provision.

Schwappach et al (2014) reported a systematic overview of the evidence on self-management support for patients with long term conditions. They concluded that

effective self-management support interventions are multifaceted, should be tailored to the individual, their culture and beliefs, a specific long term condition and position on the disease trajectory, and underpinned by a collaborative/communicative relationship between the patient and clinician within the context of a health-care organisation that actively promotes self-management. Again consistent with the findings on cocreating health, they identified core components including ; provision of education, recognising the importance of understanding patient's pre-existing knowledge and beliefs; psychological strategies to support adjustment to life with a long term condition; strategies specifically to support adherence to treatments; practical support tailored to the patient's condition, including support around activities of daily living for disabling conditions, action plans in conditions subject to marked exacerbations, intensive disease-specific training to enable self-management of specific clinical tasks; and social support as appropriate. In line with the findings on cocreating health, their review demonstrated that implementation requires a whole-systems approach which intervenes at the level of the patient, the clinician and the organisation. They also felt that the healthcare organisation should provide the training and time to enable clinicians to implement, and patients to benefit from, self-management support, regularly evaluating self-management processes and clinical outcomes. Their conclusion was that supporting self-management is required for high-quality care of patients with long term conditions and that this should be provided as a normal, expected, monitored and rewarded aspect of care.

7.2.4 Implementation-Achieving Health Behaviour Change

Achieving behavioural change of both clinicians and patients was considered a key aspect of cocreating health, consistent with the work of Silverman (2011) who argued that within healthcare, many adverse outcomes can be avoided by simple behavioural changes. Participants, particularly at the policy level suggested that in cocreating health, behavioural changes can be made by clinicians such as avoiding focus on individual patient needs to the detriment of population health or looking at upstream and downstream impact of their behaviours. Similarly, clinicians and senior leaders pointed to the importance of behavioural changes made by patients such as adjusting diet, increasing exercise, quitting smoking or by not engaging in high risk activities such as drink driving. It was acknowledged by participants that policies and strategies

introduced by Government or by Health providers may not drive behavioural changes within individual clinicians, managers or citizens because individuals may have difficulty in grasping the importance of change to themselves or other individuals affected by their actions. This chimes with Kotter's (1996) theories suggest that change occurs only when individuals internalise and understanding of urgent need for change and poor service quality can become accepted normal practice both in receipt and delivery.

In cocreating health, many participants spoke of the need for clinicians to support patients to make changes in the way they lived their lives. Health behaviour change refers to a replacement of health-compromising behaviours, such as sedentary behaviour by health-enhancing behaviours, such as physical exercise. To describe, predict, and explain such processes, health behavioural change theories have been proposed to examine a set of psychological constructs that jointly aim at explaining what motivates people to change and how they take preventive action.

A number of participants were aware of, and used the Transtheoretical Model of Behavior Change devised by Prochaska and co-workers (1994) to assess patients, readiness to act on a new healthier behaviour, and provides strategies, or processes of change to guide the individual through the stages of change to Action and Maintenance. Prochaska and colleagues (1994) described the following phases :

Precontemplation. At this stage, people do not intend to start the healthy behaviour in the near future (within 6 months), and may not accept the need to change. Clinicians might interact here to provide such people with information about healthy behaviour, to encourage them to think about the pros of changing their behaviour and to consider the effects of their negative behaviour on others. People assessed as Precontemplators typically underestimate the case for change, overestimate the negative aspects, and are often unaware of their mistaken internal model. By interaction, clinicians might support such individuals by encouraging them to reconsider their decision making and more conscious of the benefits of changing an unhealthy behaviour.

Contemplation. At this stage, people have an intention to begin healthy behaviour within the next 6 months. Although more aware of the positive implications making a

change this is balanced by their reasons not to change, ambivalence about changing can result in repeated postponement of positive action. Within their interaction, clinicians might provide insight for the patient into the kind of person they could be if they changed their behaviour and to learn more from experiences of similar people who have made a change. In this way, clinicians would support patients to understand the positive consequences of behavioural change.

Preparation. People at this stage are prepared to begin taking action within the next month, have changed their internal model of behaviour and have begun to carry out small actions that they believe will help them make the healthy behaviour a part of their lives. For example, they tell their friends and family that they want to change their behaviour. Clinicians interacting with patients at this stage might encourage them to ask for support from trusted friends and family, tell people about their plan to change their behaviour, and to reflect on how they would feel if they behaved in a healthier way. Clinicians would seek to allay their primary concern of failure by emphasising the importance of preparation in achieving progress.

Action. People at this stage have changed their behaviour within the last 6 months and need to continue to work hard to keep progressing. For patients at this stage, clinicians would concentrate on supporting patients to strengthen their commitment to change and to fight the strong tendency to regress to previous behaviours. Clinicians might use techniques such as advising on substitution of activities related to unhealthy behaviours with positive ones, suggesting rewards for taking positive actions, and avoiding people and situations that might lead to unhealthy behaviours.

Maintenance. People at the maintenance stage changed their behaviour more than 6 months ago and they may need support from clinicians to make them aware of factors such as stress that might prompt regression back to unhealthy behaviours. Within the maintenance phase, people often benefit from support from others with similar issues who have successfully overcome these.

Respondents agreed with Prochaska et al (1994) that interventions to change behaviour are more effective if they are "matched to each individual's stage of change." Making appropriate decisions requires consideration of the potential benefits and costs associated with an action.

Self-Efficacy is "the situation-specific confidence people have that they can cope with high-risk situations without relapsing to their unhealthy or high risk-habit." (Prochaska et al, 2008). Self-efficacy describes the perceived ability to perform a task as a mediator of performance on future tasks. A change in the level of self-efficacy can predict a lasting change in behaviour if there are adequate incentives and skills.

It has been shown that, for people to progress they need:

1. An increasing awareness that the advantages (the "pros") of change outweigh the disadvantages (the "cons") i.e. decisional balance
2. Confidence that changes can be made and maintained under conditions that tempt them to return to their previous, unhealthy behaviour i.e. self-efficacy
3. Strategies to help them make and maintain change.

Using behavioural change models within the clinical interaction was described by participants as challenging and through cocreating health represents a change in clinician's role.

7.2.5 Reflective Practice-Use of Clinical Audit to Inform Patient-Clinician Interaction

The seven elements of the cocreating health framework are supported by clinician engagement in reflective practise and service improvement. Clinical audit is a quality improvement process that seeks to improve patient care and outcomes through systematic review of care against explicit criteria and the implementation of change. In the process of clinical audit, selected aspects of structure, processes, and outcomes are systematically evaluated against explicit criteria. Where required, changes are implemented at an individual, team, or service level, with further audit cycles used to confirm improvement in delivery. The key requirement is that performance outcomes are reviewed to ensure that what should be done is being done. Although clinical audit is an essential and integral part of clinical governance and policy is for clinical audit to be a standard part of patient care, in this study this was found not to be systematised, being largely left to junior clinicians in training who do not have ownership of the improvement cycle. Currently, only a minority of clinicians have built clinical audit processes into their internal model of working as a means of evaluating the quality of

care delivered to patients. More recently, clinicians in this study have become aware of clinical audit policies developed to reflect the movement to the multidisciplinary approaches and a change in focus from a clinician-centric view of service delivery towards a more patient-centred approach. Many clinicians and leaders understood the need to report and improve on patient reported outcome measures (PROMS) and patient reported experience measures (PREMS) in addition to clinical outcomes, which can be narrowly focused on what clinicians consider should be measured. However, participants cited time pressures to explain why this was not being carried out, seen as an 'extra' to the value work of direct patient contact.

Most patients interact with clinicians seeking help with issues that are impacting on their physical or emotional well-being, their sense of well-being or quality of life. To capture this, the cocreating health framework incorporates clinical audit that requires a focus on patient's perspectives of care, treatment outcomes and completion by patients of measures of health status and well-being. In particular this would include use of PROMs as standardised, validated instruments to measure patient's perceptions of their health status (impairment), their functional status (disability) and their health-related quality of life (well-being) applied before and after interventions to assess outcomes. In the cocreating health framework, patient defined outcome measures and PROMS would be used to inform patients choices of interventions; measure and benchmark providers; incentivise good practice and; enable clinicians to monitor and improve practice (Devlin and Appleby, 2010).

Built into the cocreating health framework, the clinical audit cycle has four stages that follow the systematic process of: establishing best practice; measuring against criteria; taking action to improve care; and monitoring to sustain improvement. As the process continues, each cycle aspires to a higher level of quality. The first stage involves measuring processes related to patient outcomes. This pre-supposes that patient outcomes are routinely collected, but this was shown not to be currently widespread practice in the participants interviewed. The second stage requires definition of audit criteria to define elements of the patient-clinician interaction. The third stage involves data collection with small sample sizes within reasonable timescales. In the fourth stage, outcomes are compared with established criteria and standards to reach conclusions on how well standards are being met and, if applicable, identifying opportunities for improvement. The fifth Stage involves continuous improvement and feedback. Sustaining

Improvements are made by continuous audit cycles to demonstrate improvements made. Changing behaviours requires that people have the skills and ability to change and the rewards and recognition processes encourage and reinforce these desired behaviour changes. John E. Jones said: *“What gets measured gets done. What gets measured and fed back gets done well. What gets rewarded gets repeated.”*

Clinical audit has a very valuable part to play in informing the conversation between clinicians and patients regarding preference-sensitive options. Since there is variation in practice, a clinician can use results of clinical audit to inform patients of their likely experience and outcomes from a chosen option. Such information can also be used to determine whether a different clinician may have better outcomes from a specified intervention, albeit this is complicated by issues such as case mix. Although there is data within NHS Choices containing results of patient surveys, infection rates and survival rates after a number of surgical procedures, there is little evidence that patients currently use this (Fung et al, 2008). Most patients are unaware that this data exists and of those who are aware, many do not understand it, do not trust it, or don't consider it useful (Werner and Asch, 2005). Similar findings have been found for clinicians, who tend to rely on informal sources of information when advising patients on referral (Dixon et al, 2010).

7.2.6 Service Improvement

In this research, it was pointed out that the lack of evidence-base for many treatments and practice variation amongst clinicians gives rise to considerable uncertainty about treatment outcomes. This argues for audit of both patient experience measures and patient outcome measures to be routinely collected to inform patients about likely outcomes from current interventions. It also argues that clinicians should routinely be involved in clinical research and development to ensure that new interventions are developed, evaluated and implemented and that clinician's knowledge is current. It has been estimated that the half-life of clinical knowledge is around 5 years which means that for clinicians exiting formal training after five years, half of their knowledge is out of date before they start practising.

Evidence-based medicine (EBM) seeks to make 'explicit and judicious use of current best evidence in making decisions about the care of individual patients' (Sackett et al, 1996). However, a number of authors have pointed to the importance of the doctor as a therapeutic agent, once loosely called 'bedside manner' and for example the view Balint expressed of the clinician acting as a drug. The application of EBM has limitations in that illness and disease are not synonymous and many ill people who seek interaction with clinicians have no disease, but still have an ill health or issues with well-being that requires clinician attention and support. Evidence-based medicine is usually based on randomised controlled trials (RCTs) in secondary care where nearly all patients have a diagnosed disease. However, the overwhelming majority of interactions occur in primary care where more holistic and simultaneous care of a number of different patient concerns is required. There have been relatively few RCTs in Primary Care since a GP providing continuous personal care to an individual patient may perceive or worry that they are exposing the patient to an experimental protocol which is inferior to current treatment, giving obvious ethical and practical concerns. Clinicians working in Primary Care tend to draw on knowledge of both secondary care derived EBM and the insights of their individual experiences. In addition, there is the therapeutic effect of the clinician themselves whereby their own knowledge, skills and attitudes may have a significant effect on both the process and the outcome of treatment and may deliver an effect greater than the evidence-based treatment. This supports an argument within the cocreating health framework for clinicians continuously collecting and acting on clinical audit cycles and participating in action research, providing a robust knowledge base to inform their interactions.

Whereas clinical audit measures existing practice against evidence-based clinical standards, research generates new knowledge where there is no or limited evidence available and which has the potential to be generalisable or transferable. In the cocreating health framework, action research is proposed as a way of using research in an interventionist way, so that the clinician is both a discoverer of problems and solutions, and is involved in decisions about what is to be done and why. In this way, service improvement occurs through a cyclical process where new developments in the evidence base guides practice and practice in turn informs the evidence base. There is increasing knowledge that conventional research evidence does not rapidly

influence development of practice or quickly result in improved outcomes. Action research within the cocreating health framework acknowledges the value of professional judgement in applying scientific practice. In the cocreating health framework, the purpose of research is to better understand and ultimately improve practice at the same time as generating findings for wider dissemination. It is argued that action research within the cocreating health framework is more meaningful to clinicians since they more closely reflect reality by responding to events as they naturally occur in practice.

Methodology advised for the cocreating health framework is that advocated by Berwick (1998) of small-scale, short-cycle tests based on a Plan-Do-Study (reflect)-Act (PDSA) learning cycle. The aim of this is for clinicians to learn from action and reflective practice rather than on the basis of theory alone. In health, action research has been used successfully in a variety of change programmes (for example: Shani and Eberhardt, 1987; Barker and Barker, 1994; Potter, Morgan and Thompson, 1994; Cullen, 1998). Within the cocreating health framework, 'Plan-Do-Study-Act' cycles are used in order to adapt specific interventions for use in a local context with its own specific conditions. PDSA cycles are recommended in cocreating health since they provide quick knowledge and have been termed 'real-time science' (Miles, quoted in Berwick, 1998), aiming to generate information used to inform the clinician in their interaction with patients. This principle is consistent with the views of Berwick (1998) who suggests that 'in trying to improve the process of care, wisdom often lies not in accumulating all of the information but in acquiring only that amount of information necessary to support taking the next step'. In practical terms, clinicians engaged in action research within the cocreating health framework would use a balanced set of process, outcome and cost measures, using qualitative and quantitative measures, small representative samples, building measurement into their everyday conversations with patients and reflecting on the story this tells (Nelson *et al.* (1998)).

Supporting the use of action research in the cocreating health framework, an HTA review (Waterman *et al.*, 2001) suggested that action research has the potential to play a role in developing innovation, improving healthcare, developing knowledge and understanding in practitioners, and involvement in patients and clinicians. Their review indicated that action research is suited to developing innovative practices and services

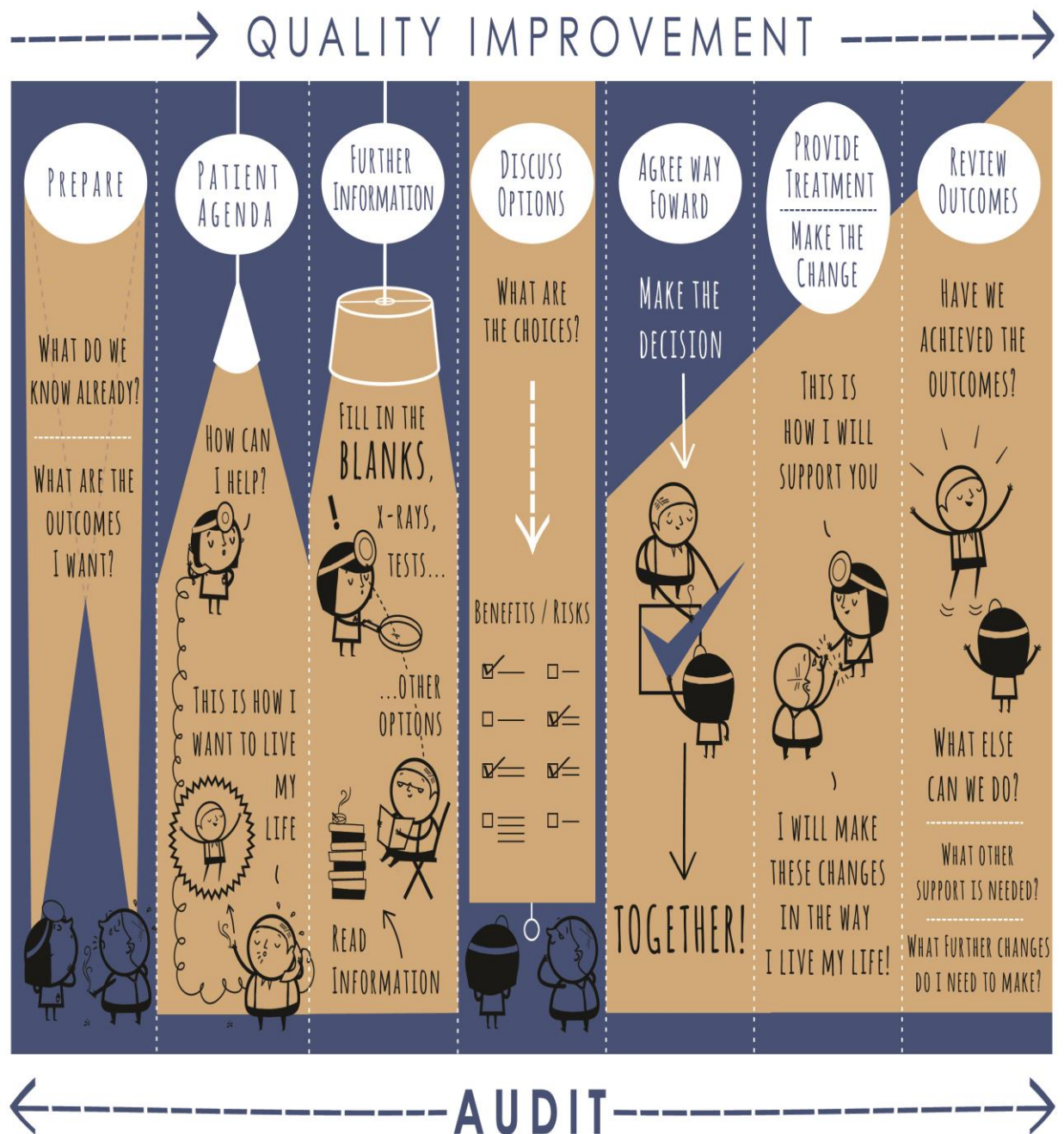
over a wide range of healthcare situations and that it can assist in the establishment of environments that promote the generation and development of creative ideas and implementation of changes in practice. The results of the HTA review suggested that action research has the potential to assist clinicians to provide high-quality healthcare since not only can it produce evidence (or knowledge) that is similar to that produced through traditional quantitative or qualitative research methodologies but it also produces types of evidence and knowledge that can inform healthcare practices, services and organisations. Their findings indicate that action research can play a role in changing healthcare practice, because it crosses the 'boundaries' of research and action (or development) and the iterative process also allows for evaluation to be fed back into the care setting and to be used to inform current and future practice. In this approach, the production of action research is not viewed as separate from developments in practice, in contrast to linear progression from research findings to the dissemination and use of findings espoused by the evidence-based practice movement.

7.3 The Cocreating Health Framework

The developed framework has been articulated in different ways to best communicate its meaning differently to clinicians, leaders and policy makers.

Evidence from the semi-structured interviews and questionnaires demonstrated that clinicians required a simple, short description of the framework that would capture their interest with clear wording and in a brief format. The test framework shown as the 'waves' diagram was not considered to accurately describe the framework. Following these insights, a further diagrammatic representation was developed (figure 7.1). This was presented to respondents for their views with a conclusion that this was more understandable. One of the major changes following this feedback was to describe a seven element framework, rather than a nine element framework, with reflective practice and quality improvement informing each of the seven elements, rather than being considered separate elements in their own right. This diagram is helpful in explaining the framework elements but it does suggest a linear process.

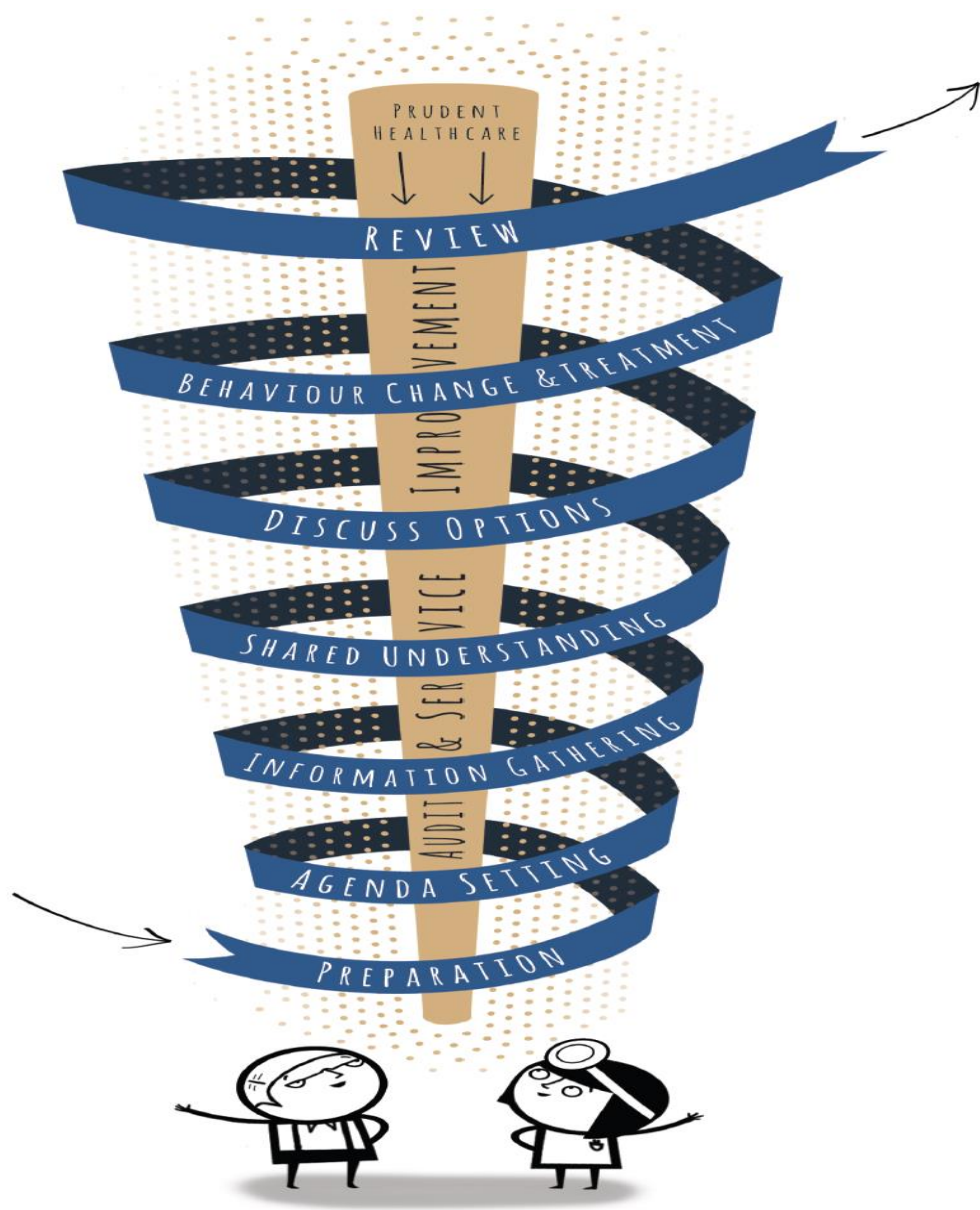
Figure 7.1 : Description of the Cocreating Health Framework articulated for Clinicians



In actuality, health and wellbeing is changing and subject to iterative interactions between patients and clinicians. To emphasise feedback loops, particularly evident in chronic conditions, a 'spiral' diagram was created to describe the cocreating health framework. This has the elements of the framework set in coils around a 'rod of light'

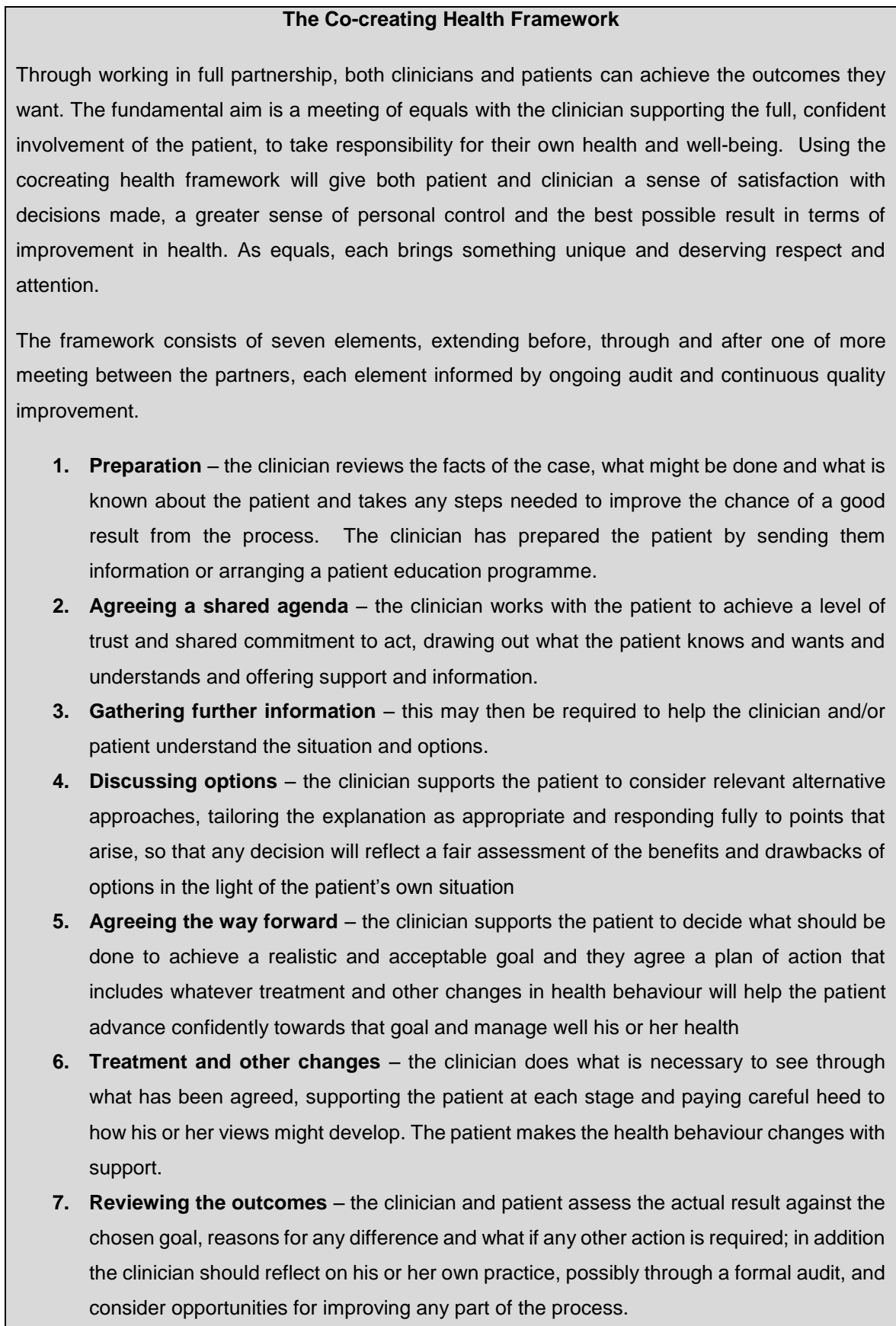
of service improvement and audit that informs each element, and is shown in figure 7.2 below. This diagrammatic representation was intentionally set out to symbolically represent the rod of Asclepius, a symbol very familiar to clinicians. The cocreating health framework is set out as an upward spiral of health with the likelihood of further iterations.

Figure 7.2 : Depiction of Cocreating Health Framework emphasising iterative nature



In recognition of this, a short one page explanation was developed and shown in figure 7.3 below :

Figure 7.3 : Short narrative description of the cocreating health framework



However, to fully explain the framework, a narrative description was developed for leaders and policy makers and is given in figure 7.4 below.

Figure 7.4 : Full description of the cocreating health framework

The Cocreating Health Framework

The cocreating health framework consists of seven elements that can be used by clinicians in establishing a cocreating health interaction with patients. The framework supports clinicians to use all or few of the elements within the interaction, it is intended to be iterative rather than prescriptive. The cocreating health framework is designed to support clinicians to becoming 'activated', transforming the current clinical encounter experienced as a medical consultation into a human interaction where both patients and clinicians are acknowledged as experts.

Within the cocreating health framework, the role of the clinician is to:

- Support the patient to increase their resilience to improve their own health and well being
- Prepare self and patient for interaction as an active and equal partner, allowing them to bring their agenda and supporting them to consider their agenda
- Assess the ability and willingness of the patient to manage their own health and well being
- Acknowledge patient expertise and assets, including the actions they are currently taking, effort made, their networks within community and social context.
- Support patient to identify sources of ongoing support within community context and social care including coaching interactions by third sector who support people to achieve non health goals and actions that lead to increased well-being and better health
- Work collaboratively with both the patient and clinician agenda
- Understand potential outcomes for patient according a number of 'care aims'
- Ensure patient understands their condition
- Ensure patient understands benefit and dis-benefit of potential options
- Support patient to make decisions about options available to them
- Support the patient in managing their condition
- Provide effective treatment or ensure these are put in place
- Support patient to change their health behaviours where appropriate

- Review patient outcomes and discuss further options as necessary
- Agree or negotiate when no further progress is possible and discharge or refer on having explored appropriate plan for continued action and signposting or agreeing re-access protocol.
- Understand the likely outcomes for patients by undertaking routine clinical audit and review of the evidence base and findings of clinical research.
- Continuous engagement in service improvement to offer new interactions
- Report outcomes of clinical audit to service designers, engage in service redesign activities- particularly to prioritise prevention

First Element – Preparation

Preparation requires both patient and clinician to evaluate information known prior to their interaction. The clinician will need to consider the patients preparedness for a cocreating health interaction from the knowledge they have from clinical records and any referral. This may require consideration of whether the patient has an appropriate standard of health literacy, level of understanding about their condition and ability to manage their own health and well-being (level of 'activation'). To support cocreation, the clinician may need to send written information or links to electronic information including relevant previous test results. In addition, the clinician may send questionnaires to the patient to gain basic clinical and patient-centred information and to understand their level of activation and to start the reflective and active process of the patient considering what is important to them. The clinician may also refer the patient for self-management education, such as an Expert Patient Programme. The clinician would also need to determine whether they could accept the referral based on their ability to support the patient to achieve a specific, measurable outcome within their scope of practice, experience and clinical skill, if this is not the case, the clinician may decide not to accept the referral. Immediately prior to interaction with the patient, the clinician will thoroughly evaluate the patient's clinical record, answers to questionnaires including activation, and their person-centred information to become fully informed and emotionally prepared for the interaction, separating themselves from the consequences of their previous patient. Preparation is supported by both patient and clinician having access to the patient's clinical record and to a shared information source about the clinical condition(s). The clinician would prepare the environment for an interaction between equals. In this way, the clinician would give consideration to the way they are dressed, the seating arrangements for patients and family, how they might access information during the interaction and how they will record information shared during the session. There is a real opportunity to integrate exploration at this stage of areas such as 'circles of support', what matters to me/personal profiles, what I am currently doing well. In addition to preparation for agenda setting the clinician may utilise simple tools to get and record this information if not done earlier in the 'preparation phase'. This also supports the 'cultural shift' towards 'what matters to me rather than what's the problem'.

Second Element – Agenda Setting

Interactions might be face to face, conducted over the telephone or through a telemedicine discussion. The clinician will begin the interaction using appropriate language to indicate the collaborative nature of the agenda setting that addresses the patients and clinician's requirements, described in day to day language and impact rather than a list of symptoms. It is helpful for the clinician to clarify the length of the appointment. Within the interaction, the clinician indicates that there is mutual recognition of three sources of expertise. The clinician will affirm that the patient brings expert knowledge of their own health, social circumstances, attitude to risk and social networks. The clinician understands what they bring is expert knowledge of human function, interventions, their knowledge of what is realistically possible and achievable based on experience and evidence from audit and service improvement as well as understanding of navigating through complex health services. The clinician will ensure that the patient is supported to access the 'third source of expertise'; namely sources of information, and knowledge bases held electronically, such as clinical outcomes, patient reported outcome measures, patient reported experience measures, evidence based research and appropriate literature describing the patient's conditions. In agenda setting, patient and clinician build a relationship around their mutual commitment to impact positively on the patient's health and well-being within the context of a continuous, consistent and ongoing relationship. In agenda setting, there is exchange of information, opinion and the parameters of the patient's issue established. The clinician engages empathically with the patient, to consider their emotional and social circumstances in addition to their physical concerns and to manage their own emotions accordingly. The clinician acts as coach in supporting the patient to explore and set their agenda and discuss their goals and small step actions to work towards these. It is important to agree the priorities before moving on to more detailed exploration using scaling confidence, although it can be helpful to ascertain levels of importance earlier on and this together with open questions to explore health beliefs for example 'what are you doing that's' helping, what do you know about?' can give cues to the level of activation. Open questions are asked of the patient to build rapport, with the clinician reflecting and affirming the patient's perspective. The clinician will use active listening skills, use the patient's own words to let them know that they have heard what they have said or to check facts, and will reinforce with appropriate non-verbal body language. The clinician will be focussed on what's important **to** the patient using open ended questions, reflection and empathy. They will explore everything that the person wishes to cover in the consultation, determine their priorities and goals what they are hoping will happen, allowing time for their response. This includes understanding the patient's activation, confidence & problem solving skills, their capability, capacity, and health literacy. The clinician will be supported in gaining an understanding of patient-centred factors by using tools such as scaling of importance and confidence. In coproducing the agenda, the clinician will identify and share the clinical agenda, clarify the boundaries and agree or negotiate the scope of their engagement. Using this information, supported by questionnaire results of patient activation, the clinician can determine the patient activation level and start to consider and negotiate or agree the possible scope of any intervention. At the end of this phase, patient and clinician will jointly agree further steps including

additional information required to inform an agreed management plan. In doing this the clinician will use person centred language and avoid jargon in sharing their own agenda and perspective with the patient, reflecting the patient's agenda and perspective.

Third Element – Information Gathering

Where additional information is required, this may be from the results of diagnostic tests, review of knowledge by either patient or clinician or the patient having discussed issues with friends, family or the wider community or merely to spend some time considering their own attitudes to risk or possible interventions. The purpose of this is to ensure that both clinical and patient-centred knowledge is available to fully characterise the patient's physical, emotional and social circumstances. The clinician needs to gain an understanding of the functional impact or future impact of the patient's circumstances. This will support the clinician to decide if they have the appropriate scope of practice, clinical skill, and experience to interact with the patient or if the patient needs further investigation or referral to other clinician(s) or service(s). Typically, the clinician would review this information in a further preparatory phase prior to further patient interaction.

Fourth Element – Discussion of Options

Having gained appropriate information, patient and clinician interact to discuss their shared knowledge and come to a mutual agreement about the nature and extent of the physical, emotional and social issues impacting on the patient. At this stage, the clinician would consider the aims of any intervention based on the level of the activation of the patient. These aims might include : Prevention, to decrease the risk of future harm, and/or preventing any anticipated difficulties, complications or impacts ; Stabilisation of functional ability or slowing down the deterioration or loss of function ; Participation, to support the patient to participate more in their activities of daily living ; Resolution, to support the patient in developing well-being, problem solving skills to become curative ; Improvement, to support the patient to increase their skills and improve their condition towards rehabilitation ; Adjustment, to support the patient to gain acceptance of their condition and the impact of this on their life as a result of a change in feelings, attitudes or insight. Comfort, to support the patient in achieving reduced pain or discomfort, whilst acknowledging that their condition or overall impact of these hasn't changed. In considering the aims of interaction, the clinician will be mindful that patients at low activation, in the pre-contemplation stage would often benefit from the biggest change in their health behaviours but at the lowest levels of activation will face the biggest challenges in self-efficacy. The clinician will be mindful that patients interacting with them may have already made some health behaviour changes, prior to their interaction. It is important to recognise that even small improvements can reinforce patient's self-efficacy. The clinician will be aware of their role not only to consider the patient's human needs for sustenance and safety, but also their needs for empathy/understanding, love, creativity, community, recreation, autonomy and meaning/purpose. In a cocreating health interaction, the primary role of the clinician is to support the patient to increase their resilience to improve their own health and well-being, rather than simply focusing on the treatment they can provide which may reduce their self-confidence and ultimately disempower the patient. In enacting

this role, clinicians will be mindful that patients may not wish to be active participants, being more comfortable in passively receiving expert care or fighting for treatment that they believe they are entitled too and that the clinician has the power to provide. In considering how to respond to this patient view, clinicians should be mindful of the context of the interaction, the level of activation of the patient and the possible health gains from adopting the different approaches.

In discussing potential options, clinicians may choose to use tools such as option grids or electronic decision support tools. Clinicians will be mindful that patients need adequate time to consider their options. Options presented to patients will be informed by the National evidence base, and outcomes achieved by patients in the care of the clinician involved and the characteristics of the patient including their level of activation. Patient's preference-sensitive choices of active interventions might otherwise include referral to a specialist clinician, additional diagnostic tests, or interventions such as prescribed medication, surgical treatment or the provision of aids to daily living, therapy, support for maintaining healthy behaviours. In discussing these options, both patient and clinician are guided by accessible clinical outcomes, patient reported outcomes and patient reported experience measures, possibly from a number of potential service providers or individual clinicians. In addition, the clinician would be informed by review of incidents, complaints, claims, harm review, by audit and service improvement of their own practice and by recent literature on research and development. Clinicians will not present options where outcomes are not achievable by the patient.

Fifth Element – Agreeing Way Forward

Having discussed appropriate options, patient and clinician agree the way forward including any goals that the patient wishes to achieve within a specific timeframe. It may be that the patient is reassured, having become fully informed, and autonomously chooses not to take up any further intervention, a situation which the clinician accepts despite their own views. Alternatively, the clinician having had training in supporting patient self-management would be able to support the patient in effectively managing their own condition outside of formal health services including self-efficacy and resilience based on appropriate health literacy, evidence, knowledge and skills. In supporting the patient to adopt or maintain healthy behaviours, the clinician is guided by an understanding of the patient's level of activation and phase of behavioural change that assists them to determine the readiness and motivation of the patient to make the behavioural changes. In their interaction, the clinician looks for cues from the patient to signify that they are potentially ready to engage in 'brief intervention' around health behaviours such as referral to smoking cessation, national exercise referral scheme, weight reduction programmes, alcohol reduction programmes. The patient and clinician agree a management plan with appropriate SMARTER goals that are ; Specific, quantifiable, and related to the aim of intervention ; Achievable and Realistic ; have an agreed Timescale ; and meaningful and person centred, relating to the patient's life plan that are subject to Evaluation and Review. Pre-intervention patient defined and clinical outcome measures are obtained to help define the planned outcome and provide basis for review. The clinician will support the patient to move from a goal to an agreed plan by supporting the patient to identify their first action, the importance of this, the timescale

for carrying this out, the frequency of action, the potential barriers to acting, the potential ways around the barriers and the confidence that the patient has in achieving the plan. The clinician will acknowledge that supporting patients to develop problem solving skills is key to achieving the plan. The role of the clinician is to support patients to find solutions that will work for them in the context of their lives, rather than suggesting solutions. The agreed plan including the option(s) chosen, rationale and both clinician and patient responsibilities is documented by the clinician in the clinical notes and a copy provided to the patient, with a follow up plan agreed.

Sixth Element – Implementation

Once the way forward is decided and a plan jointly agreed to meet the patient's needs, the next step is for the patient to make the required health behaviour changes and for the clinician to facilitate the agreed way forward, either by personally carrying out an intervention, agreeing another time for this to be carried out, making the appropriate referral, or informing the patient of the mechanism that would allow the patient to interact with them as required. When the clinician carries out an intervention, they must be assured that this is not dis-empowering the patient or reinforcing psychological dependency by achieving a goal that the patient may have been capable of reaching themselves or by continuing with a treatment or intervention which is not delivering progress towards the jointly agreed goals. Any intervention by a clinician must have an evidence base that is grounded not only in literature but in the knowledge of their own practise. In discussing health behavioural change or providing an intervention with the aim of health behaviour change, the clinician should acknowledge that ambivalence is a normal part of change that ambivalence can occur at any stage. Furthermore, motivation is particularly difficult after illness, exacerbation or difficult life events. The role of the clinician is to provide sensitive support to help the patient explore and reflect on their ambivalence to support their autonomy and help them move forward in their contemplation of change. The clinician will acknowledge that there are costs, downsides as well as benefits to any change and will not attempt to persuade the patient of the health benefits in making change or of the dangers of staying the same. By reflecting back to the patient the benefits and downsides that patients themselves have identified using their words, supporting this with empathy to demonstrate understanding of their dilemma or tensions and allowing time for contemplation, the clinician will support the individual's self-reflection and also achieve a shared understand.

Seventh Element – Review and Further Actions

The patient and clinician jointly review the outcomes of their interaction to evaluate whether the action plan has achieved the agreed person-centred and clinical goals. Where the goals have been achieved there is a further discussion regarding the actions required by both patient and clinician to ensure that desired outcomes are maintained and progressed and the mechanism for the patient to seek further support as appropriate. If goals have not been achieved and it is jointly agreed that further improvement is possible, then the patient and clinician would discuss the main reasons for this, how issues might be overcome and discuss further iterations of similar or different interventions and health behaviour changes. Where the patient has not made the agreed health behaviour changes the role

of the clinician is to further explore the reasons for this and discuss alternative ways to support the patient. At this point, the clinician will undertake measurement of both patient-centred and clinical outcomes against the baseline measurement. Further action planning, goal setting, review and evaluation may be repeated until there is agreement between patient and clinician not to pursue further interaction. In this event, the patient is either discharged or the purpose of referral is agreed to another source of support.

Underpinning the seven elements of the framework are reflective learning and service improvement

Clinicians will routinely complete a reflective learning cycle by reflecting on information gained from clinical audit, complaints, incidents, claims and sentinel events such as harm reviews. The clinician will routinely audit clinical any patient-centred outcomes to determine whether interventions are resulting in appropriate improvement for the population of patients served. The outcome of reflective learning is used in discussion with patients about potential harm and benefit arising from interactions with the clinician. Reflective learning is routinely shared within the multidisciplinary team, discussed with colleagues, compared with benchmarks and used to improve the service delivered; it will inform prospective preference-sensitive choices of patients. Multidisciplinary teams should consider person centred reviews for a group of service users to ascertain what is working, what is not working and what is important for the future , than bringing them together in a stakeholder workshop and working through robust methodology, based on appreciative enquiry to co-produce service improvement and redesign. Outcomes are also shared with service planners and commissioners to ensure that appropriate resource allocation; shifting resources down from specialist services into prevention and enhancing both individual self-efficacy and community resilience where evidence supports this.

Service Improvement and Action Research using small size PDSA cycles, introducing novel aspects of service provision are key to success and sustainability. This creates knowledge to inform and change practise for both teams and individuals within their local service context. The aim of this is to continuously refresh clinical practise with current evidence to provide improved clinical and patient-centred outcomes. It will be important for clinicians and multidisciplinary teams to disseminate their learning through presentations, discussions of professional groups and formal articles.

7.4 Implementation of the Cocreating Health Framework

The second research aim was to determine the factors related to implementation of the cocreating health framework. To be successful, the cocreating health framework would need the potential for widespread implementation, becoming ‘the way we do things round here’, part of the internal model of behaviour of patients, clinicians and

organisations. It is known that whilst some innovations are adopted by individual clinicians and then spread at different rates, some innovations are never adopted at all and others are subsequently abandoned (Greenhalgh et al. 2005). This research showed that successful implementation of the cocreating framework would require evidence of clear, unambiguous advantage in either effectiveness or cost-effectiveness (Dirksen, Ament, and Go 1996; Marshall 1990; Meyer, Johnson, and Ethington 1997; and Rogers 1995). Views of participants were that if clinicians cannot determine a relative advantage in cocreating health, they are unlikely to consider it further (Rogers 1995). However, it was clear from this research that relative advantage does not guarantee adoption of new practice (Denis et al. 2002; Fitzgerald et al. 2002; and Grimshaw et al. 2004). The views of participants were that even where there is consensus on implementing cocreating health, there can be considerable time spent in negotiation among potential adopters, in which meaning is discussed, contested, and reframed during which the perceived relative advantage of cocreating health can increase or decrease (Ferlie et al. 2001). It is clear that the cocreating health framework is not currently compatible with the values, norms, and perceived needs of all clinical groups, with particular challenge from doctors (Denis et al. 2002; Ferlie et al. 2001; Foy et al. 2002; and Rogers 1995). Although cocreating health is consistent with government policy, participants considered that it is not currently compatible with organisational internal models of behaviour such as organisational and professional norms, values, or ways of working (Denis et al. 2002; Fennell and Warnecke 1988; and Ferlie et al. 2001). Particularly in consideration of time constraints and lack of supporting infrastructure, the new framework is not perceived as easily implemented (Denis et al. 2002; Grilli and Lomas 1994; Marshall 1990; Meyer and Goes 1988; Meyer, Johnson, and Ethington 1997; and Rogers 1995). However, participants did consider that the framework is capable of being split into more manageable parts and adopted incrementally (Plsek 2003; and Rogers 1995). For ease of implementation, it will be necessary for potential adopters to be able to experiment with the framework, to adapt, refine, or otherwise modify it to suit their own needs (Grilli and Lomas 1994; Plsek 2003; Rogers 1995; and Yetton, Sharma, and Southon 1999), particularly within a “trialability space” (Øvretveit et al. 2002; Plsek 2003; and Rogers 1995). Reinvention is important to innovations such as the cocreating health framework that arose spontaneously as “good ideas in practice” and has spread through informal, decentralized, horizontal social networks (Rogers 1995). Respondents considered

that it will be necessary to make the benefits of the new framework visible to potential adopters, Denis et al. 2002; Grilli and Lomas 1994; Meyer and Goes 1988; and Øvretveit et al. 2002).

Insights from participants concluded that to be successful, the cocreating health framework will need to take account of the 'complex social interactions' that occur within multidisciplinary teams (Powell et al, 2009). Whereas the rhetoric of the management and leadership agenda calls for transformational change to be enacted across the different professional sub-cultures with urgency and pace, it is clear that implementing the cocreating health framework will take time and require close attention to the complexity of the processes involved, especially the interpersonal dynamics. Consistent with the work of Goodrich and Cornwell (2008) this research signposted the importance of relationships in embedding cocreating health, particularly at the level of the 'clinical micro-system' and requiring at least 'permission' from senior doctors for patients and other clinicians to cocreate health.

The participants in this study considered that the cocreating health framework tackles the issue that the NHS may fail to focus on one of its key deliverables, concern over how the patient is treated, not as a disease or condition but as a person (Dickson, 2008). It was felt that the framework has the potential to transform the status of relationships at all levels and between all stakeholders, clinicians, patients and their families (Baker, 2007; IFAS, 2008; Parker, 2008; Szczepura et al., 2008). Findings of this study were consistent with the view of Baker (2007) that there is a need for a new way of thinking about relationships in the context of health services, that the goal of culture change initiatives should be to shift the focus away from tasks and towards relationships (Robinson and Gallagher, 2008). The cocreating health framework could meet the need for greater recognition and promotion of 'relational practice' which Parker (2008) described as those activities 'necessary to develop and sustain interpersonal relationships' based on an understanding of individual circumstances and their contexts.

A significant challenge for implementing the cocreating health framework is the economic constraint on health service organisations under pressure to shorten, routinise and reduce relationship-centred interactions (Parker, 2008). The work of

Williams (Williams, 2001; Williams et al., 2009) highlighted the tensions between Pace and Complexity inherent in cocreating health interactions.. Parker (2008) argued that relational practice such as cocreating health requires a number of factors to be in place and comprises several dimensions including; accessibility, that is clinicians need to be available when they are needed; boundary management, where clinicians need to make emotional connections with patients, but also avoid being overwhelmed; connection, or the ability to create engagement/empathy and demonstrate emotional authenticity; collaboration, signifying that all parties need to share information and be involved in relational work; continuity as the ability to relate past and present experiences. Whilst such relational practice could occur with individual clinicians choosing to cocreate health, consistent with the work of Parker (2008) this research found that the nature of the group interactions between clinicians is also pivotal, and that cocreating health requires: Inter-group support; informal and formal coordination systems; the management of membership and boundaries; and a clear understanding of interdisciplinary relationships and status. It was clear from participant insights and similar to the findings of Parker (2008) about relational practise that cocreating health depends, not only on the skills of individual clinicians but also on the extent to which the multidisciplinary team and the organisation are structured and operated in ways that support cocreating health. This need to engage more widely presents a clear challenge to implementing the cocreating health framework beyond early adopters with inherent values consistent with cocreating health.

The findings of differences in views on cocreating health between doctors, nurses and therapists and difficulties in implanting within acute care settings is consistent with the findings of Liaschenko and colleagues (Liaschenko, 1997; Liaschenko and Fisher, 1999; Stein-Parbury and Liaschenko, 2007) who considered that successful collaboration in acute settings depends on the appropriate use of three types of knowledge. These were defined as biomedical, scientifically derived knowledge that is independent of a particular individual or context, based on objective and standardised measures and considered largely to be the domain of doctors. Patient knowledge was considered to be much more contextual, concerning an individual's reaction/response to a disease and its treatment, requiring an appreciation of biomedical knowledge but also the ability to go beyond this. It represents the individual in context and requires knowing the patient, consistent with patient centred service delivery and was thought

by Liaschenko and colleagues to be the primary form of knowledge used by nurses, needing a better understanding of the complexity and idiosyncrasies of the individual patient. Person knowledge was seen as an appreciation of what it is to live a certain kind of life, to be a person with a unique biography, which is more consistent with the knowledge held by therapists. Stein-Parbury and Liaschenko (2007) suggested that 'to know a patient as a person is to know what the recipient of service delivery knows, what matters to the recipient and why'. This is consistent with cocreating health, but Liaschenko (1997) argued that such person knowledge is not valued and is increasingly seen as "fluff" in healthcare, a view challenged by the cocreating health framework.

The importance of creating a supportive environment in which cocreating health could be routine is well recognised (McGilton et al., 2003), with an understanding that relationships should be based on equal partnerships between patients and clinicians (NMC, 2009). Further research is needed to understand how the cocreating health framework could be implemented within the 'complex social interactions' in acute care settings (Powell et al., 2009) that would take into account the interdependent nature of relationships between clinicians (Baker, 2007; Davies et al., 2007; Dewar, 2007; Youngsen, 2007).

The cocreating health framework aims to address the Pew-Fetzer foundation (1994) view that the dominant care model of western health service systems is inadequate to address the major health challenges facing modern society. Cocreating health argues for a need for a move away from a health service based on fixing, where the goal is to provide a service, to one where the main aim is to be of service, consistent with the views of Youngson (2007). The cocreating health framework is consistent with the work of Heifetz (1994) who described the differing approaches needed to resolve technical and adaptive problems requiring management. Technical problems are those where the goal is clear and there is an agreed approach to the solution and its application, consistent with a pace driven, biomedical approach that might be tackled by the 'medical' model. In contrast, the cocreating health framework could be argued to suit complex adaptive or wicked problems where the definition is unclear and there are multiple stakeholders, often with differing assumptions, typifying the complexity found in patients with chronic conditions. Consistent with the views of Youngsen

(2007) the cocreating health framework would mean moving away from the biomedical model of the quick or technical fix.

This research demonstrates that implementing the cocreating health framework would require transformational change within the internal working models of organisations and individuals, requiring interventions targeted at a number of levels ranging from the individual practitioner right through to society as a whole. The research on implementation of the framework was consistent with findings from the Royal College of Nursing (2008) which suggested that such change requires attention at : the micro level, that is focusing on individual clinicians, ensuring that they challenge poor practice; the meso level, focussing on the culture of the organisation and the extent to which they resolve system issues and; at the macro level, the need to challenge conflicting policy directives which both encourage a different relationship between clinicians and patients but then make this difficult with process targets that have dominated health service policy.

Insights from participants supported the views of Fahey (2003) that change initiatives need not only to consider the facility or organisation, but also require changes both in clinician's behaviour and public policy and the values and expectations that people have of the health system. It may be that implementing cocreating health will only be possible on a large scale by transforming people's expectations of clinicians, the health system and their own responsibility for their health and well-being (Baker, 2007).

Powell and colleagues (2009) carried out a systematic review of Quality Improvement programmes in health services and found that there are two main approaches to change; either by mandate or by persuasion. They concluded that persuasion is the best route to success but that mandatory change still remains the predominant internal working model in the NHS. Views of the participants of this research were that mandating change to a cocreating health approach would not be successful as this approach would not consider the relational dimensions of change, in particular the complex human factors.

This research showed that successful implementation of cocreating health will require the use of words, actions and practices that are consistent and coherent (Alvesson,

2002). The findings are consistent with the results of Patterson et al (2011) who suggest that if cocreating health approaches are to replace the current internal working models then certain things need to be in place including: cocreating health needs to be seen as important and legitimate work ; clinicians have to believe that they have sufficient resources to deliver ; supporting infrastructure ; clinicians need training to develop the skills necessary to deliver cocreating health and; clinicians need to be prepared to give something of themselves, to practise in a way that might be uncomfortable and to have peer support mechanisms in place.

Participants' views were consistent with views expressed by Nolan and colleagues (2009) that the individual and organisational context is important and that it is not realistic to attempt to apply cocreating health approaches in a uniform and prescriptive way. The findings of this study are that to be successful, the cocreating health framework needs to be sufficiently flexible to be modified according to the local context and organisational history and in so doing recognise the 'complex mix of organisational and human factors' that operate (Bate, 2008). The insights of participants also point to the need for supporting policy, the importance of the methods of appreciative enquiry and positive feedback in at least initially focussing on what is done well, for leaders to give positive feedback in order to instil some pride and a sense of confidence in clinicians fundamentally changing their practise.

It is clear from these findings that achieving transformation to cocreating health approaches away from 'perform or perish' cultures that participants felt dominate behaviours within the NHS will require both stamina and time (Patterson et al, 2011). Participants considered that attempting to embed cocreating health by achieving quick fixes, reinforced by target setting transactional approaches, and short-term perspectives would be counterproductive to this transformational change which was considered to require both time and persistence (Patterson et al, 2011). It was also clear that large scale transformational change towards cocreating health approaches will require evidence of efficacy including a shared, coherent, intellectually well-grounded position on what cocreating health should look like, and what is required to achieve this. It is clear from this research that successful introduction of cocreating health will require a systematic approach, underpinned by an overarching vision that supports implementation. Against this, participants have suggested that the NHS

tends to set in motion a number of new initiatives arising from government policy, rather than a focussing on a smaller number of more fundamental but longer term interventions. This research corroborated the findings by Patterson et al (2001) of the importance of strong leadership in supporting local culture change. It was clear from this work that the strong values, beliefs and meanings of individuals that determine their internal models of working will be difficult to adjust and that transformational change to cocreating health will require changes in behaviour of both patients and clinicians.

7.5 Significant Issues in Implementing Cocreating health

Analysis of interviewees views on implementing the cocreating health framework based on number of data items coded gave the top eight issues displayed in rank order of importance in table 7.1 below :

Table 7.1 The Eight Most Significant Issues Perceived by Interviewees in Cocreating Health

| Issue | Rank Order | Number of Data Items |
|--|------------|----------------------|
| Conflict between cocreating health framework and medical model | 1 | 182 |
| Power Relationships | 2 | 174 |
| Context of Interaction | 3 | 158 |
| Patient self-efficacy | =4 | 154 |
| Clinician understanding cocreating health | =4 | 154 |
| Clinician activation and patient activation | 6 | 134 |
| Time Constraints | 7 | 130 |
| Clinician Training | 8 | 123 |

7.5.1 Conflict between cocreating health framework and medical model

Given the familiarity of the medical model and its dominance in healthcare, it is not surprising that the most frequently cited barrier was the acknowledged very significant difference between the current medical model and the cocreating health framework.

Interviewees acknowledge that the cocreating health framework represents a transformational change in thinking for all clinicians, and doctors in particular, that challenges the fundamental basis of their training and everyday practise. Clearly, moving to a cocreating health style of interaction would be a very significant challenge that would require bespoke training for different clinical groups. In particular, this research shows that to change their attitudes and behaviours, doctors will need to see clear evidence of benefit in terms of patient outcomes and nurses would need to be assured that cocreating health was consistent with best care for patients and didn't expose them to unnecessary risks. This research suggests that the therapy professions and in particular, those such as occupational therapists who have basic professional training in the biopsychosocial model may find cocreating health most similar to their existing practise. However, this work shows that all clinical professions will also require skills training in the elements of cocreating health including self management support, supported decision making, assessment of readiness for health behavioural change and brief intervention, and quality improvement in addition to the clinical skills they already have and underpinned by training in communicating with patients.

Many participants, particularly nurses demonstrated concern about risks to patients in adopting a cocreating health approach. However, Mead and Bower (2002) have demonstrated that a patient-centred consulting style where clinicians are sympathetic and encourage patients to discuss their issues (Britten et al, 2000) increases the probability that important information will be shared. Patient-centred approaches are known to result in better patient experience and better outcomes including reduced mortality (Meterko et al, 2010). The cocreating health framework emphasises the importance of good communication between patients and clinicians and it is known that patients are more likely than clinicians to consider poor communication as a safety issue with the potential to result in diagnostic delay, physical and psychological harm (Kuzel et al, 2004). A number of studies have demonstrated that poor communication between patients and clinicians increases the risk of preventable adverse events that lead to harm (Bartlett et al, 2008 ; Divi et al, 2007).

There was further evidence in this study of participants considering that where patients are not fully informed of preference sensitive treatment that they have not

appropriately given informed consent about the risks and benefits. Consistent with Wennberg (2010) participants in this research considered that operating on patients who might not have wanted a surgical procedure had they been fully informed is a serious medical error. Insights from this study suggested that patients are often more risk averse than clinicians and are less likely to want to undergo surgical procedures when fully informed, a view shared by O'Connor et al, 2009. Policy leaders were particularly supportive of cocreating health in the knowledge that health economies with highest levels of funding tend to have high intervention rates and perform less well in terms of quality of patient care (Baicker and Chandra, 2004).

It was emphasised in this research that because of time constraints, clinicians currently make important decisions in the first few minutes of the consultation. In the current medical model the first few minutes is pivotal in determining which symptoms coalesce to define an individual as a “heart patient” or a “stroke patient” or “asthmatic,” sending them down a pathway to further tests, evaluation and eventual intervention. The cocreating health framework was thought to lessen the “anchoring bias,” arising from an incorrect diagnosis leading clinicians to ignore new symptoms or information that could lead to a different intervention.

This literature suggests that not only could a cocreating health approach to relationship-centred patient-clinician interaction lead to better outcomes and experience for both, but might be less costly and safer than the current medical model of consultation.

7.5.2 Power Relationships

Consistent with the study by Stapleton et al (2002) this research demonstrated a strong hierarchy within health services, with doctors at the top, clinicians other than doctors in the middle, and patients the bottom. In this study, non-medical clinicians were concerned about the consequences of cocreating health and discussing options that contradicted clinical norms defined by doctors. In information produced for health services, many of the choices describe options reflecting the preferences of doctors rather than those of patients or non-medical clinicians. The practice of junior doctors was similarly found to be constrained by power differentials. In this study, participants noted the importance of continuity of clinician in developing trusting relationships in

which patients feel more able to ask questions. Such relationships seemed to reduce imbalances in power and facilitate a cocreating health approach. It was considered very difficult for patients to question practice norms in the absence of such support.

Another strong finding, consistent with the work of King and colleagues (2013) was that clinicians often consider that they are already practising in a cocreating health way and are unaware of the language and non-verbal symbols they use in interacting with patients. This study found that cocreating health training delivered by an expert trainer with feedback from role play can develop awareness in clinicians that their current practise is oriented towards a patriarchal/matriarchal stance and lead to both attitude and behavioural changes towards true cocreation. For nurses and therapists, such training can confer 'permission' to practise differently, particularly if doctors are undertaking the same training.

Within the data there was strong evidence of the centrality of existing power relationships between patients and clinicians and between clinical groupings. In particular, senior doctors are seen by themselves, by patients and other clinicians as being very powerful in the system, consistent with the work of Stapleton et al (2002). It is also clear that there are hierarchies of power within medicine with consultant staff holding considerable power over junior medical staff. Nurses and allied health professionals were found to defer to medical staff to an extent that therapists considered that they needed to modify their fundamental practise from the biopsychosocial model to the medical model to be accepted within the multidisciplinary team. It was also clear that senior doctors dominate the thinking in multi-disciplinary teams. There are a number of consequences of this, in particular this research found that doctors are the 'least activated' profession towards cocreating health and the cocreating health model challenges their basic assumptions of good healthcare, use of their time and their power. In this context, doctors are very important in giving, or withholding 'permission' to patients and other clinicians to engage in cocreating health. Participants echoed the views of Tuckett *et al* (1985) that in cocreating health, consultations should be seen as 'meetings between experts'. By specifically ensuring that the sharing of ideas occurs, doctors could break down the stereotypical model of doctors as experts and patients as individuals with little knowledge or feelings about their problems.

Similar to the work of Starr (1982), it was clearly demonstrated in this work that the power differential between patients and their clinicians is deeply engrained in the culture of medicine and is rooted in differences in status and knowledge. Consistent with Charles, Gafni and Whelan (1999) participants considered that this power differential is expressed and reinforced through the traditional, passive patient role and the dominant, paternalistic clinician role enacted during a medical consultation.

A Sociological perspective is relevant in discussing these power relationships as this is concerned with how people mutually influence each in their interactions, and how organisations influence the actions and decisions of individuals. In the context of this research, a sociological perspective provides an alternative to the medical model which considers health and illness primarily in bio-medical or psychological terms. The term “medicalisation” describes medicine assuming a progressively larger role in society, leading to excessive treatment and unwarranted applications of the concept of illness.

Insights from this research were that current ‘medical consultations’ can be an expression of power in society and the unequal distribution of resources particularly between clinician and patient. The research also confirmed unequal power distribution between clinical groups. Consistent with Friedson (1970) this research found a “professional dominance” of doctors over other clinicians based on their legitimised right to define clinical reality such as taking responsibility for diagnosis and overall patient care although many non-medical professionals interviewed had considerable autonomy. It was emphasised in this research that in most circumstances the clinician and the patient come from different social and cultural worlds and that this provides a social positioning that may shape their understanding of role, conceptions and knowledge, and the same information may have a different relevance, be interpreted differently and assume a different importance. Many participants of this research viewed medicine as embedded in an ideology and as a wielder of power and control. Consistent with Foucault (1998), this research found that power is exercised in the human interaction, and is inherent in the medical consultation, shaping the patient’s role, expectation and behaviours.

Participants in this research were well aware that development of clinical practice and the growth of the power of the state has consequences of the enforcement of new,

strict requirements to normality (Foucault, 1973, 1998). Although participants did not consider that professional regulators would take issue with cocreating health they did express some concern that stepping outside the extant professional framework may incur grave consequences (Måseide, 1991).

Mead (1934) coined the term symbolic interactionism in describing his view that the self is defined by an individual's social interactions and communications, in combination with an internally maintained compendium of self-attributed qualities. Symbolic interactionism is a process of interaction in the formation of meanings for individuals where all communication is symbolic and based upon interaction and meaning. The basis of language is the use of symbols reflecting the meanings that people give to physical and social objects. In any setting in which communication takes place, such as a patient-clinician interaction, there is an exchange of symbols where people identify clues in interpreting the behaviour and intentions of others. Since communication is a two-way process, this interpretative process involves a negotiation between the people concerned. According to Aggleton (1990) 'People construct understandings of themselves and of others out of experiences they have and the situations they find themselves in. These understandings have consequences in turn for the way in which people act, and the manner in which others react to them.'

There were cues in this research of symbolic interactionism in the encounter between patients and clinicians where the behaviours of each were created by the reactions of the other. In this way, a patient from their interaction with a clinician is either empowered to manage their own health and well-being or a victim of their illness. In particular, patients were found in this research to adopt different behaviours dependent on the assumed role of the different professional interacting with them, learning their role through interaction (Lee (1990)). In this research, clinicians were understood to use clues such as clothes, positioning behind a desk and manners of speech or movement to reinforce the power of their role. The interaction between patient and clinician was observed to be a process involving a negotiation where clinicians and patients are continuously constructing understandings of themselves and each other from experiences they have and the situations they find themselves in. These subconscious understandings consequently influencing the way in which they act in their interaction and the manner in which others react to them ((Aggleton,

1990:91)). In this way, the social identities of 'clinician' and 'patient' were seen in this research to be influenced by the reactions of the other.

A cocreating health approach redefines the symbolic interaction of patient and clinician through a social constructionist perspective where health and well-being is co-produced by individuals creating knowledge directed towards the health of the patient (Berger and Luckmann (1967)). In cocreating health, understanding is created through interactions between patients and clinicians and their interpretations of this knowledge. A cocreating health approach makes no distinction between the scientific clinical knowledge held by the clinician and the social knowledge of the patient. However, this research shows that implementing cocreating health needs to address the deeply held attachment of both clinicians and patients to the current 'medical model' which reinforces the power imbalance between them.

7.5.3 Context of the Interaction

A strong conclusion was reached in this research that applying the cocreating health framework would be most effective in settings outside of hospital, with patients with chronic conditions. In the inpatient setting where the emphasis is on expert treatment of patients and discharging them quickly, there were strong views that cocreating health would be less effective and that 'the sicker patients are, the more that things are done to them'. Participants in this study corroborated the findings of Alexander et al (2012) considered that individuals suffering from acute illness could be less responsive to differences in how power is enacted given the infrequent contact with clinicians. It was felt that in secondary care, patients may not believe that they need to be involved in managing their health, especially when interacting with clinicians who reinforce a traditional passive patient role. However, some therapy professionals working in secondary care agreed with the work of Alexander et al (2012) that patient-clinician relationships are an important factor in patients taking a more active role in their health and health care. These clinicians agreed with Hibbard et al (2009) that by carefully targeting interventions to patient's cognitive ability, level of illness and activation level, it is possible for clinicians in secondary care to support patients in improving their ability to manage their own health and improve health outcomes.

7.5,4 Patient Self-Efficacy

The issue of a patient's abilities to make decisions about their own health and to affect behavioural change came up in many workshops and interviews. This was consistent with the work of Bandura (1997) who argued that a personal sense of control is important in health behavioural change. Self-efficacy was a strong theme in this research, relating to a patient having a sense of control over their environment and behaviour. This is important in cocreating health since self-efficacy beliefs determine whether health behaviour change will be initiated, how much effort will be expended, and how long it will be sustained in the face of obstacles and failures. Many interviewees spoke of the importance of self-efficacy in terms of the effort patients make in changing risk behaviour and their resilience in the face of the barriers and setbacks that may undermine motivation. This is consistent with the literature that demonstrates a person's self-efficacy influences the challenges that they will take on and that people with strong self-efficacy select more challenging goals and focus on opportunities, not on obstacles (DeVellis and DeVellis, (2000)). In the Transtheoretical Model (Prochaska and DiClemente, 1984), self-efficacy and perceived positive and negative outcomes are considered to be the main social-cognitive variables that change across the stages. Self efficacy is often low in early stages, increasing when people move on to the later stages.

Self-efficacy describes an individual's belief that they are capable of carrying out a specific behaviour, which implies that they also have the knowledge and skills to do so (Bandura, 1998). Ross and Wu (1995) showed that having a higher sense of self-efficacy and control predicts better physical health and is related to longer life expectancy. Bandura (1998) considered that a strong sense of self-efficacy is required for people to exercise control and that individuals only feel in control of a situation if they believe that they have the ability to carry out the action required of them. In terms of cocreating health, this argues that self-efficacy is a prerequisite for a sense of control, and experience of exercising control continuously builds up self-efficacy (Bandura, 1995). Results from this research suggest that clinicians working with patients to increase self-efficacy will help them to make health behavioural changes. This is consistent with the work of Shaikh and colleagues (2008) who reported a link between higher levels of self-efficacy and positive health behaviours, while Turner et

al (2001) suggested that health behaviour changes can precede increases in self-efficacy, which in turn supports maintenance of new behaviours, setting up a 'positive feedback cycle' of cocreating health involving further increases in self-efficacy.

7.5.5 Clinician Understanding of Cocreating Health

Since the cocreating health framework is both novel and potentially open for clinicians to mistakenly believe they are already practising in that way, it is important that the concept and individual elements are clearly and concisely articulated to clinicians. This research provides a concise diagrammatic articulation of the clinician's role, with an accompanying short narrative description. A longer description was also produced to describe the framework in detail. To support these descriptions it will be important to provide evidence tables for the cocreating health framework as these become available. Many clinicians may prefer to access information about the framework electronically and e-learning modules were developed to facilitate this.

7.5.6 Clinician Activation and Patient Activation

Clinician activation arose as a theme in early workshops and was then studied by questionnaire and interview and patient activation was a theme running through all of the workshops and interviews. According to Hibbard and colleagues (2004), activated patients are defined as ; a) those who believe patients have important roles to play in self-managing care, collaborating with providers, and maintaining their health; b) they know how to manage their condition and maintain functioning and prevent health declines; c) they have the skills and behaviour repertoire to manage their condition collaborate with their health providers, maintain their health functioning, and access appropriate and high-quality care. They defined the factors influencing engagement as :

- Patient (beliefs about patient role, health literacy, education)
- Organization (policies and practices, culture)
- Society (social norms, regulations, policy)

A recent Kings Fund report (Kings Fund, 2014) concluded that "people who have low levels of activation are less likely to play an active role in staying healthy. They are

less good at seeking help when they need it, at following a doctor's advice and at managing their health when they are no longer being treated; Highly activated patients are more likely to adopt healthy behaviour, to have better clinical outcomes and lower rates of hospitalisation, and to report higher levels of satisfaction with services ; Patients with low activation levels are more likely to attend accident and emergency departments, to be hospitalised or to be re-admitted to hospital after being discharged ; The relationship between patient activation and health outcomes has been demonstrated across a range of different populations and health conditions ; Intervening to increase activation can improve a patient's engagement and health outcomes and is an important factor in helping patients to manage their health. Improvements in patient activation scores have been seen for up to 18 months following intervention ; Tailoring service delivery according to patient activation levels can maximise productivity and efficiency by ensuring that the level of support provided is appropriate to the needs of the individual.

Given that this study found a wide range of clinician activation scores within and between different professional groups, the results of a study by Alexander et al (2012) indicating that patient role relationships with their clinician are associated with their level of activation is important. They considered their findings to confirm that the relationship between the clinician and patient is a leverage point for changing patient behaviours and attitudes toward their health. A number of authors have pointed out that the quality of interaction depends on relationship building, building rapport and trust, and establishing a constructive working dynamic (Blanquicett et al. 2007; Berry et al. 2008). This study corroborates the findings of Alexander and colleagues (2012) that by implementing a cocreating health approach, clinicians can redefine their role in relation to the patient, developing a partnership with patients to improve their health. However, participants in this study, consistent with the findings of Alexander and colleagues considered cocreating health as a departure from the traditional patient-clinician role might take patients out of their "comfort zone," making it less likely that they would become activated. Further research will be required to investigate this.

The self-concept literature (Hage and Marwell, 1968), suggests that clinicians change their role behaviour and patients subsequently change theirs in response. However, it is likely that patients also play a role in changing clinician behaviour during their

interaction. For example, more activated patients may insist on clinicians treating them as equal partners in the care process, resulting in a shift in clinician behaviour away from traditional dominant roles.

Interviewees clearly pointed out that some doctors such as surgeons would prove less amenable to cocreating health than others, such as general physicians. However, surgeons do practise some of the elements of cocreating health within their private practise and it is clear that redesigning healthcare systems including flexible appointment lengths and continuity of clinician would support doctors to engage in cocreating health. The conclusion of this work is that doctors are highly unlikely to be able to implement significant elements of the cocreating health framework without being allocated considerably longer appointment slots with patients. Training for doctors in cocreating health would be more effectively aimed at gaining their permission for other clinicians to work in a cocreating health way by providing a convincing evidence base. Once doctors see the benefit of cocreating health they might receive training to consider asking about the patient's agenda with questions such as 'what brought you to see me today' rather 'what's wrong with you and to prompt patients to ask them three questions proposed by the Health Foundation in their MAGIC programme (King et al, 2013) i.e. What are my options? ; What are the benefits and possible risks?; and How likely are these risks and benefits?

From participants' views, it was clear that clinicians starting to work in a cocreating health way with patients were often challenged by the patient expectancy of the clinician role to 'fix' them whilst they maintained a passive approach themselves. Any differences in internal model or perspective between patients and clinicians within their interaction can result in misunderstanding, conflict and poor outcomes. Participants considered that patients may be over-optimistic about the benefits of interventions and clinicians' understanding of the possible benefits. Smith (2001) described a 'bogus contract' that called for clinicians to be honest about the limitations of their knowledge, experience and practise (Figure 7.5)

Figure 7.5 : The Bogus Contract

The bogus contract : Patient's perspective

Modern healthcare can do remarkable things and solve many of my problems

The clinician can see inside me to find out what's wrong

The clinician knows everything its necessary to know

The clinician can solve all my problems, even my social problems

So we give clinicians high status and a good salary

The bogus contract : Clinician's perspective

Modern clinical practise has limited powers

Worse, it's dangerous

We can't begin to solve all of a patient's problems, particularly social ones

I don't know everything, but I do know how difficult many problems are to solve

The balance between doing good and harm is very fine

I'd better keep quiet about all this to avoid disappointing my patients and losing my status

This study suggested that within a "Cocreating Health Contract", patients, clinicians and 'the system' would need to acknowledge Smith's (2001) view that :Death, sickness and pain are part of life ;Clinical practise has limited powers, particularly to solve social problems and has risks ; Clinicians don't know everything: they need decision making and psychological support ; We're in this together ; Patients can't leave problems for clinicians to solve ; Clinicians should be open about their

limitations ; Politicians should not make extravagant promises but instead concentrate on reality

Such a cocreating health contract would have relevance for discussion during the agenda setting element of the cocreating health framework.

7.5.7 Time and Other System Constraints

Time constraints within current organisational systems were found to be a major barrier to implementing the cocreating health framework, as other authors had described for elements such as supported decision making and self-management support (Gravel et al, 2006). Clearly, doctors in primary and secondary care have the shortest appointments with patients, amounting to ten to fifteen minutes whilst clinical nurse specialists and therapists can have forty five minutes to an hour. Taking into consideration the current attitudes and behaviours of doctors and the organisation of clinical services, this research suggests a pragmatic approach of training doctors in the 'ask three questions' approach, working with the patient's agenda and gaining senior doctor's 'permission' for other clinicians to interact with patients to co create health. For nurses, therapists and other clinicians, this research found that cocreating health requires longer initial appointments but may result in shorter and fewer subsequent appointments as patients develop self efficacy and increasingly self manage their condition. As clinicians become more familiar with and practised in working in cocreating health, the time requirement was found to reduce. The research also provided evidence that initial appointments could be shortened by using paper based and electronic information and patient education to prepare patients before the first interaction.

Respondents acknowledged that people live complex lives and in cocreating health, part of the role of a clinician is to increase people's awareness that they have choices and control, developing their self-efficacy. In particular, cocreating health requires that conversations need to be joined up over time, where this research found that these are currently fractured and without continuity of clinician. Respondents considered that continuity could be facilitated by personalised care planning with conversations recorded on a jointly accessible and owned electronic system. If such system redesign is completed for cocreating health this research suggests that it will be important build

evidence of the health economic effects of such changes to determine whether these lead to reduced number of hospital admissions, shorter lengths of stay and reduced healthcare costs.

Responses from interviewees highlighted the importance of leadership provided by senior clinicians to changing current practise. Specifically for doctors in secondary care, the support of senior consultant medical staff in their own specialty was found to be key, and in particular during clinical training. A very strong finding was that without this 'buy in', very little change is possible due to the power of consultants in the system. To facilitate cocreating health, medical leadership is required to generate enthusiasm for change, provide permission and to show the way. For nurses, therapists and other clinicians, the leadership support of the professional hierarchy such as heads of nursing, heads of therapies was considered important to cocreating health, but was not a limiting factor for the practise of individuals. This research found that individual therapists in particular felt able to implement aspects of cocreating health into their practise without strong leadership support as long as this was consistent with regulatory requirements and they had the appropriate training. Interviewees considered that management support to redesign services to provide additional time for appointments, software support and multi-condition clinics was also central to implementing cocreating health. It was clear that interviewees had evidence of leadership at every level of organisation and professional hierarchy contributing to implementation of cocreating health.

Although this research found that many clinicians and patients may not currently feel comfortable in becoming 'activated' towards cocreating health, it is known that half as many people with long term conditions are as involved in management of their own health as would want to be and only three per cent have a care plan. The findings of this work suggest that patient training through the Educated Patient Programme (EPP) develops patient self-efficacy and leads to their activation. This was found to be an important enabler for cocreating health but currently few patients access EPP and training capacity needs to be increased as clinicians implement the preparation element of cocreating health.

Other enablers to cocreating health were consistency of relationships, system redesign, and access to authoritative information. Although clinicians reported that many patients appear comfortable with a passive role as patients, they may be ambivalent to change rather than resistant as clinicians operating a cocreating health approach reported engagement from eighty to ninety per cent of patients.

This research gave quantitative data from the clinician activation questionnaires and qualitative data from interviews that showed clear differences in perception of role between the other clinical groups. It was found that nurses and therapists were significantly more willing to support patients taking an active role in their own health, making decisions jointly and having expertise, whilst doctors were more inclined to view the patient's role as following their expert advice. This work found that doctors are particularly uncomfortable with the notion of the patient having expertise. Investigating this further, a basic incompatibility was found between the current medical model and the development of patient health literacy and self-efficacy, leading to very few referrals from doctors to patient education programmes such as EPP. Doctor's views were that 'patients like being told what to do' and 'are not interested in taking responsibility for their own health'. This conflicts with views of therapists operating elements of the cocreating health framework in patients with chronic conditions. In these contexts, therapists interviewed consistently said that eighty percent of patients when supported to manage their own health chose to do this immediately. Patients who had lived with chronic conditions for some time and realised that there was no cure were more likely to belong to this group, Taking part in patient education programmes was considered by participants to be extremely valuable in developing self efficacy in patients that would make them more likely to take responsibility for their own health and to be more effective in doing so. Of the remaining twenty per cent of patients, half were willing to engage following a period of up to six months of reflection and the remaining ten per cent of patients in the view of clinicians would never be willing or able to take responsibility for managing their own health. Patients in this latter category were more likely to be older people with little support from families or friends, from lower socioeconomic groups and with lower levels of health literacy. These patients were likely to disengage from health services, choosing not to attend appointments and being discharged from services.

7.5.8 Clinician Training

This research has confirmed that training of clinicians both in developing skills to implement individual elements of the cocreating health framework and to integrate these holistically into their practise will be key. Insights from participants pointed to the need to prepare clinicians for training by introducing them to key concepts, to provide face to face training in skills development through role play and to provide a source of ongoing support to maintain and consolidate these skills in practice. To this end, three training packages were developed to support cocreating health. The first is an e-learning module written in 'Articulate' software of an hour's duration that introduces the seven elements of cocreating health along with audit and prepares clinicians for their face to face training. This signposts clinicians to training prerequisites such as e-learning in quality improvement. The second set of training is three days face to face training for skills development, delivered with a month's gap between training days to allow practice, peer support and consolidation of skills. In this face to face training, clinicians have the opportunity to learn, practise and give each other feedback on cocreating health. The third set of training materials developed is a ten module e-learning course written in Articulate software that provides further depth of understanding and support in developing cocreating health skills. Each element of training was informed by the insights developed within this research.

Many participants pointed out that the best hope for teaching doctors cocreating health would be during their fundamental training in medical school and ensuring this was reinforced during their training as junior doctors. For those who are already in practise, this research suggests that training of doctors would most effectively concentrate on moving them from the 'pre-contemplation' phase by providing evidence of good outcomes for patients from cocreating health. Additionally, this research found that training for doctors in cocreating health is most effectively delivered within their peer groups to provide them with mutual reinforcement and to provide evidence that cocreating health is consistent with being 'a good doctor'.

7.6 Development of a Grounded Theory Model of Clinician's Practise

It was clear from participant's views that the cocreating health framework is significantly different from most clinician's current practise. It is known that a number

of factors influence clinicians practise, including individual motivational predispositions to change as well as economic, political, and organizational contexts (Davis and Taylor-Vaisey, 1997). If the cocreating health framework is to be implemented by clinicians then it will be required to understand the perceived barriers and facilitators. Although theoretical perspectives have been used to explore the determinants of clinician's behaviours, Grol et al (2007) have shown that many decisions to change clinical practise are made by individual clinicians. Because of this, a better understanding of implementation of cocreating health by individual clinicians might be gained from social psychology theories (Michie et al, 2005).

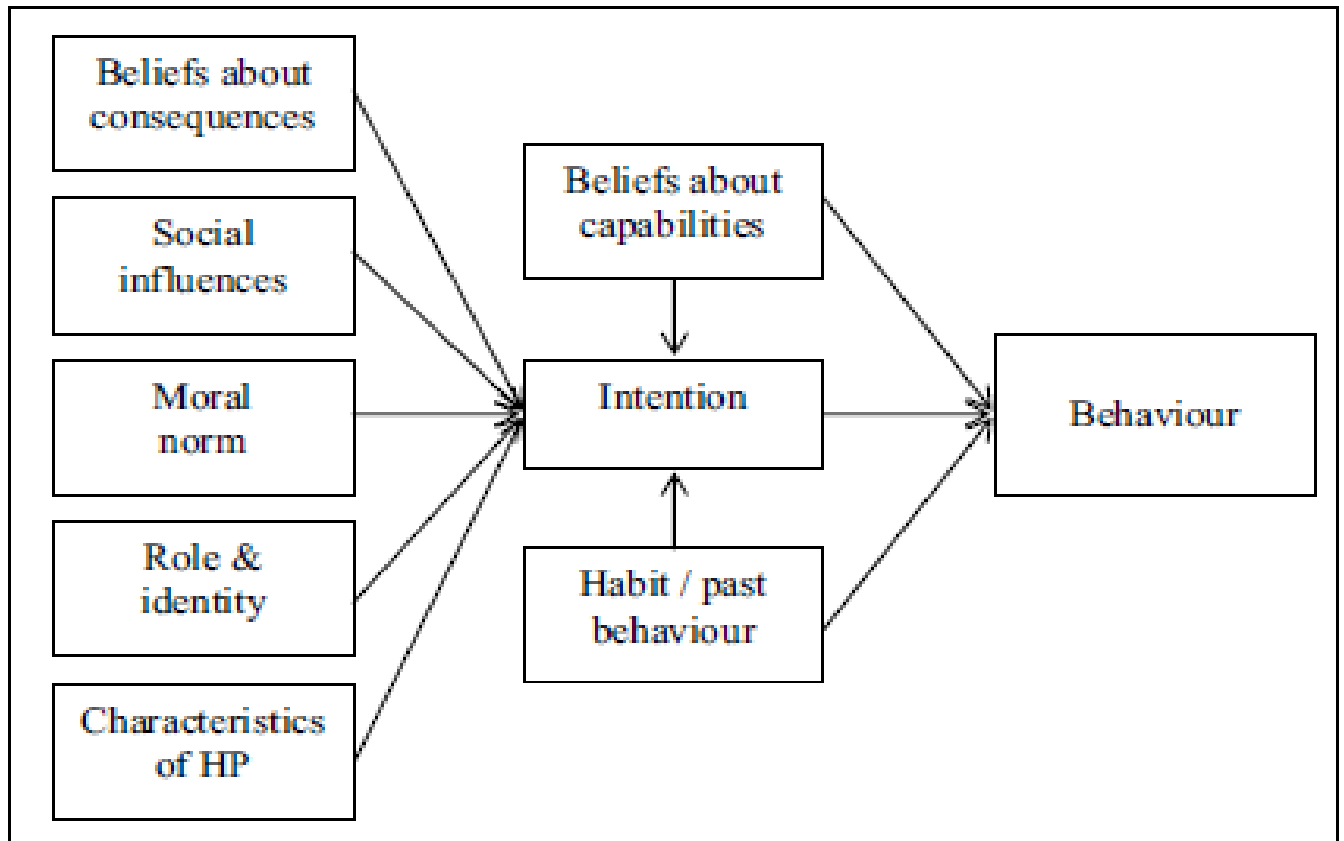
The theory of reasoned action (TRA) and theory of planned behaviour (TRB) build on the proposition that an individual's behaviours can be predicted by their intentions to perform those behaviours. TRA and TPB emphasise two core variables that influence the strength of an intention: the expected value of behavioural performance and subjective norms. TPB is an extension of TRA that also measures self-efficacy beliefs, also known as perceived behavioural control. In the context of this work, the first factor, expected value, relates to a clinician's perceptions about the advantages and disadvantages of cocreating health. The perceived outcomes of cocreating health are behavioural beliefs, a perceived association between cocreating health and the occurrence of some consequence or outcome. The second factor is subjective norms, which is made up of two components. The first component is normative beliefs about cocreating health, or the beliefs that relate to a clinician's perception of what important others (referents) think they should do in regard to interacting with patients in a particular context. The second is the clinician's level of motivation to comply with the different referents. The third factor that may influence a clinician's intentions to co create health is perceived behavioural control, or self-efficacy beliefs. Perceived behavioural control refers to a clinician's perception that they can co create health and overcome the obstacles that stand in the way of implementing it. Even though cocreating health may have a positive expected value and even though the clinician may have positive normative beliefs, the clinician may not interact with patients in a cocreating health way if they think it cannot be done. For some clinicians, normative influences may be the primary determinant of the behavioural intentions to co create health, whereas for others expected values may be of primary importance.

In applying TRA and TPB approaches to cocreating the first step would be to understand the key beliefs, attitudes, social norms, and perceived behavioural control issues that clinicians hold in relation to this specific behaviour. Once this is known, implementing cocreating health would address the educational challenges, that is barriers to TRA or TPB, of specific clinicians on the basis of their attitudes, social norms, and perceived behavioural control. For clinicians with high behavioural control and negative attitudes toward implementing cocreating health (goal behaviour), such as doctors, an intervention would focus on their attitudes, assuming that there was a strong correlation between attitudes and intentions or behaviour. This would include a training course that provides the evidence base behind cocreating health and the goal behaviour as well as the possible benefits to patients and the organisation. The goal would be to deliver an intervention that will impact a mediator that may result in a change in behaviour. For clinicians who already have very positive attitudes toward this goal behaviour but have low levels of perceived behavioural control, such as therapists, the previously described intervention would likely provide only modest benefits. For this group it would be necessary to modify the intervention to problem-solve with the clinicians to enhance their self-efficacy and perceived behavioural control in using cocreating health in their clinical practise, focusing on skill development rather than attitudes.

Godin and colleagues (2008) carried out a systematic review to quantify the extent to which studies based on social cognitive theories explain intention of clinicians to adopt clinical behaviours and predict clinician's behaviour. Their results suggested that the TPB appears to be an appropriate theory to predict behaviour. whereas Triandis' theory better captured the dynamic underlying intention. In their view, the two categories of variables predicting behaviour most often were intention and beliefs about capabilities. Beliefs about capability included the concept of perceived behavioural control, one of the TPB determinants of behaviour alongside intention. The work of Godin and colleagues found that the determinants of intention were more complex with five categories of variables : beliefs about capabilities, beliefs about consequences; moral norm; social influences; and role and identity. Godin et al considered that, according to Triandis' theory, these variables would correspond to facilitating factors, cognitive attitude, moral norm, social norm, and role beliefs. In their model, they added habit as one of the important determinants predicting behaviour,

following the work of Weinstein (2007) and consistent with Triandis' theory. Godin and colleagues proposed a theoretical model to explain clinician's intention and behaviour shown below in figure 7.6.

Figure 7.6 : Theoretical Framework for Clinician's Behaviour and Intention



Reference : Godin et al, (2008)

Gravel and colleagues (2006) performed a systematic review of the perceptions of 2784 clinicians from 15 countries of the barriers and facilitators to implementing shared decision-making in clinical practice. The five most often identified barriers were: time constraints, lack of applicability due to patient characteristics, lack of applicability due to the context, perceived patient preferences for a model of decision-making that did not fit a shared decision-making model, and not agreeing with asking patients about their preferred role in decision-making. The five most often identified facilitators in order of highest frequency first were: motivation of health professionals, perception that shared decision-making will lead to a positive impact on the clinical process, perception that shared decision-making will lead to a positive impact on patient

outcomes, perceptions that shared decision making is useful and practical, patient preferences for decision-making fitting a shared decision-making model and patient characteristics. Possible positive impacts on process included: believing that clinicians involving patients in decision-making promotes trust and honesty and, in turn, leads to better diagnosis and care; helping patients address all their concerns; improvement of clinician-patient interaction; and providing clinicians with more background information about patients, which would enable them to judge patient needs and preferences better. Possible positive impacts on outcomes included: patients' acceptance of advice and adherence to medication; patients' satisfaction, either by reducing their worries or by increasing their understanding of disease and treatment options; satisfaction with the decision made; and better health outcomes.

Consistent with the work of Gravel and colleagues (2006), this study found that time constraint is the most significant barrier to implementing cocreating health across many different professional and organisational contexts. This research found other similar perceived barriers to Gravel et al, such as disagreement about the rationale for cocreating health, including the perceived lack of applicability due patient characteristics, lack of applicability due to the clinical context, perceived patient preference for clinicians to make decisions about their healthcare and challenge to the principle of engaging patients in cocreating health. There was some evidence in this study to back up the findings of Gravel et al that these barriers might lead clinicians to triage the patients they believe can engage in cocreating health, choosing younger patients from advantaged backgrounds who have strong family support although Bruera et al (2002) had shown that clinicians can misjudge patients' desire for active involvement in decision making. This study gave clear evidence to support the findings of Holmes-Rovner and colleagues (2000) that implementation of cocreating health will need interventions directed at clinicians, at patients and the system for this to be implemented in clinical practice.

This research found that to implement cocreating health, doctors will need an evidence base of the effectiveness of the cocreating health framework. However, for therapists and nurses contributing to this research, the three most frequently reported facilitators to implementing cocreating health were related to clinician's attitude including clinician's motivation to put cocreating health into practice, clinician's perceptions that cocreating health leads to improved patient outcomes, and the perception that putting

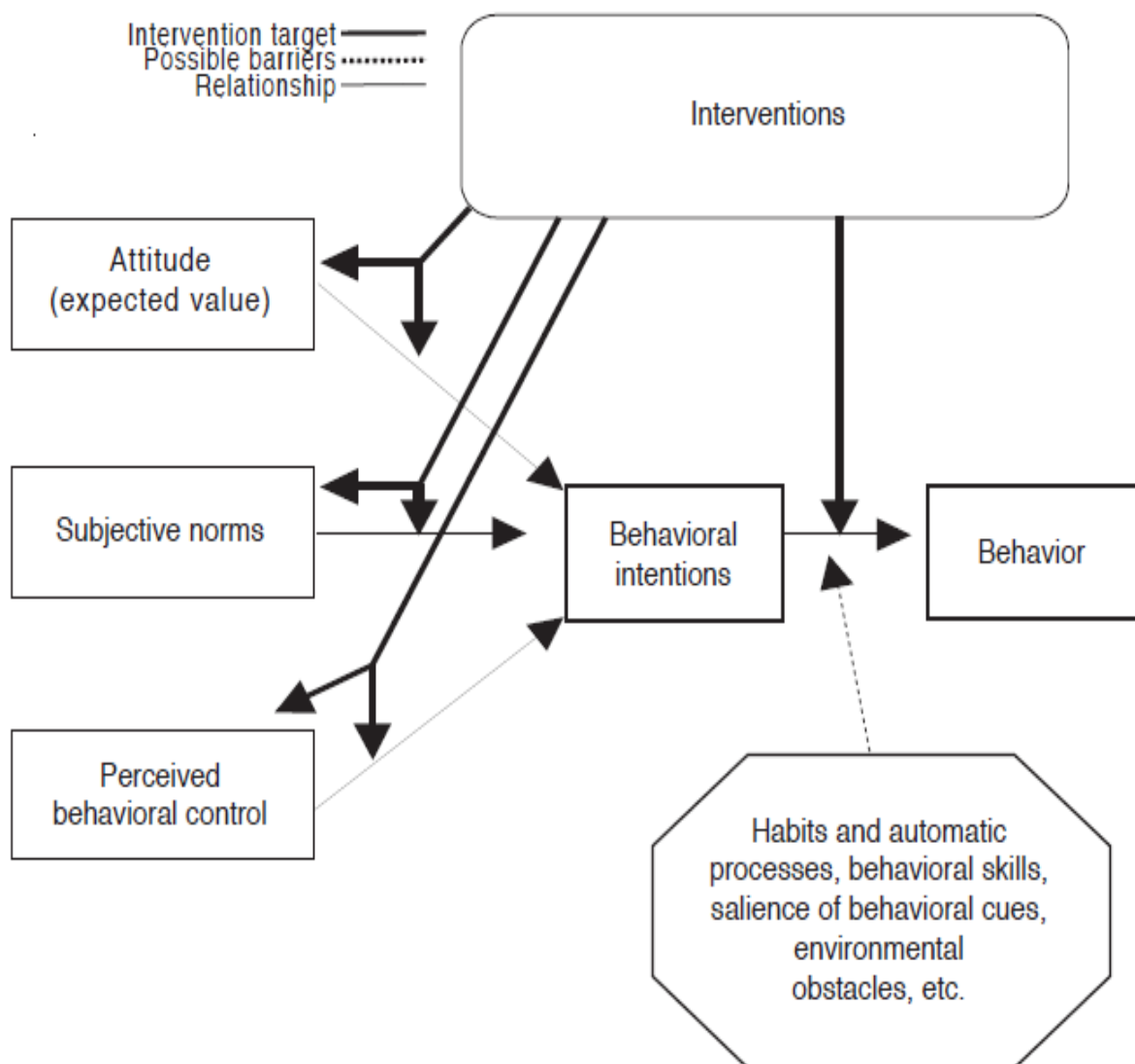
cocreating health into practice will lead to improved health care processes. The literature on changing the behaviour of clinicians together, with these results suggest that anticipating positive outcomes before trying a cocreating health may influence its implementation by therapists and nurses. That is, therapists and nurses need to be able to perceive that cocreating health will have positive outcomes on the patients themselves or the processes of care. Further work is required to understand clinicians' attitudes, subjective norms, and perceived behavioural control and how to provide the necessary support in order to find the keys to implement cocreating health.

One finding from this study is that even if training is able to change the attitudes of clinicians, thereby increasing intentions, behaviour change from a medical model to a cocreating health approach would not invariably follow. Even for clinicians with intentions to cocreate health, this work shows that obstacles may prevent implementation. The consequence of this is that support to cocreate health by removing barriers is necessary even when intentions are strong. Grol and Wensing (2004) proposed that barriers and incentives be addressed at six levels: the innovation itself, the individual professional, the patient, the social context, the organisational context, and the economic and political context. Perkins et al (2007) concluded that individual, social, economic, political, and organisational factors coalesce to influence individual clinicians who perform specific clinical behaviours.

Perkins and colleagues developed a model (Figure 7.7) for understanding the influences that affect clinician behaviours and points that may be targets for intervention. The model proposes different target areas for interventions and addresses the obstacles that get in the way even after behavioural intentions are formed. The model suggests that it is possible to intervene by changing the relative importance or impact of the construct without actually changing the construct itself. For example implementing cocreating health might require intervention that encourages clinicians to reflect on the positive aspects of cocreating health (attitudes) or to ignore what important others (referents) expect (that is, norms) if those norms interfere with cocreating health. In the view of Perkins and colleagues, it is possible to influence the relative impact of the three constructs on clinician's intentions to cocreate health without actually changing the constructs themselves. Using the model of Perkins et al, an approach to implementing cocreating health would be carefully designed and informed by the application of TRA or TPB (to determine relevant

mediators to target) and by effective strategies for overcoming obstacles and translating intentions into cocreating health in practise. Walker et al, 2001 and Sable et al, 2006 suggest the need to plan for and anticipate obstacles and then assist clinicians in forming strategies to address the obstacles to cocreating health providing evidence that actual behaviour performance can be greatly enhanced, even when intentions are high.

Figure 7.7 : Model for Influences on Clinician Behaviours



Reference Perkins et al (2007)

The modern medical model with its focus on meeting safety and physiological needs is entirely consistent with Maslow's (1954) hierarchy of needs, tending to ignore other

than patient's physiological requirements. However, the cocreating health framework has more in common with the principles defined by Max-Neef and colleagues (1989). In contrast to the hierarchy of Maslow (1954), Max-Neef et al (1989) considered that human needs were not hierarchically determined and developed ideas of human needs and human-scale development that they saw as arising from the condition of being human and being few, finite and classifiable, distinct from the concept of economic "wants" that are infinite and insatiable. They considered that this approach was constant through all human cultures and across periods of history. Max-Neef and colleagues concluded that what changes over time and between cultures are the strategies by which these needs are satisfied. In this way, human needs can be understood as a system in that they are interrelated and interactive and apart from the basic need for subsistence or survival there is no hierarchy, simultaneity, complementarity and trade-offs are features of the process of needs satisfaction. Max-Neef and his colleagues developed a taxonomy of human needs and a process by which individuals and communities can identify their "wealths" and "poverties" according to how their fundamental human needs are satisfied. Consistent with the principles inherent in cocreating health, this is described as "focused and based on the satisfaction of fundamental human needs", on the "generation of growing levels of self-reliance, and on the construction of organic articulations of people with nature and technology", of "global processes with local activity", of "the personal with the social, of planning with autonomy", and of "civil society with the state further considered the taxonomy of human needs".

The first application of the term 'cocreating health' in the context of the needs of clinicians interacting with patients was described by Conway and White (2006). Table 7.2 illustrates the application of 'human needs' to clinicians interacting with patients in cocreating health (Conway and White, 2006). Although the descriptions are phrased somewhat differently, the needs of clinicians to cocreate health with patients found in this study are entirely consistent with those identified by Conway and White (2006)

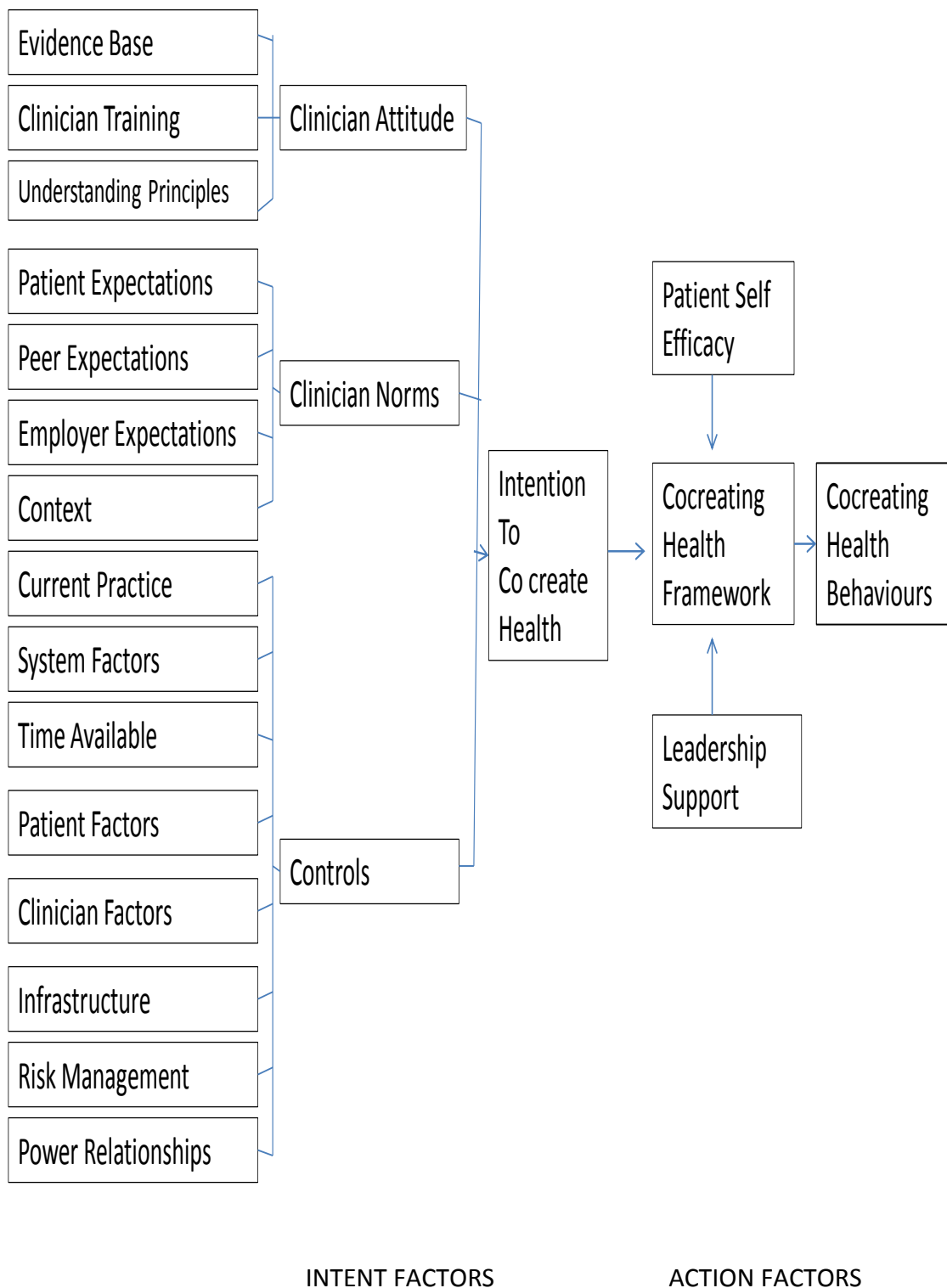
Table 7.2 Human Needs of Clinicians Interacting with Patients to Co create health

| Need | Having | Being | Doing |
|---------------|----------------|-------------|---------------|
| Subsistence | Salary | Employed | Peer Support |
| Protection | Treatment | Supported | Adhering |
| Understanding | Training | Literate | Learning |
| Participation | Role | In Team | Train others |
| Creation | Opportunity | Resourceful | Communicating |
| Identity | Expert Patient | Disclosed | Advocacy |
| Freedom | Choice | Able | Deciding |

Reference Conway and White (2006)

In this study, participant interviews gave a number of themes and elements within these that gave rise to a grounded theory for the implementation of a cocreating health framework. This model has its roots in the theory of planned behaviour (Ajzen 1991) and builds on the work of Perkins et al (2007) and Godin et al (2008). The grounded theory model developed from this work describes that intent to co create health is related to clinician’s attitudes to clinical practise, their normative behaviours with this intent mediated by control factors. The developed model described in figure 7.8 adds detail to the models developed by Perkins et al and Godin and colleagues. In particular, the developed model for implementing cocreating health provides detail on some of the interventions required to address clinician attitudes, to understand clinician norms and provides some clarity on maintaining clinician perceived behavioural control in moving from a medical model of practise to the cocreating health framework. The model also describes the factors required to move clinicians from intention to co create health to implementing this in their practise.

Figure 7.8 : Grounded Theory Model Developed in this Research to Describe Implementation of Cocreating Health Framework



7.7 Normalising the Cocreating Health Framework in routine practise

The barriers and facilitators to implementing cocreating health were examined through the lens of normalisation process modelling (NPM). NPM developed by May (2006) has been used across a range of contexts (Chew-Graham et al, 2001 ; Rogers et al, 2001 ; Dixon, 2000 ; Wileman et al, 2002 : Chapple, 1997). In this context, Normalisation is defined as the routine embedding of the cocreating health framework within health services. Table 7.3 describes the constructs and dimensions of the normalisation process model that were applied to investigate the potential for wide spread Implementation of the cocreating health framework.

Table 7.3 : The Normalisation Process Model in Relation to Embedding the Cocreating Health Framework

| NPM Constructs | Normalisation Process Model Dimensions | |
|---|--|---|
| <p>Interactional Workability: People operationalise the cocreating health framework when they engage in work characterized by patterns of conduct (congruence), and expectations about their outcomes (disposal).</p> | <p>Congruence requires shared expectations of the normal conduct and purpose of the clinical encounter; the roles of participants; and the legitimacy of the cocreating health framework</p> | <p>Disposal of participants' problems requires agreement about the meaning and consequences of implementing the cocreating health framework; and expectations of the goals and possible outcomes of the clinical encounter</p> |
| <p>Relational Integration People implement the cocreating health framework through working to share knowledge and practice (accountability), and beliefs about its value and meaning (confidence).</p> | <p>Accountability requires agreement about the knowledge and expertise that underpins the cocreating health framework; beliefs about their validity and significance; and agreement about the contribution of participants.</p> | <p>Confidence requires agreement about the authority and credibility of the knowledge and expertise through which the cocreating health framework is framed; or beliefs about the utility of this knowledge and the criteria by which it is evaluated.</p> |
| <p>Skill-set workability People distribute the work connected to implementing the cocreating health framework according to specific formal or informal roles (allocation), and evaluated by reference to shared beliefs about action (performance).</p> | <p>Allocation requires agreement about the assignment of tasks relating to implementation of the cocreating health framework to participants; beliefs about the ownership and appraisal of the skills; the distribution of resources and rewards; and mechanisms to record participation.</p> | <p>Performance requires agreement about the content of tasks assigned to participants related to implementing the cocreating health framework; shared beliefs about the boundaries of their responsibility; and mechanisms to decide the degree of autonomy available to them.</p> |
| <p>Contextual Integration People enact the cocreating health framework by assigning the necessary intellectual property, personnel, and resources (execution); and to seek to link it to its operational contexts by sustaining the allocation of these resources (realization).</p> | <p>Execution is made possible by agreement about distributing responsibility implementing the cocreating health framework; policies for allocating intellectual and capital resources to participants; and mechanisms for linking participation to organizational structures.</p> | <p>Realization is made possible by participants' agreement about the value of the cocreating health framework; policies about the procurement and delivery of personnel and equipment; and mechanisms for modifying organizational objectives.</p> |

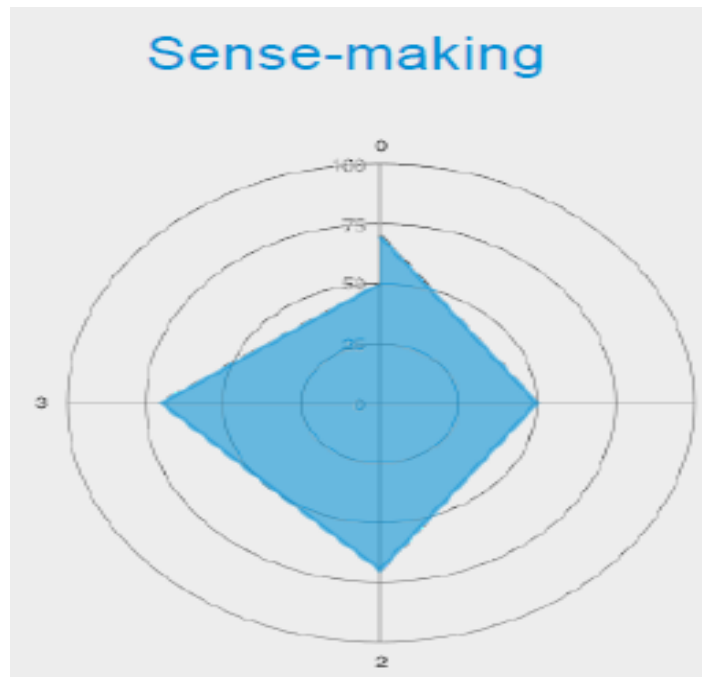
7.7.1 Summary of Normalisation Process Model Applied to Implementation

The toolkit for application of the normalisation process model uses a subjective assessment based on a researcher's knowledge of an innovation that provides heuristic prompts to think through an implementation process. Since Normalisation Process Theory focuses on the "work" that people do, it is considered to be particularly helpful in exploring self-care processes such as cocreating health (May, 2006). Initial subjective application of the knowledge gained from participants views gave the 'radar plots' below. In these radar plots, positive responses extend further out from the centre than negative ones. Areas where the responses are closer to the centre show that participants cannot make sense, or have not signed up to the innovation. If responses were close to the centre it would suggest that clinicians may not be able to enact the cocreating health framework in a way that would work for them, or may not be able to understand the benefits of using the framework and their value. As responses project further out from the centre this demonstrates increasing ability for clinicians to enact cocreating health into their normal working practises. As the intent factors and action factors described in the grounded theory model for implementing cocreating health (Figure 7.8) are accepted into normal practise, the radar plots would increasingly extend away from the centre. In the summary shown below the monitoring and sense-making elements are more positive than the action and participation elements.

7.7.2 Sense Making

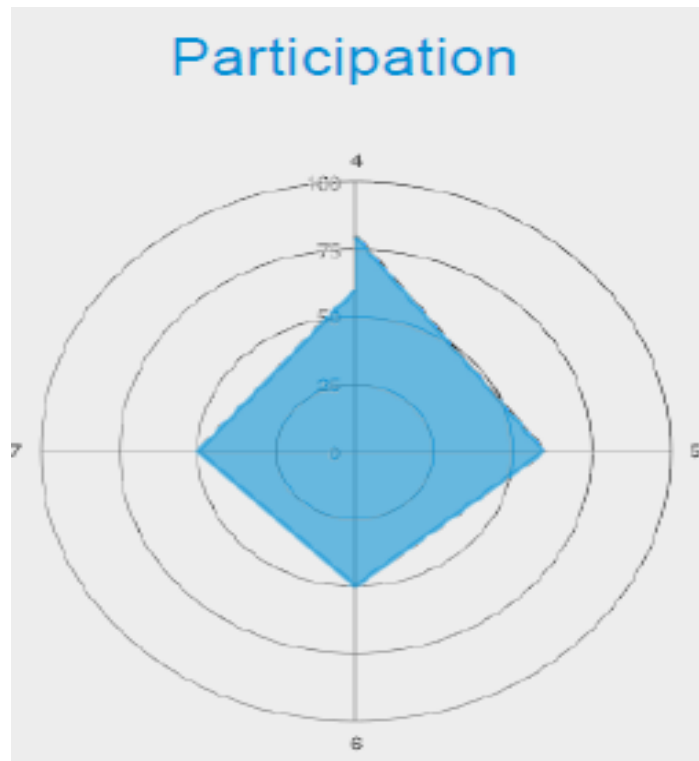
In NPT, sense-making within co-creating health would refer to the clinician's work in providing patients with knowledge of treatments and their consequences, that is the fourth element of the cocreating health framework, discussing options. For successful implementation of the cocreating health framework, clinicians would need to distinguish the cocreating health framework from their current ways of working, agree about the purpose of changing their practise, individually understand what the framework requires of them and to understand the potential value of the framework in their work. This research demonstrated that face to face training and in particular, role play, is required for clinicians to reflect and understand that they currently do not practise in a cocreating health way. However, the questionnaire data and review of the literature showed that appropriate training can support clinicians to successfully discuss options with patients. Further research is required to evaluate and refine the full cocreating health training package and to provide clinicians with

evidence tables demonstrating the relative advantage of cocreating health over current practise.



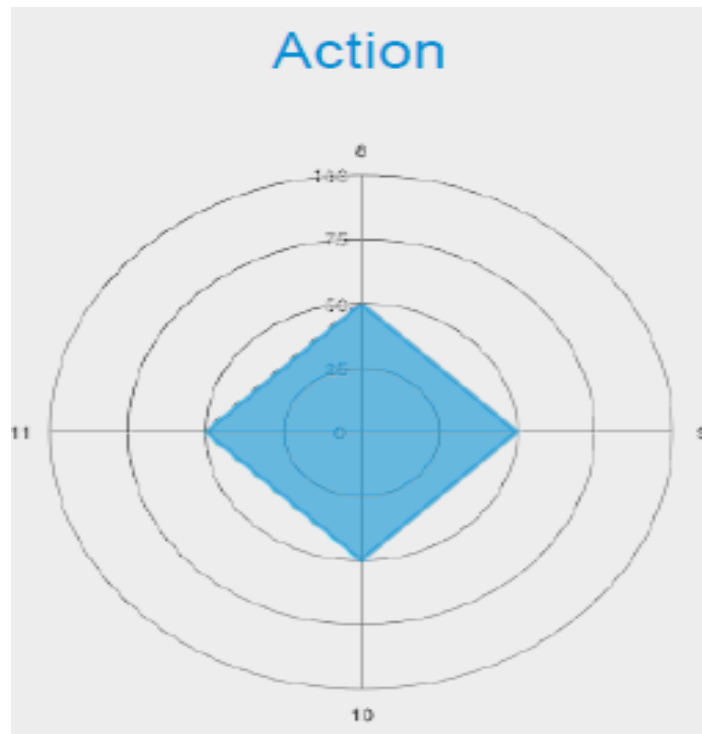
7.7.3 Participation

In NPT, participation refers to organising the work and engaging with others, corresponding with the fifth element of the framework, agreeing the way forward. This would require the support of key individuals to lead implementation, that clinicians agree that the cocreating health framework should be the context for their work, that clinicians and patients 'buy' in to the cocreating health framework and continue to support it. Currently, systems are designed with very short appointment times, there is lack of system enablers such as IT and lack of broad agreement to practise in a cocreating health way. These insights suggest that participation in cocreating health could only proceed in a patchy way amongst enthusiasts at present. This plot reflects the strong leadership support for cocreating health but lack of significant agreement amongst clinicians about its merits, limits to widespread 'buy in' and fragility of support.



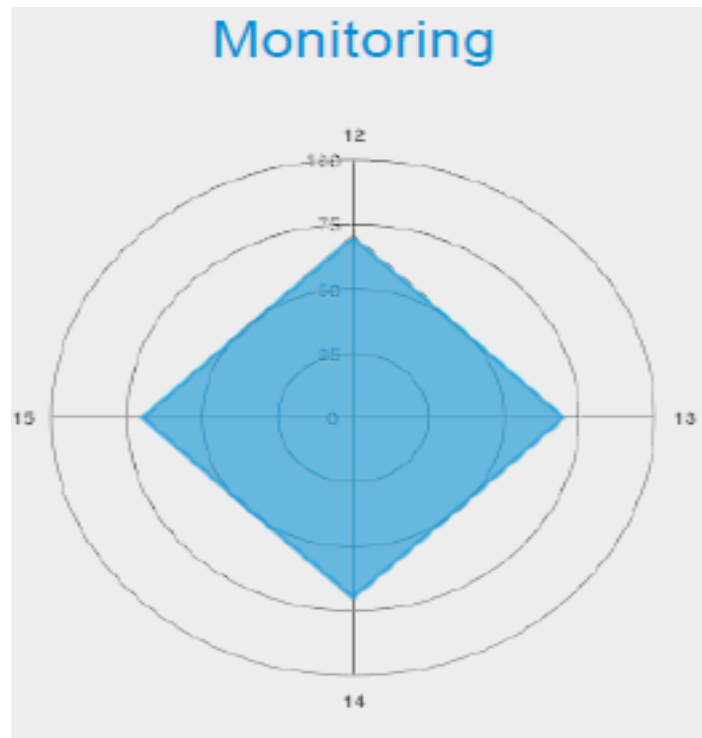
7.7.4 Action

Action refers to ‘doing the work’, providing treatment, supporting health behavioural change, the sixth element of the cocreating health framework. In terms of implementing the framework this would require clinicians to practise in a way consistent with the framework, for clinicians to maintain trust in each other and to acknowledge the expertise of patients, to ensure that the work of implanting the framework as previously defined, is allocated and that the framework receives leadership support from employers. This research demonstrates that although policy leaders are requiring ‘action’ to move to cocreating health, clinicians and leaders are in a pre-contemplation or contemplation phase of change. To move to the action phase will require additional evidence of benefit, system changes and widespread clinician and patient training. The relative closeness to the centre of the action factors reflects current ‘medical model’ practise, power relationships amongst multi-disciplinary teams, current unwillingness to acknowledge patient expertise and patchy allocation of the work of embedding cocreating health within the NHS in Wales.



7.7.5 Monitoring

Monitoring refers to reflection, monitoring, appraisal, corresponding with the seventh and eighth elements of the cocreating health framework. Successful implementation of the framework would require clinicians to have access to information about the effects of using the framework, to collectively assess implementation of the framework as worthwhile, to individually assess implementing the framework as worthwhile and to modify their work in response to their appraisal of implementing the cocreating health framework. This research showed that the pressure on clinician's time currently gives them very little time for formal monitoring, with this seen as a 'luxury'. However, there is widespread 'informal' monitoring that takes place on a small scale, generally face to face between individual clinicians or in small groups. There is a growing interest in measuring and acting on patient outcomes to demonstrate value in Health Services. With the maturity of commissioning in the NHS in Wales, this monitoring element is likely to strengthen, completely independently of uptake of cocreating health approaches, reflected in subjective analysis of this as a stronger element.



7.7.6 Conclusion on Potential for 'Normalising' the Cocreating Health Framework.

Further research is necessary to devise a questionnaire that would examine the normalisation of the cocreating health framework within the routine work of clinicians. A theoretical, subjective determination using the NPM was applied to determine whether the application of the NPM could give an understanding of how the interpersonal work done by clinical teams in Wales might support successful embedding of the cocreating health framework in practice. In particular, this would require flexibility on the part of clinicians to adapt their clinical practise. Insights from participants were that patients may start interactions with a belief that the clinician should decide upon the 'correct' course of action for them. NPM allows investigation of areas of incongruence between parents and clinician's views on how the outcome of the interaction should be measured. It is considered that patients may be more likely to rate success based on a positive change in their health status in a social context, whereas clinicians may measure effectiveness by evaluating the technical quantitative aspects, a paradox exemplified in the difference between clinical outcome measures and measures of patient experience. Further work will be required to determine if the cocreating health framework supports greater congruence between patients' and clinicians' goals leading to improved outcomes valued by both patients and clinicians. However, use of NPM techniques above suggests that health systems, patients and

clinicians are generally in 'pre-contemplation' phase and do not currently have the 'activation' factors necessary for widespread implementation of the cocreating health framework.

Newman and Hughes (2007) argued that when introducing new practices that too much emphasis is placed on achieving change using transactional mechanisms, such as compulsion and too little on the use of transformational approaches where change is promoted by coaching people to reappraise the values that underpin their internal models of behaviour and change because they believe in the new model. Newman and Hughes (2007) concluded that the more the change initiative required a change in internal models of behaviour, the more the need for a transformational rather than transactional approach. Since participant's views were that introduction of the cocreating health framework would fundamentally transform the relationship between patients and clinicians and between patients and their own health and well-being, it is appropriate to consider whether cocreating health has the potential to promote either transactional or transformational change. Given the conclusion reached above, this research suggests that implementation of cocreating health requires willing advocates to embed cocreating health approaches within their multidisciplinary team work, collecting evidence and case studies to generate 'permission' and buy in from influential leaders. Rather than attempting to 'persuade' highly experienced clinicians with many years of working to the medical model, this research suggests that cocreating health might be more successfully implemented in the initial training of clinicians in the curricula of their medical schools, schools of nursing, although clinicians would also require appropriate reinforcement during their early years of training.

7.8 An Activated System

This work has shown that cocreating health requires 'activated' clinicians and 'activated' patients, concepts that have been explored by other researchers. The developed model for implementation described in figure 7.2 above could be broken down into elements related to 'activated patients', 'activated clinicians' and an 'activated system'. To support patients and clinicians to interact to cocreate health, a health system would need to provide clinician training in the elements identified in the

framework, patient education programmes, appropriate employer expectations set through policy, information technology such as an electronic patient record and sources of information about clinical conditions that are openly available to both patient and clinician to read from and write to, and adequate time and flexibility for appointments. Further research will be necessary to develop a questionnaire, the 'system activation measure' for both patients and clinicians to answer, similar to the patient activation measure and clinician activation measure developed by Hibbard and colleagues (2010).

7.9 Conclusions

This research has defined a framework for clinicians to work with patients in cocreating health. The study has also developed a model for implementation of cocreating health and determined the barriers and enablers for embedding the framework in the everyday work of clinicians. It is clear that different clinical professions of doctor, nurse and therapist have different perceptions of cocreating health and this different way of interacting is transformational for doctors in particular. From insights gained it appears that in terms of stage of behavioural change, doctors and nurses are currently at pre-contemplation, whereas therapists are at the contemplation phase. These different clinical groups would need different training programmes to move to actioning the cocreating health framework. In cocreating health, clinicians from medical and therapy backgrounds expressed irritation about patients not looking after their own health behaviours. It will be particularly challenging in a limited consultation time for doctors to find a solution that meets people's needs without withdrawing professional cooperation from them if they are non-compliant with instruction. In operating the cocreating health framework, clinicians are moving towards a role of developing patients self-efficacy where being technically competent isn't the ultimate goal. In this person centred interaction, clinicians work with patients to understand the outcomes they are wanting to achieve and the way they want to live their lives, rather than rushing to a treatment that might achieve clinical outcomes but not patient desired outcomes. In the current 'medical model', patients can come to ask for what they know they can have, not what they might require to meet a need. In having these conversations, clinicians acting as gatekeepers can be in conflict with patients over

eligibility with patients 'fighting' to get what they think they can have. In the limited time available for interaction in current models, clinicians can prioritise diagnosis and rush quickly to the treatments they are able to provide. However, this can be disempowering of patients, taking away their responsibility for managing their own health, where this might be appropriate. In addition, the expert model where clinicians are increasingly specialised has led to clinicians treating specific disease rather than providing person-centred care. The cocreating health framework is considered to address this, moving to a model where the consistent relationship between patient and clinician was considered central to achieving good outcomes. In this relationship centred model framed around cocreating health, clinicians have the opportunity to consider the patient's human needs as defined by Max-Neef (1989) rather than just those of sustenance and physical safety defined by Maslow (1954) that form the key organising principle of the medical model that is organised around a hierarchy that can ignore other human needs. The cocreating health framework recognises that patient's needs are not organised in the hierarchy determined by Maslow (1954) and that people can choose to put themselves at significant risk of harm to fulfil their autonomous needs. Rather than acting in a risk averse way to minimise harm, cocreating health provides clinicians with a role of determining the foreseeability of harm, predicting how to reduce the risk or impact of this and supporting patients to increase their resilience and improve their well-being. In this way, the cocreating health framework requires clinicians to support patients to develop self-efficacy providing them with hope and ensuring they have a meaning and purpose to their lives. The current medical model encourages people to aspire to expert care because of a belief that this is the person who can best 'fix' them, reinforcing a psychological dependency. When people find that they aren't 'fixed' this stimulates them to ask for more treatment or to seek higher levels of expertise, leading to conflict between patient and clinician with the clinician acting as gatekeeper to additional resource, which is limited and patients working hard to get what they feel they want. To deal with this, clinicians are trained to use expert pathways and prescriptions, referring to guidance and making judgements to decide when patients should see them and about whether patients are sick enough to access the service. In this way, we currently train patients in their role of how to jump over barriers and that only the most expert clinician will be able to help them, spending much time 'fighting' to get the resources they want and reinforcing their psychological dependence.

Chapter Eight : Conclusions, Reflections and Recommendations

8.1 Introduction

The purpose of this chapter is to draw together the findings of the field research to describe the contributions made to practise, to knowledge and to policy. The contribution to practise is primarily the development of a seven element cocreating health framework with supporting factors that synthesises elements of cocreating health described in the literature with relational models of clinical practise and human interaction described by Paget et al (2001), Max-Neef et al (1989) that in turn built on the thinking of Helman (1981), Neighbour (1987) and Pendleton (2003) and the biopsychosocial model of Engel (1980)). The contribution to knowledge includes a model for changing clinician's practise that has its roots in Ajzen's (1991) theory of planned behaviour and builds on the model proposed by Perkin's et al (2007). This describes elements of clinician attitude, clinician norms and controls impacting on the intention to cocreate health with action factors of patient self-efficacy, the cocreating health framework and leadership support leading to actual cocreating health behaviours.

A number of barriers and enablers to implementing cocreating health were identified in the primary research including ; conflict between the cocreating health framework and the current 'medical model'; power relationships; the context of the interaction; patient self-efficacy; clinician understanding of cocreating health; the conflicting expectancy of patients about the clinician's role; time constraints and ; clinician training. Implementation of the cocreating health framework was examined through the lens of normalisation process theory. Results of an evaluation of participant's views using normalisation process theory suggested that neither patients, clinicians nor health systems are currently sufficiently 'activated' for successful widespread implementation of the cocreating health framework. It was concluded that implementation of cocreating health requires willing advocates to embed cocreating health approaches within their multidisciplinary team work, collecting evidence and case studies to generate 'permission' and buy in from influential leaders.

The research explored the properties of an 'activated' health system, that would provide clinician training in the elements identified in the framework, patient education programmes, appropriate employer expectations set through policy, information technology such as an electronic patient record and sources of information about clinical conditions that are openly available to both patient and clinician to read from and write to, and adequate time and flexibility for appointments. Finally, the sociological characteristics of cocreating health interactions between patients and clinicians were described within a symbolic interactionist paradigm. It is considered that this work has also made a contribution to policy within Welsh Government and the NHS in Wales with one of the principles of prudent healthcare established as 'Any service or individual providing a service should achieve health and wellbeing with the public, patients and professionals as equal partners through co-production'.

The third section, 'Reflections on Cocreating Health', discusses the concepts of cocreating health in the context of different professional groups and at levels of policy, leadership and clinician. There follows a discussion of the implications for cocreating health from the different perspectives of doctor, nurse and therapist. This section continues to reflect on the cocreating health interaction between clinicians and patients as a 'complex adaptive system' as distinct from the 'simple linear' approach utilised in current medical models of interaction.

The fourth section provides a description of the limitations of this study from the researcher's standpoint, with a fifth section giving recommendations for future research. It is clear that significant further research will be required to investigate practicalities in implementing the framework and to build an evidence base of outcomes that will influence clinicians to adopt a cocreating health approach. The final section presents a reflection on the research journey undertaken.

8.2 Contribution to Practice, Knowledge and Policy

8.2.1 Contribution to professional practice

As a reflective clinical practitioner, the primary aim of this thesis was to make a contribution to professional practice as an integral part of this professional doctorate (Duke and Beck (1999), Bareham et al. (2000), Dent (2002)). In recognition of this, the

research design of this thesis takes the importance of practical relevance into account and commits to utility as the chosen axiology. The thesis aims to make the research findings accessible and useful to clinicians, health service leaders and policy makers with different articulations of the framework written specifically for these assumed users.

The cocreating health framework provides a practicable method for clinicians to interact with patients. A number of the elements of cocreating health have been described as single entities in the literature, implemented within the context of the 'medical model' of practise. The contribution to practise made in developing the cocreating health framework as a coherent model of practise is that this incorporates a number of theoretical concepts and elements of relational care and cocreating health previously described in the literature, such as patient education programmes, self management support, supported decision making and health behavioural change. Following development of the framework and clinician training, cocreating health has been implemented by a number of clinical teams within a Health Board in Wales. Within this Health Board, the 'integrated medium term plan' commits to each clinician being trained in cocreating health over three years, with six hundred clinicians having received initial training to date. The framework has been adopted in Wales as a method for delivering the principle of 'Prudent Healthcare' relating to patients and clinicians working in coproduction. A pilot project to train three groups of clinicians in cocreating health entitled 'prudent interactions' has been completed and the intention of Welsh Government is for this training to be rolled out across the NHS in Wales. Discussions on using the framework in initial clinical training at a number of Universities are at an early stage.

There are implications for the organisation of healthcare, in determining the structure of interactions between clinicians and patients. The research demonstrated a need to organise clinics differently to allow time for cocreating health and to remove artificial barriers such as measurement of new to follow up ratios, with flexible appointment times. This research demonstrated the contextual relevance of cocreating health to situations where patients are able to consider preference-sensitive choices, such as in outpatient clinics, but less relevance to acute illness where a patient might need life saving treatment or a stay in an acute hospital.

It is relevant that this research found that doctors had lower levels of clinician activation than therapists or nurses. This is a particularly strong barrier to cocreating health since other clinical groups and patients were found to have a strong deference to the opinions of senior doctors, and hospital consultants specifically.

For doctors, cocreating health may be seen as a direct threat to their power and autonomy. In addition, doctors tend to have very short interactions with patients. These factors, coupled with a current lack of evidence base for the efficacy of the new framework will make it challenging for doctors to embrace cocreating health within their practise. The implication of this research for doctors is to gain their 'permission' for other members of the multidisciplinary team to cocreate health with patients and to incorporate consideration of the patient agenda into their practise. The research demonstrated that doctors are not a homogeneous group with the different specialties of surgeons, physicians, GPs, pathologists and others all having different characteristics and different communication and consultation styles. The research suggested that some medically trained clinicians have specific skills such as technical skills of surgeons that might make them less suitable for cocreating health interactions. In this case, it might be appropriate to organise for other clinicians to have cocreating health conversations with patients, and surgeons for example, to do operating rather than outpatient clinics. There was broad consensus that it will be challenging for doctors to change their interaction from the medical model to cocreating health with the patient, acknowledging their expertise and autonomy and working collaboratively with the patient's agenda. However, the paradox found was that implementing the cocreating health framework will depend on gaining the approval and permission of doctors, the professional group who may feel they have most to 'lose' in terms of shifting power towards patients and working in a very different model of interaction.

The research found nurses to be aiming to practise the medical model and to develop their clinical expertise, with clinical nurse specialists sometimes competing with each other to have large caseloads of people they were 'curing'. For nurses, practising in a cocreating health way was found to be 'an uncomfortable fit' with their current model of being 'expert clinicians' who 'care for patients' and actively work to minimise risks to patients. However, cocreating health is consistent with previous models of nursing practise for nurses on wards to care for people when they are unable to do so for themselves but to support them to regain independent living when they are able to.

The implication for ward based nurses is to provide more encouragement and support for patients to care for themselves whilst an inpatient rather than reinforcing their lack of independence. This changed model of practise might have implications for ward staffing. This research demonstrated that cocreating health approaches have most relevance to nurses working as clinical nurse specialists, district nurses and health visitors. The implication for practise of these groups is to acknowledge the expertise of patients and support them in independent living, rather than trying to provide a 'fix'. Following training, those nurses who had changed their practise had received permission from senior doctors and the nursing hierarchy as well as significant peer support and support from therapy colleagues.

For therapy professions, cocreating health was a more familiar concept although they were constrained by the medical model and the roles they needed to take up within this. For example, occupational therapists have the biopsychosocial model as their underpinning philosophy but in working in multi-disciplinary teams, dominated by doctors they feel obliged to work within a medical model of practise and to undertake 'tasks' such as coordinating discharge from hospital, rather than support the patient to regain their independent functioning. However, the cocreating health framework extends the biopsychosocial model and provides therapists with practical methods of enhancing their interaction with patients. Clearly, the training in cocreating health was seen to provide therapists with 'permission' to cocreate health with patients. With training, peer support and practice, therapists were able to change their model of practise to cocreate health with patients.

8.2.2 Contribution to Knowledge

In terms of theory development, a model was developed in this research for behavioural change in clinicians towards their interactions with patients that draws on the theory of planned behaviour of Ajzen (1991) and the model of Perkins et al (2007) that related in general to clinician behaviour. The model developed expands on the Perkins et al model and provides the first model of cocreating health behaviours in clinicians. The model contains barriers and facilitators to cocreating health elements previously described in the literature by authors including Gravel et al (2006) and Coulter (2011) such as time pressures, the context of the interaction, patient self efficacy and clinician training. However, additional strong factors were found including

conflict between the cocreating health framework and the current 'medical model', power relationships, and the level of clinician activation.

8.2.3 Contribution to Policy

The research findings have implications for policy, particularly in Wales in establishing a different relationship between clinicians and patients, a main tenet of 'Prudent Healthcare'. Over the course of the five year period of developing this thesis, the researcher had multiple interactions with policy leaders at Welsh Government, members of the Bevan Commission, executive directors of NHS Wales, senior leaders in other public services and voluntary bodies and senior clinical leaders. At the end of this period, policy leaders increasingly supported coproduction as a central tenet of policy. The researcher contributed significantly to papers setting out the principles of Prudent Healthcare (for example see Bradley et al, 2014) and was an invited speaker on the subject to a number of meetings organised by policy advisors. There is a possibility from these interactions that development of the cocreating health framework has contributed to development of Welsh Government policy relating to Prudent Healthcare.

8.3 Reflections on Cocreating Health

This research has met its aims of developing a cocreating health framework for patient-clinician interaction and determining the issues related to its implementation. The insights from over five hundred stakeholders were obtained and synthesised with the literature on patient-clinician interaction in initial development of the framework. In over thirty workshops, stakeholders engaged included patients, statutory bodies, Welsh Government policy makers, NHS Wales executive leaders, clinical practitioners, local authority and third sector representatives. Questionnaires were developed or modified for this research and delivered to one hundred and sixty four clinicians who had volunteered to undertake training in cocreating health. In depth semi-structured interviews were held to refine the framework and determine factors for successful implementation with thirty one key individuals at levels of policy, leadership and practice and from clinical backgrounds as doctors, nurses and

therapists. This allowed triangulation of findings from quantitative and qualitative research across levels and across clinical groups. The factors arising from the research were organised into intent factors and action factors using the theory of planned behaviour and the potential for routine embedding of cocreating health investigated using normalisation process theory.

A number of the challenges in implementing single elements of cocreating health such as the patient education programmes, self-management support and supported decision making have been described previously. For example, a review of the educated patients programme showed that patients completing the programme showed significant improvements in self-efficacy, spent fewer days in hospital, had fewer outpatient appointments and admissions to hospital (Richardson et al, 2008). A review of self-management support and supported decision making (Health Foundation, 2014) showed that approaches aimed at enabling and supporting people to take a more active role in their health and care can improve patient experience, care quality and outcomes. However, this report concluded that "neither can succeed unless power is distributed more equally in the professional– patient relationship and collaborative approaches become mainstream", and that "collaborative care and support relies on engaged and empowered patients, professionals with the skills and attitudes to work in partnership and organisational systems that embed new ways of working into routine care. Tools such as decision aids and training programmes can help collaborative care and support, but will not substitute for it."

The model and themes from this study arose from applying the principles of grounded theory whose roots are located in symbolic interactionism. Some of the behaviours pertaining to clinicians and the roles they adopt recorded in this research were linked with interpretation and meaning given to symbols such as language, dress and non-verbal cues denoting power, noted by Blumer (1971). In patient-clinician interaction both the role of patient and of clinician are learnt through socialisation and behaviours of each are influenced by the context in which the interaction takes place. The meaning given to the symbols provided by clinician and patient within their interaction enables the behaviours of the other to be predicted. In this way, behaviour and the roles that patients and clinicians play are negotiated and renegotiated within their

interactions. Feedback from these interactions allows both patient and clinician to recognise how the other perceives them and through this to develop a perception of 'self'. The clinician 'self' is then influenced by the expectations of others, such as peers or employers and by the example they set. Reality of the clinician self and the environment are in this way, socially constructed. The grounded theory developed for implementing cocreating health makes explicit the reality of how clinicians perceive their world and the way they interact with patients.

One of the main themes within the data related to unequal power relationships between patients and clinicians and between doctors and other clinical groups that described conflicts of interest and class divisions that are key elements of conflict theory (Friedson, 1970). In the control of clinicians over curing illness, making diagnoses and providing treatment there were expressions of relations of the power in society and unequal distribution of resources. A strong theme was the professional dominance previously observed by Friedson (1970) to describe the superior power wielded by doctors in relation to other clinical professions. This power over other clinicians was understood by them to arise from the doctor's 'legitimised right' to define medical reality through guarding the right to make diagnoses and approve treatment. The power of clinicians over patients was found to partly stem from the professional guarding of information and knowledge and partly from the fact that clinicians often come from different socioeconomic groups than patients (Friedson, 1970). The social positioning of clinicians shapes their conceptions of patients and patient's abilities to understand and manage their own health. The medical model of consultation may be embedded in an ideology and effective in wielding power and control.

The insights around patient-clinician interaction gained in this work are best explained sociologically by symbolic interactionism. This study demonstrated that consciously or not, clinicians can "manage" their interaction with patients by demonstrating their authority and knowledge. Participants pointed out that in current services, it is usual for patients to wait a long time for an appointment, to be kept waiting during the clinic, to have a very short but unspecified length of appointment, the clinician wearing "business" clothes, sitting behind a desk and not introducing themselves. Clinicians can use complex medical terms to describe a patient's condition instead of plain English that might be understood by patients. In this situation, the patient may consider

their role is to gain a treatment such as a prescription or an operation or a further referral by making their case with the doctor so they can come away with 'a good deal'. Clinicians, being pressed for time may be willing to provide what is asked for, rather than engaging in discussion, as expressed by one GP "nothing ends a consultation like a prescription".

Interviewees described clinicians using external characteristics such as clothes, furniture and manners of speech or movement to perhaps sub-consciously demonstrate their power over patients and reinforce their expert status. Clearly, unless both patients and clinicians receive training to set the role of 'clinician' and 'patient' in a cocreating health context, implementing the cocreating health framework will cause the consultation to be an arena in which patients and clinicians contest the power of definition. The interviewees spoke of patients playing their role of illness dependent on their assumed expectation of different clinician's expectations. For example, not 'bothering' the busy doctor with questions about diagnosis or treatment options, assuming the nurse has a matriarchal caring role and declining to carry out tasks for themselves that they would perform if asked to do so by the therapist with their assumed role of supporting patients in their rehabilitation towards the status of independent living and 'wellness'.

In this study, attitude towards patient health behaviours was found to be different between different professional groups. Nurses, who as a group scored highest on measures of clinician activation, were least likely to be judgemental of patient's health behaviours, consistent with their perceived role as 'caring'. In contrast, the views of doctors were judgemental, often overtly expressing views to patients that they were causing their own ill health through their poor health behaviours, but not offering any support to change this, or seeking to understand the patient's readiness for change. Doctors often expressed their frustration with patients and also in not having adequate time to effectively interact with patients around health behavioural change, or having the knowledge or skills to do this. Therapists were often aware of the effect that patient's behaviours were having on their health and their own limited ability to support patients to better manage their own health without addressing this, but generally did not vocalise this to patients. Therapists in particular, demonstrated interest in learning skills to support them in delivering elements of the cocreating health framework. The

perception by clinicians and patients of the doctor's role was to diagnose the person's illness, decide how to treat it, and help the person become well. In fulfilling this role of the doctor, the perceived role of the patient was to cooperate by answering the doctor's questions accurately and following. In this way, the interaction between patients and doctors was perceived as hierarchical with the doctor giving advice and instructions, and the nurses and therapists trying to make sure that the patient follows them.

In proposing the cocreating health framework as a human interaction of equals, with shared access to knowledge and information coming together over a shared agenda, this challenges the current power balance and the well understood roles of 'patient' and 'clinician'. It was clear that the different clinical groups have different needs to change their attitudes and behaviours away from current practise. In a sense, doctors have the most challenging journey and arguably the most to lose. For doctors, cocreating health means education and training in a completely different way of thinking and practising, and relinquishing the power they currently have over patients and other clinical groups. Cocreating health would require doctors to think of the role of a 'good doctor' in a completely different way. Insights from medically qualified interviewees pointed out that doctors are not an homogeneous group and that surgeons, for example, would have an entirely different view of their interaction with patients than a general practitioner. Further insights were that the intricate and highly practised physical skills of surgeons require a mindset that might not always be compatible with the human interaction skills required for cocreating health. Participants considered that in the context of surgical intervention, a team approach was optimal, with a member of the multidisciplinary team with human interaction skills required for cocreating health having a discussion with patients around their options and when surgical intervention was chosen, passing the patient on to the surgeon to carry out the operation. Such an approach would require reorganisation of health services but would have advantages of each clinician practising in areas of their greatest skill, would give surgeons more experience of actually carrying out surgery. The literature and participants' views demonstrates that a fully informed patient making a supported decision could reduce the number of elective operations by over twenty per cent.

The research found that, whereas experienced doctors are most successfully trained to cocreate health in uni-professional peer groups, both nurses and therapists benefit from being trained in their multidisciplinary teams, although it is challenging to release doctors for this training. Since some allied health professionals such as podiatrists and audiologists often work in uni-professional teams, it was found to be effective to train these professionals within their uni-professional groups. The key to training, however, was found to be to train either the whole multidisciplinary team or the whole of the professional group in cocreating health, otherwise this led to conflict between some individuals practising according to the medical model and others practising in a cocreating health way.

In addition to training clinicians, cocreating health requires the development of self efficacy in patients by providing training in health literacy, communicating with clinicians, self-management support, understanding their options and being ready to take ownership of their own health and well-being. The research clearly demonstrated that clinicians currently interact differently with patients depending on their perceived self efficacy and health literacy.

8.4 Limitations of this Research

The obvious limitation in scope of this work was that it considered cocreating health from the perspective of health professionals. Patients and patient groups provided input into the design of the framework and professionals spoke from their experience of accessing as well as providing healthcare. However, the research cannot be said to have been cocreated by patients. Clearly, a further phase of this research could be to engage patients and citizens in cocreating the next iteration of the framework. It was considered out of the scope of a doctoral thesis to engage a larger number of patients in this work.

Although the research achieved its aims there are limitations arising from the chosen research design. One limitation concerns the choice of interpretivism as the overarching research paradigm. This means that both the research process and the research results depend in part on the subjective views, perceptions and reasoning of

the researcher. Clearly the research topic was chosen because the researcher has a specific interest and knowledge as a reflective clinical practitioner and it must be acknowledged that this has contributed to the research methodology, findings and interpretation. Grounded theory requires data collection in an environment constructed by the researcher and the participant. Although measures were put in place to maximise credibility and dependability, it is possible that another investigator with a different approach, a different view of patient-clinician interaction and different participants would have had different findings. Although interview guides were used, subjective choices inevitably occurred in semi-structured interviews and during the extraction and interpretation of the findings. It was understood that an identically qualified and experienced researcher may have interpreted the subjective communication within the semi structured interview responses in different ways. It is known that qualitative studies “generally have more validity but less reliability (Babbie, 2004)” than quantitative studies, although an attempt to improve reliability was made with a relatively large sample size, peer review and triangulation with quantitative methods.

The limitations of this work also include the selection of people interviewed with potential selection bias in that some of those consenting to an interview had at least an interest in cocreating health and these participants may have very different views than other policy makers, leaders and clinicians. Similarly, views expressed by participants may have been influenced by knowledge of the researcher’s post as an Executive Director in the NHS. Although insights were gained from over six hundred workshop participants, one hundred and sixty four questionnaire respondents and thirty one interviewees, this represents a small fraction of the ninety three thousand employees of NHS Wales and one point two million employees within the UK NHS. Specifically, it might have been advantageous to recruit a larger number of General Practitioners for semi-structured interview given their importance in supporting patients outside of hospital and in chronic disease management in particular. It is intended that further research will explore the insights of general practitioners towards the cocreating health framework in greater depth.

Limitations of scope include that the results are clearly contextualised to the culture and values of the NHS in Wales, with a collaborative nature very different to the

'consumerist' policies and organisation of the NHS in England. Healthcare policy in England has diverged to become consumerist with patients highly dependent on the 'agency' of doctors allowing them choice of interventions within the financial resources available.

From the insights gained by participants, the context of the patient-clinician interaction is fundamental to valid use of the framework. In an emergency situation, where their life was endangered, the patient would wish a clinician to take rapid decisive action without engaging them in making choices. The framework is most appropriately used in the context of managing chronic diseases where a patient may have large numbers of interactions with the same clinician over an extended time period and where their own health behaviours will significantly influence the outcome. Similarly, the framework is more appropriate to out of hospital or outpatient interactions than inpatient episodes where there are multiple interactions with different clinicians in a short period and patient's choices will have less impact on outcomes. Clearly, the current 'medical model' is appropriate in life threatening circumstances, where patients need decisions to be taken for them rapidly, by expert clinicians. The 'medical model' of consultation is understood, accepted and practised many million times each day and change to cocreating health may not be supported immediately by either patients or clinicians. An important factor in implementation of cocreating health approaches would be for politicians and clinicians to begin conversations with citizens around their expectations of what they expect from health services.

8.5 Recommendations for Future Research

This section addresses a number of areas for further research. Most of these areas have already been identified in earlier sections, but it was felt that highlighting and producing a coherent a view of the areas that may require further investigation is a useful exercise. Each of these questions is beyond the scope of this thesis, but are worthy of further study to provide an evidence base that will inform implementation of the cocreating health framework. The strands for future research that arise from this work are :

8.5.1 Engaging Patients and Citizens in cocreating the next iteration of the framework

It was out of the scope of this doctoral thesis to gain full patient and citizen engagement in cocreation of the framework. In the next phase of the research it will be necessary to determine the factors for successfully engaging patients in cocreating health. This research has demonstrated that these would include health literacy, socio-economic grouping, age, health condition, context of the interaction, health behaviour change and patient training, but these factors require detailed research.

8.5.2 Engaging the Medical Profession in Cocreating Health

This research clearly found that doctors are less activated than other professional groups but are of crucial importance in implementing cocreating health, with the first step being for patients and other clinicians to gain their 'permission'. A critical question is how to engage doctors in cocreating health? Doctors might be seen to have much to lose in terms of expert power in cocreating health and have been shown by this research to dislike referring patients to education programmes that develop their expertise. The model developed by this research suggests a number of factors that influence clinician behaviour, but this model requires testing in practise. In particular, since the framework is most applicable to out of hospital interactions, further work will be necessary to gain additional insights from General Practitioners.

8.5.3 Clinician Activation

The research demonstrated that clinician's skills in cocreating health can be improved with training. A simple further question would be whether they become more activated after training. This leads to a follow up question of whether activated clinicians through their cocreating health interaction lead to activated patients as measured by the patient activation measure. This is an important question since there is a very strong correlation between high levels of patient activation and good outcomes.

8.5.4 Investigating the Potential Benefits of Cocreating Health

A key facilitator of changing clinician practise to cocreating health has been shown to be developing an evidence base that shows whether a cocreating health approach provides patients with outcomes they value and also whether it provides good clinical outcomes. To influence policy makers and clinical leaders it will also be important to carry out health economic evaluation to determine if cocreating health leads to reduced use of resource, particularly for patients with chronic conditions and in preference sensitive options such as in elective surgery.

8.5.5 Applicability of Cocreating Health to Chronic Illness

From synthesis of the existing literature and this research, it appears that cocreating health might be used most effectively for clinicians interacting with patients having chronic conditions. This requires further testing, in particular in the context of patients with both multiple chronic physical illness and mental health issues interacting with General Practitioners.

8.5.6 Cocreating Health within a Multidisciplinary Team

Within this research, cocreating health approaches were found to have been successfully applied by uni-professional groups and individual nursing and therapy members of teams with the 'permission' of medical staff. It will be important, therefore, to determine whether cocreating health can be used successfully as a multidisciplinary team approach including doctors.

8.5.7 Training for Cocreating Health

Participants responsible for University schools of nursing and therapy training programmes were supportive of incorporating the cocreating health framework into their curricula. Since this would be a radical departure from current education, it will be important to determine whether the cocreating health framework can be successfully built into basic professional training in medical schools, schools of

nursing, education of AHP's. In particular, such a transformative change in clinical practise is likely to prove challenging in clinical placement with highly experienced clinicians practising in a very different way to the cocreating health approach.

8.5.8 Activated Health Economies

Hibbard and colleagues have developed measures both of patient activation and clinician activation. This research determined a third aspect, namely whether the health economy itself is activated in a way to support patients and clinicians in cocreating health. An obvious further piece of work would be to develop a measure of 'system activation' as a questionnaire tool. This would enable policy makers and senior leaders to put in place the resources required to support clinicians in cocreating health with patients.

8.6 Concluding Reflections

The impetus for this research came from the researcher having initial clinical training and then development in practise that was consistent with the 'medical model' of interaction with patients. Over the course of a twenty two year clinical career in five different locations across the UK as a clinical scientist the researcher first adapted his own practise and then trained others in a more 'relational' style of practise that built on principles of relational care and the biopsychosocial model. Taking up post as an Executive Director of a Health Board in Wales gave a wider responsibility and the opportunity to work with a broader group of clinicians including doctors, nurses, therapists, healthcare scientists and psychologists. It was this exposure to differing models and philosophies with practise, coupled with a population health responsibility as a Board member that led to an understanding that changing outcomes required a transformational change in the relationship between patients and clinicians.

A review of existing literature on patient-clinician interaction demonstrated an increasing theoretical interest in relational care but absence of any practical framework that could be used by clinicians to deliver relational practise. Accordingly, this was seen as an appropriate topic for a DBA dissertation. To be true to the espoused

principles of cocreation, the research began with an exploration of ideas around cocreating health in workshops held with a wide variety of stakeholders across Wales. Very rapidly, it emerged that the potentially transformative issue was for clinicians to consider the patient's agenda alongside the clinical agenda in their discussions with patients. Accordingly, the researcher organised training in this aspect and self-management support from an experienced trainer engaged in this work with the Health Foundation. Clinicians volunteered to attend this training and questionnaire data was obtained from one hundred and sixty four participants over four years using modifications of questionnaires that had been developed elsewhere. At the same time, stakeholder workshops continued with elements of cocreating health arising from these discussions that were incorporated into a test cocreating health framework. In depth semi-structured interviews were then held to examine the framework and its implementation with a total of thirty one policy makers, senior leaders and clinicians across Wales. This led to a second iteration of the framework and two different narrative descriptions, along with an implementation model. Both the framework and implementation issues were then subjected to peer review and fed back to interviewees for further comments. Information from both of these processes was used to finalise the framework and implementation model set out in this thesis.

It is appropriate to reflect on the personal journey undertaken by the researcher in completing this research. This included the challenges in learning new research techniques, particularly related to qualitative research, such as grounded theory methodology and use of computerised qualitative analysis tools. The research was conducted against a backdrop of a full time post as an Executive Director and family responsibilities. This was a hard journey, in terms of workload that diverted attention away from other professional, family and personal commitments and in the cognitive effort involved. However, on reflection, the most significant element of the personal journey was affecting the movement from the perspective of clinical practitioner to doctoral researcher. The motivation to carry out this work came from an understanding that clinicians continue to interact with patients within the patriarchal/matriarchal model despite the publication of biopsychosocial and relational models. Engaging people in taking responsibility for their own health and well-being felt not only 'the right thing to do' but appeared to be the key to long term sustainability of publically funded healthcare. There was clearly a developing social movement

towards coproduction in public services, led by social services but this had not been taken up by clinicians despite supportive Government policy and a will from clinicians to change their practise. For clinicians, it appeared more comfortable to continue practising in the clinical model that they had been taught and found efficient than adopt the unknown practise of 'cocreating health' that might have significant professional and personal consequences and for which there was support in rhetoric but no blueprint. From this researcher's perspective there was then a clear gap between Government policy and clinical practise that required a framework to support clinicians and patients working together in cocreating health. There was also self-interest from the researcher in needing to develop a framework to inform his own practise to be able to work with patients in cocreating health. In addressing this gap, it was pragmatic for this thesis to consider cocreating health from a public service perspective, rather than that of patients, since these participants and interviewees were relatively uncomplicated to engage. The practical and ethical issues in engaging patients in this work were outside the scope of a doctoral thesis, although further research is required to investigate patient's insights on cocreating health.

In addition to this doctoral thesis, this research journey has led to a number of other outputs. Firstly, the cocreating health framework has been developed in a number of pictorial and narrative forms. There is a short narrative description to introduce the concepts and a longer version that explains each element in detail. The cocreating health framework in the form provided in this thesis has been presented to Welsh Government policy officials and at a number of National meetings and learning events. Secondly, the framework was adopted as the basis for training clinicians in working in coproduction with patients within the 'Prudent Healthcare' agenda. A three day face to face course has been developed by a steering group including this researcher as a 'Prudent Interactions Collaborative' to train clinicians in cocreating health. This training is based on the cocreating health framework and takes account of the insights gained in implementation, particularly clinician training. It consists of an introductory e-learning module, a three day face to face training programme and a longer e-learning module to explain the concepts and evidence base in greater detail. Initial evaluation of this course was positive and following modification to content and timing, it is intended that this is rolled out across the NHS in Wales. Thirdly, published materials arising from this research include a chapter on cocreating health within a 'how to guide'

(Cooper, Phillips and Dineen, 2014) and a peer reviewed publication on coproduction (Phillips and Morgan, 2014). Finally, there is evidence of change in practise from the six hundred clinicians trained in elements of cocreating health. It is hoped that by more clinicians adopting some or all of the elements of the cocreating health framework that health and well-being could be improved for the entire population.

Partly as a consequence of engaging in this research, the researcher has gained a Board level post with responsibility for leading Allied Health Professionals in New Zealand. The strategic thinking skills and application of these to practical issues facing health services were key in developing the researcher as an Executive Director. As a small health economy with a significant burden of chronic disease, there is great interest in New Zealand in practising cocreating health and it is hoped that this research will enable the researcher to make a significant contribution. As financial and staffing resources become even more constrained and demand increases, it is expected that cocreating health approaches will become normalised practise in Western health economies. A number of smaller Nations have already adopted a 'Prudent Healthcare' approach, seeing this as 'the right thing to do', not only the best use of resource. The shift in thinking towards cocreating health is very significant for clinical professionals previously trained in the 'medical model'. However, as more clinicians are trained in a cocreating health approach in their University courses, backed up in clinical placement, this could increasingly become 'the way things are done around here'.

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Appendix 1 : Questionnaires Used in the Study

Advanced Development Programme For Clinicians

Post Training Questionnaire

When working with clients/patients to what extent do you agree with following statements :

| | Strongly Disagree | Disagree | Not Sure | Agree | Strongly Agree |
|--|-------------------|----------|----------|-------|----------------|
| The person and the health care professional are equals and experts | | | | | |
| | Strongly Disagree | Disagree | Not Sure | Agree | Strongly Agree |
| The person and the health care professional share responsibility for decisions made during the consultation | | | | | |

| | 1 None | 2 | 3 | 4 | 5 Expert |
|--|--------|---|---|---|----------|
| How much did you know about supporting self-management at the start of this training? | | | | | |
| | 1 None | 2 | 3 | 4 | 5 Expert |
| How much do you know about supporting self-management at the completion of this training? | | | | | |

How important is it to you to do self management support with your clients/patients on a scale of 0 to 10 (0= no importance 10 = extremely important)

0 1 2 3 4 5 6 7 8 9 10

How confident **were** you at the beginning of this course to do self management support with your clients/patients on a scale of 0 to 10 (0= no confidence 10 = extremely confident)

0 1 2 3 4 5 6 7 8 9 10

How confident are you **now** to you to do self management support with your clients/patients on a scale of 0 to 10 (0= no confidence 10 = extremely confident)

0 1 2 3 4 5 6 7 8 9 10

When working with clients/patients how confident are you to...

Please tick box (0 = no confidence 10 = extremely confident)

| Confidence to; | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
|--|---|---|---|---|---|---|---|---|---|---|----|
| Explore with the person how their condition affects their life | | | | | | | | | | | |
| Identify all the person's concerns | | | | | | | | | | | |
| Know the person's priority and their expectation | | | | | | | | | | | |
| Jointly agree the purpose of the consultation | | | | | | | | | | | |
| Introduce and discuss the areas of diet and exercise | | | | | | | | | | | |
| Collaborate with patients in setting personal health and well being goals & action plans | | | | | | | | | | | |
| Undertake joint problem solving to support patients to meet their goals & action plans | | | | | | | | | | | |
| Jointly agree how and when progress will be monitored | | | | | | | | | | | |
| Help patients to develop the skills needed for effective self-management | | | | | | | | | | | |
| Sign post people to health and well being programme/clinic/education/events | | | | | | | | | | | |
| Adopt a culture of continuous service improvement | | | | | | | | | | | |

Has attending this training altered your attitudes and beliefs and if so how?

Have you made any changes to your practice or the service you deliver as a result of this training and if so please can you briefly describe them?

Do you intend to make any changes to your practice or the service you deliver as a result of this training and if so please can you briefly describe them?

Please continue over if necessary

Thank You

Co-Creating Health Questionnaire

Thank you for taking the time to participate in this audit. The questionnaire is designed to ask about your interaction with patients in your everyday clinical work. It should take you less than 30 minutes to carefully consider the questions and answer the questionnaire.

There are no right or wrong answers but please make sure that you answer every question the best you can.

First, a little information (in confidence) about yourself (please circle)

Can you give your Professional Group

Can you say which team you work on or what type of patients you work with

| FOR RESEARCHER USE ONLY | Date | Initials |
|-------------------------|------|----------|
| Received | | |
| Entered | | |

| Instructions | | | | | | | | | |
|--|--|--|--|--|--------------------------|-------------------------------------|--------------------------|-------------------------------------|--------------------------|
| Please indicate how strongly you disagree or agree with the following statements by checking the response which best describes your opinion. | | | | | | | | | |
| Example. Ms Jane Staff has answered these questions in the following way: | | | | | | | | | |
| Check a box by crossing it: <input type="checkbox"/> <input type="checkbox"/> <input checked="" type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> | | | | | | | | | |
| <u>Example Questions:</u> | | | | | Strongly agree | Agree | Not Sure | Disagree | Strongly disagree |
| 1. We receive enough training to provide a good quality of service to patients | | | | | <input type="checkbox"/> | <input checked="" type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 2. The team takes time to reflect on its performance | | | | | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input checked="" type="checkbox"/> | <input type="checkbox"/> |
| For Question 1, Jane's answer shows that she <u>agrees</u> that she has had enough training to provide a good quality of service to patients. For Question 2, Jane <u>disagrees</u> with the statement that the team takes time to reflect on its performance | | | | | | | | | |

Check box by crossing it:

The following questions ask about your everyday working life

How much do you agree that in your everyday work, you regularly.....

Strongly agree Agree Not Sure Disagree Strongly disagree

- 1** Use the results of your own personal service development or research work in discussions with patients

Please explain your answer Keep them up to date with developments in cochlear implantation and rehab.

- 2** Use the results of other people's service development or research from the knowledge base in discussions with patients

Please explain your answer.

- 3** Contribute to service development or research

Please explain your answer

- 4** Contribute to audit of your own practise

Please explain your answer

- 5** Use the results of audits of your own practise in your discussions with patients

Please explain your answer

- 6** Measure clinical outcomes from individual patients

Please explain your answer

Check box by crossing it:

The following questions ask about your everyday working life

How much do you agree that in your everyday work, you regularly.....

Strongly agree

Agree

Not Sure

Disagree

Strongly disagree

- 7** Use the results of individual patient outcomes to inform your discussion with individual patients about their treatment

Please explain your answer

- 8** Agree an individual management plan with your patients

Please explain your answer

- 9** Find that your patients are well informed about their condition before they arrive for their appointment

Please explain your answer

- 10** Ensure within the appointment that your patients have the knowledge and understanding to be able to engage in discussion about their condition as an equal partner

Please explain your answer

- 11** Give your patients written copies of any information held about them

Please explain your answer

- 12** Ensure that your patients understand their condition and the options available to them when their appointment has concluded

Please explain your answer

CLINICIAN ACTIVATION MEASURE

Clinicians have different views and expectations about their patients. Please respond to the statements below as they apply to you and your practice. If the statement does not apply, select N/A. **As a Clinician, how important is it to you that your patients:**

| | | | | | |
|--|---------------|--------------------|-----------|---------------------|-----|
| 1. Are able to take actions that will help prevent or minimise symptoms associated with their health condition(s). | Not Important | Somewhat Important | Important | Extremely Important | N/A |
| 2. Are able to figure out solutions when new situations or problems arise with their health condition(s). | Not Important | Somewhat Important | Important | Extremely Important | N/A |
| 3. Bring a list of questions to their clinic visit. | Not Important | Somewhat Important | Important | Extremely Important | N/A |
| 4. Are able to make and maintain lifestyle changes needed to manage their health. | Not Important | Somewhat Important | Important | Extremely Important | N/A |
| 5. Can follow through on treatments you have told them they need to do at home. | Not Important | Somewhat Important | Important | Extremely Important | N/A |
| 6. Know what each of their prescribed medications is for. | Not Important | Somewhat Important | Important | Extremely Important | N/A |
| 7. Are able to determine when they need to go to a health professional for care and when they can handle the problem on their own. | Not Important | Somewhat Important | Important | Extremely Important | N/A |
| 8. Understand which of their behaviors make their condition better and which ones make it worse. | Not Important | Somewhat Important | Important | Extremely Important | N/A |
| 9. Understand the different treatment options available for their condition(s). | Not Important | Somewhat Important | Important | Extremely Important | N/A |
| 10. Tell you the concerns they have about their health even when you do not ask. | Not Important | Somewhat Important | Important | Extremely Important | N/A |
| 11. Want to be involved as a full partner with me in making decisions about their care. | Not Important | Somewhat Important | Important | Extremely Important | N/A |
| 12. Look for trustworthy sources of information about their health and health choices, such as on the web, news stories, or books. | Not Important | Somewhat Important | Important | Extremely Important | N/A |
| 13. Want to know what procedures or treatments they will receive and why <u>before</u> the treatments or procedure are performed. | Not Important | Somewhat Important | Important | Extremely Important | N/A |

Appendix 2 : Statement on Ethical Issues

It is a requirement of all research involving NHS patients or staff that ethics approval is granted through the appropriate research ethics committee. It may be necessary to apply for National multi-site ethical approval for this study, dependent on advice received. However, approval to proceed will be sought from the Research and Development departments of each site. There are two ethical issues of particular importance – informed consent and confidentiality. Each interviewee will be asked to sign a consent form acknowledging that: they are sufficiently informed about the nature of the research and the interview specifically; they consent to being audio-recorded; and that they have been informed that they could withdraw from the study at any time. Secondly, the confidentiality of all research material gathered will be assured. Each transcript will be assigned with a code that relates to the case study site, researcher, transcript number and date of interview. Digital recordings and electronic files will be password protected, and transcripts and paper copies of surveys will be stored in a locked filing cabinet at ABMU Health Board Head Quarters. Questionnaires will be given individual identification codes and details of people and clinicians carers who complete a reply slip indicating a wish to participate in telephone interviews will be separated from any survey on arrival and entered into a separate unconnected password protected spread sheet. Direct observation of meetings and discussions in the field will be undertaken by the researcher. However, field notes will be taken but no audio recordings made in the clinical environment.

Ethical Approval

To be completed by DoS/Supervisor or Proposer (research grant applications)

I will ensure that the following projects under my supervision are mindful of: -

- University Ethics Guidelines
- Professional Governing Body where applicable
- Informed consent

Type of work covered by this form: **DBA Research Project** ✓

Title of work : Development and evaluation of a co-creating health model of patient-clinician interaction

Module code/project reference number SD5D001.

Unproblematic

No ethical issues have been identified as arising from this proposal.

✓ **Straightforward**

Attached are the ethical issues, which have been identified as arising from this proposal and a statement of how they have been, or will be addressed.

Not straightforward but unproblematic

Advice is sought from the Faculty Ethics Champion on the ethical issues noted on the attached. (It would be helpful if proposer can suggest ways of addressing them.)

Not straightforward and problematic

Ethical issues that fall into this category **must** be discussed with the Faculty Ethics Champion

DoS/Supervisor(s) signature(s)

Dr Kath Ringwald

Date:

Dr Simon Brooks

Date:

Signed by proposer: A.J.Phillips Date:

FESG use: Date considered:

Approved

Ref'd back to sup'n team

Ref'd to UESG

Signature of FESG Chair:

Email Confirmation of Ethical Approval from University of South Wales

Dear Andrew

Your registration and ethics statement were considered by the Faculty Research Programmes Committee today and I am pleased to inform you that they were approved.

Kind regards

Alison

Alison Crudgington

Graduate Research Administrator

Room A021, The Lodge, Graduate Research Office

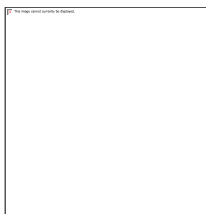
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Email Confirmation of consideration Ethical Approval from NHS Research Ethics Committee- subsequently followed up by telephone call

Hi Andy

Many thanks for your email, NHS REC review is not required for any research study involving staff as participants. However, on the basis of the information provided, I would agree the study is potentially under the remit of service evaluation and therefore would not require R&D approval either.

I will confirm both points with the Chair of our Local Ethics Committee and the the Chair of our Scientific Committee & will confirm back to you asap.

Best wishes

Jemma

From: Andrew Phillips (ABM ULHB - Therapies And Health Sciences)

Sent: 22 July 2013 13:44

To: Jemma Hughes (ABM ULHB - Research & Development)

Subject: University of South Wales Doctoral Research Project

Hi Jemma

Thank you for taking time to discuss my project with me today.

I am engaged in a doctoral thesis for a DBA in Public Services Management with the University of South Wales. I have previously developed and implemented a framework for patient-clinician interaction that uses the principles of co-production. This work started 13 years ago under a Kings Fund community of practice. I then implemented this framework in an Audiology Service in Reading, Berkshire. I am now seeking to refine and then evaluate the framework for use in the NHS in Wales. I have provided training for about 180 clinicians in ABMU so far. This training is provided by the Health Foundation in partnership with ABMU through adverts to self-selected interested clinicians on the ABMU intranet. Ive given a brief outline below :

Phase 1 : Audit of Clinicians in Reading to determine if they continue to use the framework-Audit Form supplied, data collected

Phase 2 : Evaluation of Training provided-All those receiving training have completed a pre/post training questionnaire-data collected

Phase 3 : Semi-structured interviews with clinicians to determine if they are using the training. Use of 'Clinician Activation' Questionnaire-planning phase

Phase 4 : Encourage clinicians who have had the training to use the 'Patient Activation' Questionnaire in their service audit-planning phase

Phase 5 : Variety of methods to gain qualitative information from managers and clinicians around potential for framework to be used more generally

Phase 6 : Use of Normalisation Process Theory to determine generalisability of framework for implementation

Thank you for pointing me towards the MRC/Health Research Authority Decision Support Tool. I answered 'No' to each of the following questions :

Are the participants in your study randomised to different groups?

Does your study protocol demand changing treatment/ patient care from accepted standards for any of the patients involved?

Are your findings going to be generalisable?

I answered 'No' to the third question following the advice in the rubric that 'Having said this, the methodology used to support audit or service evaluation may be useful for others to use in similar clinical areas if they wished to conduct an audit of activity locally

Although I will not collect data from patients, I may ask clinicians to consider collecting audit data from patients using the 'patient activation measure' and I may use information from this in my own study.

I have submitted a request to the Research Ethics Committee of the Faculty of Business Studies of the University of South Wales along the lines above. This has been supported by my supervisors, Professor Catherine Farrell and Dr Gina Dolan.

I would be most grateful for a decision from the ABMU HB Research Ethics committee regarding whether I need to submit for full consideration of ethical approval

Best wishes

Andy

Andrew Phillips

Cyfarwyddwr, Gwyddorau Therapi ac Iechyd

Director of Therapies and Health Science

Bwrdd Ieched Prifysgol/Abertawe Bro Morgannwg University Health Board

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andrew.phillips3@wales.nhs.uk

Appendix 3 : Initial Open Coding Structure

| Name | Sources | References |
|--|---------|------------|
| Clinical Framework | 31 | 372 |
| Preparation | 17 | 31 |
| Clinician Evaluating Information on Patient | 8 | 10 |
| Clinician Understanding Benefit or Risk of Interventions | 1 | 3 |
| Electronic Information Available | 15 | 37 |
| Patient Health Literacy | 21 | 48 |
| Patient Reading to Understand Condition | 23 | 44 |
| Agenda Setting | 31 | 288 |
| Information Gathering | 8 | 10 |
| Further Clinical Information | 3 | 4 |
| Further information gathering by patient | 7 | 11 |
| Discussion of Options | 31 | 208 |
| Agree Way Forward | 31 | 114 |
| Implementation | 15 | 21 |
| Review Achievement Of Goals and Further Actions | 26 | 55 |
| Service Audit | 18 | 34 |
| Service Improvement | 20 | 33 |
| Implementing Change | 20 | 74 |
| Barriers | 31 | 104 |
| Communication | 29 | 154 |
| High Level Support | 19 | 130 |
| Individual Internal Model | 16 | 29 |
| Conflict with Existing | 31 | 182 |
| Consistent with Existing | 28 | 71 |
| Need for mutual support | 3 | 4 |
| Return to medical model | 7 | 15 |
| Transformational | 26 | 70 |
| Large Scale | 14 | 67 |
| Leadership | 14 | 50 |
| Mutual Organisational Support | 15 | 40 |
| Need to Develop Evidence Base | 21 | 53 |
| Normalising | 11 | 19 |
| Organisational Change | 29 | 76 |
| Realisable Benefits of Cocreating Health | 8 | 54 |
| Regulatory Framework | 19 | 40 |
| Supporting Infrastructure | 22 | 34 |
| IT | 17 | 37 |
| Patient Held Record | 9 | 26 |
| Seamless Across Boundaries | 5 | 11 |
| Pace-Complexity | 17 | 25 |
| Benefits of Engaging with Complexity | 24 | 55 |
| NHS Financial Cost | 8 | 15 |
| Societal Cost | 4 | 8 |
| Time Management | 31 | 131 |
| People | 4 | 5 |
| Age Context | 16 | 26 |
| Clinician Improved Job Satisfaction | 3 | 6 |
| Clinician Morality | 6 | 14 |
| Clinician Permission | 10 | 16 |
| Clinician Profession | 6 | 9 |
| Doctor | 29 | 75 |

| | | |
|---|----|-----|
| Nurse | 14 | 63 |
| Scientist | 1 | 1 |
| Therapist | 22 | 56 |
| Clinician Reflection on Current Practise | 12 | 37 |
| Risk Management | 24 | 55 |
| Clinician Regulation | 6 | 7 |
| Clinician Training | 31 | 123 |
| Community of Practice | 1 | 3 |
| Embed in Initial training at start of career | 23 | 42 |
| Need to Practise new ways of working | 11 | 17 |
| Release for Training | 5 | 8 |
| Training Quality | 8 | 13 |
| Whole MDT | 21 | 44 |
| Benefits of whole MDT trained | 7 | 15 |
| Difficulties due to partial training within MDT | 2 | 8 |
| Whole Profession | 5 | 8 |
| Doing Too Much to People | 13 | 41 |
| Empowerment | 24 | 117 |
| Patient Capacity to Understand Options and Set Agenda | 17 | 46 |
| Patient Conflict with expectation of clinician role | 31 | 134 |
| Patient Deference to Authority | 12 | 23 |
| Patient Group Work | 2 | 3 |
| Patient Health Behaviours | 31 | 97 |
| Patient Improved Clinical Outcome | 3 | 4 |
| Patient Improved Experience | 5 | 6 |
| Patient Improved Quality of Life | 2 | 2 |
| Patient Self Efficacy | 31 | 154 |
| Patient Socio-Economic Context | 9 | 14 |
| Patient Training | 6 | 24 |
| Power Relationships | 31 | 174 |
| Relationship Centred Practise | 21 | 62 |
| Place | 31 | 158 |
| Welsh Context | 27 | 103 |
| Public Service Context | 15 | 84 |
| Strong Deference to Authority | 11 | 15 |

Appendix 4 : Insights From Interviewees Informing a Model of Implementing Cocreating Health

1 Clinician Factors

The research demonstrated that clinician attitudes towards cocreating health are formed by the evidence base supporting this different type of interaction, training in cocreation in particular in working with the patient’s agenda and the way in which concepts and frameworks for cocreating health are communicated to them.

1.1 Evidence Base

Doctors are highly influenced by the evidence base, including numbers and statistics, particularly if these are produced locally to their practise. We will need an evidence base of the effectiveness of cocreating health to engage doctors. The evidence base isn’t as important to nurses or therapists. We will need to examine the literature on what convinces doctors, for example to engage in change programs

Many of the interviewees pointed to the need for a strong evidence base to convince clinicians of the need to change their practise. One policy lead spoke of the need to “bring the evidence together”. Whilst another policy lead said “Any testing can’t be artificial. You need a vehicle to test the framework. In assessing the Cocreating Health Framework, you will need to build evidence to support it, to develop a case. If it works, it will need costing

A senior leader said “the goals within the cocreating health framework need to be evidence based and specialty specific”. A second senior leader said “you need to provide evidence to doctors that implementing the cocreating health framework will have an added value. Doctors are different from other healthcare professionals in that they are very influenced by data, the evidence base, their own experience of providing clinical services. You need to be able to use these characteristics to support change to the cocreating health framework. If we get this right, we will get buy in quickly. This will ensure that doctors will convey the message about the cocreating health framework to colleagues. You will also need to use evidence to change the behaviours

of other professionals and patients”. A second senior leader with a medical background said “I think the service transformation was really clear, doctors are very influenced by data, evidence, their own experience of things that have worked. And we need to use that, which is why the service transformation work starts with what does the data show us, what does the evidence show us, what is your experience of models elsewhere and how can we use those, and what was striking was that if you get it right, you can get people to buy in very quickly. Because they get it.

One clinician, a practising GP said “there is a need to describe the background and evidence around cocreating health”. A second clinician with a therapy background said “the way to do it is to present the evidence that it works. Because otherwise people will think oh, this is another soft talking therapy.

A third clinician with a therapy background said “if you’re talking to medics, what I’ve learnt is that their language is facts and figures, and statistics and evidence, and if you can say that Mr X has decided to change a few things in his practice and the result of those changes is this, and you can put some facts and figures on big screen and it’s open to the public arena and it looks good, and it proves that they have good outcomes. If you can put that up in a language that is facts and figures, and it’s local about your department here guys, that is very powerful language if you’re looking at consultant level”

1.2 Clinician Training

To co create health, clinicians need knowledge, skills, confidence, and tools. Training for cocreating health would be most effective if this is embedded in pre-registration training. Therapists and nurses are easier to train in cocreating health than doctors. Some doctors, for example GPs will be easier to train than others such as Surgeons. Facilitating practice in cocreating health within a ‘safe’ environment is very helpful, both in face to face training as in role playing and between training sessions. Some concepts are new for clinicians. Some clinicians feel that they are already practising in a cocreating health way, but training demonstrates to them that they are not. We will need e-learning modules to support face to face training, before to prepare clinicians and after to support clinicians in embedding the approach and to achieve

large scale roll out. Clinicians described the importance of current practitioners teaching cocreating health to students and trainees. Some clinicians may not be suited to cocreating health philosophically, and may not be able to develop the required communication skills. Clinicians are able to see changes in their own practise as a result of cocreating health training. Cocreating health training requires highly skilled and experienced trainers as cocreating health is challenging clinicians existing practise and way of thinking. Training the whole multi disciplinary team is the most effective way to embed cocreating health. It will not be possible to implement cocreating health without clinician training. Training in agenda setting and self-management support are the key elements requiring training within cocreating health framework.

One policy lead said “the challenge is how to get coproduction into day to day practice. Clinicians need the knowledge, skills and confidence to help patients to self manage their conditions. We need objectives of spreading coproduction beyond innovators, taking what exists already and sharing more widely, changing the mindsets and behaviour of clinicians and patients, supporting the development of policy, frameworks and incentives. Coproduction needs to be embedded in early training and for senior clinicians.

We need to train not only the emergent workforce, but also the existing through developing their behaviours. We need to bring Decision Support Tools and Clinician Training to support patient self management together. Overall, we need to train the entire workforce in coproduction”.

A policy lead with a nursing background said “I think it will probably involve a lot of work in preparing clinicians to think in this way. Because I think, particularly with medics, the position is that they know best, they have the scientific knowledge. I guess the other thing about this would be that there would be anxiety ‘I think I know what’s best for this patient’ but that isn’t what the patient’s asking for. The patient wants something different. What are my responsibilities there? In terms of the fact that I might have to put aside what I think is best practice.

I think there are two aspects. There is the transmitting the idea and the underpinning values and attitudes. But then I think the obvious thing that springs to mind with training would be role play, actually trying out the framework in ‘safe’ situations, role

playing it with your colleagues. A second policy lead with a nursing background said “the framework is similar to the reflective learning cycles that are taught in schools of nursing, You have to sign up to a way of thinking and behaving. It’s supportive for sure to think how effective was I in enabling the patient to take charge or whatever, but they have to have thought that’s the way we’re going to practice. It won’t make them practice in that way.

A senior leader said “we need to provide training in care planning and self-management support, including telehealth and care technologies. This will require a workforce development strategy to support care planning including skills embedded in professional training. The core competencies will be in care planning and self management support. Doctors need to be taught how to provide patients with self management support skills and how to provide patients with appropriate information. Doctors need training and support to develop new skills and competencies. It is often assumed that doctors have the skills for cocreating health, but they don’t. We need to be clear about the skills and competencies required for cocreating health. These should be embedded in professional training. Then supported through doctors working lives.

It will be difficult for older doctors trained in paternalistic role to adopt a different way of working. It is difficult for doctors to put themselves in the place of someone without medical training. Doctors need to be able to convey information and knowledge and ensure that patients have understood this.”

A second senior leader said “Before the cocreating health training we thought that we were already operating the cocreating health framework but we then realised this was different. **Training with other professionals is better than unprofessional training. Training in cocreating health could drive different approaches to MDT work with people from different professions, particularly nursing.** The greatest value in cocreating health training is transferring skills to a number of different areas. Scenario training and practising cocreating health with patients is good.

A third senior leader said “we need to introduce the principles of cocreating health in foundation years training. The biggest barrier to people understanding and implementing the cocreating health framework is people feeling ‘we do this already’.

But when they go through the skills training they realise they don't practice in a cocreating health way.

The way to do this is to work with individual clinical teams and use students. We need skills training and role playing as well as e-learning. How to guides are OK, but fewer people will go through these than will do e-learning". I think it's fair to say that with us there's a lot of knowledge, training development and skills, there's a fair amount of knowledge about how to engage with patients, what we haven't got is a methodology for scaling it up. Because it does require some resource in terms of training and development.

One of the biggest barriers with us is that we do this already. It might be the same with co-creating health, when they go through the skills training they realise they don't. And then the issue is we haven't got the materials, because a lot of the decision support tools originally required were complex, but I think the option grid approach has really opened that up.

A senior leader with a medical background said "Training would need to be started in medical school, and you'd have to tell orthopaedic surgeons, actually we don't want you to be doing so much surgery, we want you to be better at explaining operations and there are very few doctors who are good at that currently.

What is apparent is that people who go into different aspects of medicine at consultant level and indeed GP are different sorts of people.

And so doctors are very different. A physician is someone who would reach a diagnosis, possibly having ordered quite a lot of tests that would either confirm or deny and then they'd do some more tests and then they would provide some treatment and see how you were getting on and then they might adjust the treatment . There's another example-pathologists-never see a patient. Obsessed with standard operating procedures, process, accuracy, never speak to a patient in their entire professional careers, just bits of patient.

I think there's a tendency to assume that GPs and other professionals know how to go about having joint decision making, helping and supporting patients to have ownership of their conditions, and to have the confidence to manage them, and that includes having motivational skills, all of those, and I think they don't many of them, very often, I think we need to be very clear about that those skills and competencies are, how they should be embedded in our professional training and then how we go on and support clinicians to deliver those during their working lives. I think all of general practice is about supporting patients in general management but this particularly, co production, is around those with more complex needs, that you need a particular framework so I think it's hugely valuable. But I think we shouldn't underestimate that it does require a specific set of skills.

To apply cocreating health framework, the first issue is enthusing clinicians. Case study presentation is helpful. Clinicians need support and may need training in cocreating health. This would best integrate in the General Practice Training. Surgeons in particular need training to put the person back into the condition”.

A third clinician said “I used the cocreating health training to validate a return to patient centred practice. It didn't make me see the world in a different way but it did give me another tool to use with patients.”

A second clinician with a medical background said “What I have learned from the cocreating health sessions I have put into use, and has been memorable.

It would be more effective to try and embed something like this in teaching across all the different professions rather than trying to teach an old dog new tricks.

I used to say ‘have a seat, what can I do for you?’ and I won't do that anymore. I'll say ‘have a seat, tell me about it’. It does work better, it sets a different tone. So the real value for me was being given tools, and a proper understanding of neurolinguistics, what it really means to use it.

1.2.1 Embedding Cocreating Health in basic professional training

In embedding cocreating health within basic professional training the importance of interprofessional training, pre registration training, training on placement, during foundation years and preceptorship were highlighted. Clinicians find it difficult to change their model of interaction once in practise. There is strong support for the cocreating health framework amongst educators involved in basic professional training. Factors evaluating clinician's cocreating health skills should be embedded in clinician skills assessment tools. The cocreating health framework is consistent with the values of the NHS and with the psychological contract of new entrants to the NHS.

One policy lead said “When trying to deliver the framework to a range of professionals – this will be difficult as they are taught in silos. The cocreating health framework would be perfect for inter-professional education. In my experience, when you are taught a certain way in college you continue to practice in that way. For example, 26 years ago when I was training, multi-professional groups were not common. The movement towards inter-professional learning and delivery of services will help embed the framework.”

A policy lead with a nursing background said “building this into the initial training in medical schools, schools of nursing, schools of healthcare science would be a more effective way of doing the training. I would suspect there's some kind of lip service paid to it, but probably no more than that. I really like this and I can see the framework integrated into nurse education and I think it needs to come. I think teaching the **cocreating health framework would need to come right at the outset. Its about core values, of what professional healthcare is about.**

A senior leader with a nursing background said **people soon pick up the habits of people who are training them. Whatever we teach them academically, in the classroom, in the lecture theatre, is heavily influenced by what they then go on to see when they're on the wards and in other clinical areas. And then in foundation years, and in others trying to reiterate the principles and the practice.**

There's the need to embed training and principles of co-creating health in basic training, reinforce that in training.

A senior leader said “We need to be clear about the skills and competencies required for cocreating health. These should be embedded in professional training and then supported through doctors working lives”.

A second senior leader We need to review the assessment tools used in practice placements to ensure that a co-production approach is being used and embedded in practice for junior staff.

A third senior leader said “In implementing a preparation period, from clinician perspective it will be important that this is part of their basic training. When people are in their basic training and in student environments they pick up the habits and ways of doing things of those training them. We can put the cocreating health framework in place both during basic training, clinical practice training and in preceptorship”.

A fourth senior leader said “To embed the cocreating health model there is a need to change the training model in training schools. Training is an issue this needs to start in basic clinical training at university”.

A senior leader engaged in EPP said “for co-creating health to develop as a cultural model you’re going to need to get into the education system.

A third clinician said about the cocreating health framework “I feel so strongly about this obvious change in practise that I think it should be incorporated into the Podiatry degree”.

1.2.2 Practising New Skills

Clinicians need to practice new cocreating health skills. Clinicians can return to their old ways of working when under pressure

There was strong recognition of the need for clinicians to spend time in applying these

new skills to their practise. One policy lead said “people need to know how to do coproduction in practice. Training itself is not sufficient and takes a long time”.

A senior leader said “if they use the co-creating health framework in their clinical practice they will get better at it”.

A senior leader with a therapy background said “And that’s not different from clinical practice really is it, you get better with experience.

A clinician with a therapy background said “when I’m rushing I haven’t got time, I go back to my old techniques’, we all said it, we all did it. But I think when you’re more confident in using some of the techniques we’ve learned, you can adapt it, for the same end, and you can use maybe not Petrea’s words but your own words. With the same technique and it feels more natural to you. It’s just the confidence, as your confidence grows you can have a little play around with it.

A second clinician with a therapy background said “I think that the more it’s used the easier it will be, I think once people get used to the concept, patients and staff,

1.2.3 Training the Multidisciplinary Team

To be most effective the whole MDT should be trained in cocreating approach to ensure they have a consistent language and approach. But it is difficult to release the whole MDT for training whilst trying to keep a service going. It is particularly challenging to release doctors for training. Training for cocreating health needs to be different to current models of training that take place in professional ‘silos’. Training in cocreating health could drive different ways of MDT working. Training needs to emphasise the importance of the whole team to own the agenda and goals agreed with the patient. Training one member of the team is not helpful as this leaves them exposed, trying to work in a different way from the rest of the team and they may not influence the team to take a cocreating health approach. We will need senior medics to be trained in cocreating health to successfully embed this in practise. It is also important to train whole professions in cocreating health, particularly if they work in uni-professional teams.

A senior leader said “we found that some teams couldn’t free the doctors for training. We trained the rest of the multidisciplinary team but then we only trained non-doctors and found that we only had half a team”.

One policy lead said “one of the findings from our training programme is that training teams is important. This makes sure that everyone has a common experience and uses the same language. Some individuals in the MDT can be challenging. There is a need to **train the entire workforce in cocreating health. This provides mutual reinforcement**”.

A policy lead with a therapy background said “When you’re trying to deliver something like this to a whole range of professionals I think it’s a really difficult thing to do – currently they’re taught in silos and here’s a perfect example of where inter-professional education would be perfect for this because everybody’s receiving the information and learning,

One of the key findings in my research was that if we continue to educate people in silos why are we surprised when change is difficult to do

A second senior leader said “**Cocreating health training could drive approaches to MDT working with people from different professions, particularly nursing.**”

A senior leader with a therapy background said “**one of the delights of the training was the chance to be with members of other professions, multi-disciplinary training could be a better way I suppose than professional training. One of the delights was being able to approach this with someone from a totally different profession.**

One clinician said “We need **the whole practice to sign up to the concept. Cocreating health needs to be everybody’s job**”.

A third clinician with a therapy background said “when you are proposing a certain task, a challenge a change in service or what you think would be **an improvement in the service, you need to get that cohesive teamwork** going, and if you use the same principles of agenda setting and having a goal and the importance to the team or the colleague that you’re talking to, you’ve got a much better chance of achieving that outcome.

A fourth clinician with a therapy background said “**I think that having a team do it together is the most valuable way of doing it. Having isolated people within a team learn about it and then try to come back. What I think will happen is, you come back enthused, you’ll try and try, but bit by bit you’ll get whittled back into the old ways, and in time you’ll have gone back to how you’ve always been. The team hasn’t changed, that individual hasn’t changed and the wider team hasn’t changed.**

I work on the ward. I work with consultants, with the junior doctors, with the nurses, with the occupational therapists, with the social workers, ward sisters etc. that unit of a team I think would be a superb unit to try and go through this training together. But the whole team would need to be involved. And what you really need is the powerful players in that team to be really engaged. The consultants are the powerful players, nothing will change unless the consultants want it to change because at the end of the day they have got ultimate control over that patient’s care because the buck stops with them. Unless you can change their thought processes it doesn’t matter about the multi-disciplinary team that’s functioning under here because it’s very hard to change one person, a strong person’s opinion, so you really need to influence the whole team, but the whole team needs to then equally realise that everybody is equally valuable within the team.

People, staff and patients, will often think of the consultant as a strong person, the consultant themselves will often think of themselves as a strong person and until those barriers are broken down and everybody’s valued as being a really important part of the team equally,

if it's in an outpatient setting, ok you would lose an outpatient clinic, you would have to make that up in some form but you could do that. You could re-arrange diaries, you could re-arrange clinic appointments. If you're thinking of an inpatient team, those patients are still here. You can't book off that time and say don't book patients in for me then, those patients are here 24-7. so unless you've got a duplicate team to step in to release those people's time. and then what you'd have to do is that you'd have to understand the dynamics of those inpatient teams

A fifth clinician with a therapy background said "I think there'll always be a slightly different approach anyway because we think of things differently. I think sometimes OTs have a naturally – well, from the training, they think about client-centred approaches anyway, other professionals do to a certain extent. I would love to see the self management approach being used even more during our programmes, myself included in that.

1.3 Communication

In communicating the cocreating health framework it will be important to carefully define terms, to provide an introduction to explain the concept and its value. How the cocreating health framework is communicated will be important to its acceptance by clinicians. The language used to communicate the framework is important as cocreating health needs to be understood by different professional groups. In particular, communication should avoid buzz words, neologisms and long words. It will be important for patients not to feel that cocreating health is being used for rationing, otherwise they may react against it. It is important to explain cocreating health as a practical framework, and not an academic concept. It is important that the concept of cocreating health is understood by and supported by politicians and the media. We need to be able to support adoption of the cocreating health framework with links to other resources. We need to embed cocreating health in strategic documents. It is important to describe the cocreating health framework as an iterative loop, rather than a linear process. Clinicians, particularly doctors need to understand when they are operating a medical model that they are not currently practising consistent with the

cocreating health framework. The cocreating health framework must be presented with a visual depiction that is easily understandable. The test depiction using the waves diagram was not helpful. Engaging clinicians in cocreating the framework will help in developing ways to communicate it. Through communication we will need to reassure clinicians that implementing the cocreating health won't add to their workload. We need a visually attractive depiction to enthuse people with ideas about cocreating health to get them to read the narrative description of the framework.

A second senior leader said **“The way that you articulated it, it sounded like an intellectual piece of work, and something that was academic, which I can fully understand.**

A third senior leader said “I think it's a question of language whether or not the language would appeal to the mainstream.

I think the language of health is not focused enough on wellbeing, it's too much about crisis. It's not about long term management. With the media language when it comes to co-creating health the challenge is going to be pervasive because it's cultural. Co-creating health relies upon co-operation between the patient and clinician.

A fifth senior leader said **“It's presented as a linear thing, but is it a kind of loop?** One problem will be translating attitudes and good intentions into actually doing it. And I think that's probably the big barrier because that will take some fairly intensive attitudinal work. The other thing is the mechanics of translating it, what does it look like? Because most nurses will need some kind of framework that steers them through the process.

A sixth senior leader said “I didn't really understand the cocreating health framework. The framework isn't well articulated in the 'waves' diagram. If you want someone to take this up, they need to understand what you're talking about. I think because it's not how people work, you need to be able to explain to them in a way that they can

visualise and understand, actually what you mean. There are buzz words in the NHS from time to time and coproduction is one and cocreation is another.

A seventh senior leader said “ I felt in terms of GPs one of the challenges we’re going to have is how we phrase something that is succinct and in language that they engage with so that it doesn’t feel like we’re teaching them to suck eggs and it’s something that they’re doing anyway. We need to somehow to get across the message that somehow this is different to what we already do. The most important thing is that you involve them in the process; you involve them in the designing of that framework. And they’ll tell you very quickly what works and what doesn’t. What language to use, what they really feel is the added value and how to convey that to their colleagues

And ensure that it’s something that doesn’t add to their workload, that indeed it’s something that helps, because it’s facilitating the consultation. How could we find out what is it that’s going to get that message across to them, the importance of it, not only that it’s actually doable, but in doing it you’ll actually relieve the work at a later date.

A second clinician said “Co production was something that we talked about, that was mentioned in a few places before the last but one medical committee and the minister mentioned it in the medical committee symposium. And it’s a term which doesn’t seem to have endeared itself to any of my colleagues. It’s a clumsy term which isn’t obvious what it means. And sounds much more like an industrial process

It’s a criticism I have of a lot of stuff that we do, I don’t think the message is clear enough or upfront enough for speed reading. And that’s what you need is a clear, upfront message.

I think I would have put down your document before I got to the end of it. Because I think **it didn’t capture the interest and imagination early enough.**

You might say right, ok what’s the background, what is there to this, where’s the evidence, it sounds like a good idea, I could probably sign up to this.

I think that's the sort of thing that goes to the board when they say 'how do we do it?'. And that's the sort of background paper, but the first thing is, do we need to do it? And can we do it.

you need to gather is the **enthusiasm, imagination at an early stage, and then beyond that you go into the how.**

I think the first thing is enthusing the team, enthusing the clinicians. operation.

A third clinician said **“the way you’ve articulated the framework annoys me because it’s full of neologisms, it’s full of long words.**

You need to avoid jargon,

The framework is all far too wordy. It describes what you want to get across perfectly well, there's nothing wrong with that, but if you're talking about it as a teaching tool I don't think it's got legs.

1.4 Current Models of Clinician Practise

The normative understanding of clinicians was found to be set by their previous training, mostly within the 'medical model'. Clinicians practice was also informed by the expectations of patients to interact with them in a particular way. Clinicians feel a pressure from the expectations of peers around what constitutes a 'good clinician' including unwritten ethical and moral codes. Clinician's practise is also dependent on the requirements of the system they work in, including the expectations of policy including organisation, professional body, regulatory body and medico legal aspects including risk management. The same clinician may interact with patients in a different way within private practise than their NHS work due to the system factors and their control over these. The way clinicians practise adapts according to the context in which the interaction with the patient takes place.

The challenges in implementation were further outlined by a number of clinically qualified interviewees pointing out that it can take time even to agree what constitutes best practice within the current medical model “In discussing

enhanced recovery after surgery in pancreatic surgery, meeting with whole MDT it took a long time to get all professionals around the table to agree simple procedures such as pain control, early feeding.” A further challenge is the lack of uniformity even between different wards in the same hospital “the culture is different on different wards. We know individual wards well enough about what will work and what won’t”. However, the positive effect of clinicians working in a different way to the medical model was emphasised “the team comes from a number of different clinical traditions. Psychiatrists no longer work in the same medical model. We used to have a medical solution to problem, that is medication. We’re now less likely to go for a drug based solution. If we have an occupational therapist or social worker working alongside the doctors this can change our practice. Psychiatrists are used to working in multidisciplinary teams where there are different roles in the team. With a team based approach, you get dilution of the medical emphasis and are less likely to treat the patient using drugs”.

1.4.1 Conflict between existing clinical model and cocreating health framework

Some clinicians, particularly doctors who are in a position of power within the health system will say that they don’t want to be told how to practise. Certain professional groups would just be covert in not engaging with cocreating health. The current medical model gives short consultation times and clinicians may find that negotiating additional time for cocreating health interactions is a barrier. Currently clinicians may feel their services are there to deliver the medical model of assessment, diagnosis, treatment, cure, and discharge. Some clinicians, particularly doctors will see cocreating health as a threat to their autonomy. Operating the current ‘medical’ model, rather than listening to patients, doctors interrupt patients as they have a short time to conclude the consultation and have to complete the elements of their model quickly. Many doctors want to be in control of their interaction with patients. Some therapists are working to most parts of the cocreating health framework but they don’t have time for reflective learning or quality improvement. In the relationship between a clinician and a patient, coaching skills are important but many don’t currently have these. Cocreating health is moving towards a better agency relationship, where the agent (clinician) acts completely and solely on behalf of the patient. In the current medical

model, the agency relationship is contaminated because the professional has to satisfy other stakeholders. Clinicians belong to professions, they belong to other organisations who have agendas, who have constraints, and sometimes the clinician is compromised in meeting the requirements of the other stakeholders and can't act entirely on behalf of the patient as the consumer. The cocreating health framework is in conflict with the medical model that defines an expert clinician model for doctors and nurses. Clinicians may face a moral conflict or anxiety when they think they know what's best for patient but the patient chooses a different option. When patients choose a different option than the one the clinician would recommend, clinicians may be unsure of their responsibilities, and concerned that they may need to put aside best practice. Outcomes desired by patients may be in conflict with the legal or moral framework. In the way they are currently constructed for the medical model, systems don't support practise in cocreating health way. Cocreating health is challenging since it is difficult for doctors to put themselves in the place of someone without medical training. It is easier for doctors to say what they think rather than working in partnership with patients". Clinicians and patients need permission to change to a new way of working and doctors are important in granting this permission to both patients and other clinical professions.

Therapists can currently talk to patients about the benefits of behavioural change rather than spending time assessing the patient's readiness for change. There are system constraints around setting clinician's role, for example occupational therapists are directed to spend their time in inpatient settings in facilitating discharge rather than engaging in rehabilitation of patients. Doctors may feel that working in cocreating health challenges their professional judgement and competence. Surgeons have spent much time on developing operating skills and want to practise these and are not necessarily interested in having cocreating health conversations with patients around the options for not operating. It might need a different clinician to have conversations with patient than the surgeon doing the operation. Cocreating health will require transformational change in the practise of doctors. Cocreating health will work best in working with patients having chronic conditions. Doctors need to be prepared to work with patients who already have self-management skills. Clinicians may not refer patients to patient education programmes as clinicians feel they should have the expert role and patients shouldn't. Cocreating health is transformational for nurses, who find it an uncomfortable way of practising. Nurses are influenced by the medical

model and are currently focussed on the clinical agenda based on assessed risk factors rather than the patient's agenda. To practise in a cocreating health way, nurses need support from each other and from other members of the MDT. Clinicians have found it difficult to work with the patient's agenda within the medical model. Sometimes clinicians need to prioritise working to the clinical agenda rather than the patient's agenda, for their safety. Nurses starting to work with patients in cocreating health grant themselves permission to leave things out of their clinician's agenda. Therapists may feel they have to work to a medical model to avoid criticism by doctors. Patients come to doctors for alleviation of suffering but get treatment of symptoms, which is not the same thing. In a team, you need clinicians to practise in a cocreating health way, but also need others who can't do this, but who are very competent technically. Clinician's working in the medical model have an understanding that patients like being told what to do and don't like managing their own condition.

One policy lead said “**Doctors will say about the cocreating health framework—you don't need to tell us how to do this sort of thing.** Certain groups won't engage. They will say they are too busy. For example in podiatry they have a didactic approach in telling people what to do in gaining buy in for staff, an educational approach will be needed. The first thing is to establish what are we here to do? Currently people feel their services are there for assessment, diagnosis, treatment, cure, and discharge. Services are kept running by doing that. I don't know of any health professional who wouldn't say that the cocreating health framework is a good thing. But some will see it as a threat to their autonomy. Others are already in a position of power, and would say that they don't need others to tell them what to do”

A third, clinically qualified policy lead said “**Many doctors want to be in control**”.

A fourth policy lead said “The difference between podiatry and perhaps things like OT and things like arts therapy I suppose is **that physio and podiatry work along the lines of more like of a medical model.** A patient comes in and you diagnose and treat, hopefully cure and off they go. Occupational therapy and arts therapy are much more along the lines of a social model of care, which is taking a more holistic view. There are certain professions that I think are already doing this, certain professions

that really need to perhaps embrace it a bit more.

I don't think that we've touched the surface of looking at what coaching can do in the relationship between a professional and a patient.

certain professional groups would just be covert in not engaging with it.

'The education approach (I'm talking about therapists now) of what are we here to do and my personal professional experience is that we're here to diagnose, treat and hopefully cure and then send the patient off so the way that you keep your service running is to basically do that. The model I worked to initially is that you bring patients in and you keep them forever in some cases, because there will always be some need.

A fifth policy lead said **"The perfect agency relationship would be one where the agent acts completely and solely on behalf of the consumer now in health and social care the professional in a sense fulfils that role and responsibility, but the extent to which it's a perfect agency relationship is contaminated because the professional has also got to wear other hats. They belong to professions, they belong to other organisations who have agendas, who have constraints, and sometimes perhaps the professional is compromised in acting purely on behalf of the patient as the consumer.** I think this is moving towards a better agency relationship

. Because the nature and complexity of health and social care the consumer, the patient is unable to acquire all of the knowledge to be able to make an informed judgement and an informed decision. That's where the agent comes in. That is a seismic shift for some professionals.

A seventh policy lead said "I think the cocreating health framework will probably involve a lot of work in preparing clinicians to think in this way. Because I think, particularly with medics, the position is that they know best, they have the scientific knowledge

the other thing about this would be that there would be **anxiety 'I think I know what's best for this patient' but that isn't what the patient's asking for. The patient**

wants something different. What are my responsibilities there? In terms of the fact that I might have to put aside what I think is best practice. There are moral issues there. If you're convinced that A is the right way to do something but the patient says 'no, I want B' to what extent do you argue for A? At what point do you say, 'well ok, clearly you're not going to do A', or do you just say from the outset 'well I think A is best, but if you want to do B, that's fine'. Because that's the patient's wish, it could be a rational, logical decision, well thought out, well argued, But it would also have to fit in with the legal framework. So there will be some outcomes that patients might value that can't be supported because they're not legal. And there's also an ethical framework. Yes, there's a legal aspect, but there's also a moral aspect. Some medics would say 'that isn't my job. My job's to preserve life not to end life. And they might even say that 'withdrawing treatment isn't my job. My job is to preserve life as far as possible'. And then there are issues like abortion which is legal but which some practitioners may still disagree with.

I think **nursing is still very much wedded to the notion of the expert practitioner.**

You know, the expert can't actually articulate their expert decisions. So you walk into a situation and you just know what to do. You can't properly articulate it. But nevertheless you just have a gut feeling of doing the right thing. So getting from there to this notion that, actually, the patient is the expert. Well, not the expert. You're not saying that. You're saying that the patient is the expert in what they need as an individual and the clinician's job is to help and facilitate them to discover, and turn into action what they need.

A senior leader said "systems are structured around linear or simple clinical scenarios. In the management of patients with long term conditions we need to shift to a partnership model."

A second senior leader, a physiotherapist by background said "physiotherapists see a problem, gather information to form a diagnosis, agree a treatment plan and give goals. The cocreating health framework is not the way that physiotherapists work.

Clinicians in Wales use a medical model”. So if this is a recipe approach, I suppose this is less physio-like because physios don’t like being told what to do

A third senior leader, a GP said “. **It is often assumed that doctors have the skills for cocreating health, but they don’t.** Doctors need to support patients in less traditional ways without formal and rigid systems. **There is a culture of paternalism within the medical profession. There is a reluctance to let go from patients and clinicians.** It is difficult for older doctors trained in a paternalistic role to adopt a different way of working. Patients say ‘what would you do doctor?’ and it is tempting in the limited time available to maintain the current medical model

It is difficult for doctors to put themselves in the place of someone without medical training It is easier for doctors to say what they think rather than working in partnership with patients”.

A fourth senior leader, a dietician by background said that “we don’t use the medical model, we agree goals with patients. **But before doing the cocreating health training, I thought we were practising the cocreating health model but after the training, I then realised this was different. It is easier to tell people what to do,** but the outcome of this may not be effective.

The previous language was about ‘my patient’, that is the medical model. But patients are their own people,

More junior staff think they will need permission to change their practise and we will need to give patient permission also.

In terms of the Prochaska change model, the temptation is to assess someone as not ready for change, but to give them the change information anyway.

Clinicians need permission to be able to suggest that patients go away, understand some of the issues before coming back to discuss options, but this gives challenges in terms of new to follow up ratio, time, resources.

The sicker the patients are, the more likely it is that we will do things to people in a medical approach, tell them what to do.

I feel that a lot of health professionals think they are practicing co-production but they are not.”

Another senior leader with a background in nursing said “Although therapists have more time with patients, they are didactic, their clinical model is paternalistic. Therapists need training in asking patients about goals, choices, how they can best work with patients to deliver the outcomes that they would value. We say we need to listen to patients, but we don’t do much around sharing, agreeing goals. I think partly people are just conditioned to expect a consultation to be about dialogue, or if not dialogue, then one-way...

Even where clinicians are highly motivated to practise in a cocreating health way, there are system barriers. A sixth senior leader said “**A Constraint is the system saying that the OT role is to hasten discharge**”. She also said “I don’t know who the cocreating health framework is aimed at. I struggle to see the medical workforce using it. They will say ‘we haven’t got the time’ and they are only interested in the patient’s symptoms noted in the referral letter. For example in gastric band patients, no-one deals with the issue of the patient’s obesity”.

An eighth senior leader said “I think the issue will be with the same professional groups as always. Doctors. There’s certainly the question around questioning their judgement, questioning their professional competence. I think there would be a lot of work needed to ensure they know this is about putting the patient at the centre of the journey.”

A tenth senior leader said “**If you’re an orthopaedic surgeon actually, what you want to do is to being doing operations. And not spend a lot of time talking to people about why they may not want one.** And really, what we’d be saying to an orthopaedic surgeon is that we want you to spend less time operating and more time

in a clinic or engaging in patient consultation. So that perverse incentive is more around what the clinician enjoys doing, what they see as their function,

Surgeons after all have spent a lot of time focusing on being craftsmen, that their ultimate skill. But orthopaedics is perceived to be at one end of that and they really want to do the operation, and maybe wouldn't want to talk to the patient at all.

It clearly takes longer to have a proper conversation with the patient than to say to them 'What's the matter. As opposed to what matters to you? What's the matter, helpful hint'. We can fix that. This is what the operation involves. You will go to hip class and they'll tell you all about the details, what you need to do to get ready. I'm afraid it's quite a long wait. We'll get you in as soon as we can. Are you on aspirin or warfarin ? Goodbye'.

An eleventh senior leader said "I think doctors look on things really differently, and again because of their training. I think it call goes back to where we set out in our training, what messages come across to us, doctors want to cure people, and sometimes there isn't a cure. And I think unless they can give them a tablet or a drug or an operation, they struggle

A twelfth senior leader said "It will require change in the way doctors behave and the way they interact with patients for it to work across the board. I could see some consultants adopting it pretty readily and maybe there are some consultants who are halfway there or even there already, others being very slow to adopt.

Also, the way you described in implies it will work best in common conditions where consultants are used to practising it, know what it is. It'll be a bit harder for the rare or unusual conditions or where the doctor is just picking up their expertise. So, it's something to work towards in those situations, but it'll **work best in the high volume common conditions**. I would guess from my interactions with doctors on the patch that there are some of them doing some of these elements, but most doctors aren't doing many of them. And in fact it's a fundamentally different approach for most doctors. The framework definitely has merit, we understand, we've read the literature

about if you involve patients more in making decisions, they make different decisions, and if you ask a patient what the outcomes are for them, they're different to what the clinician is measuring. So we do know that there is huge scope for this approach, Some consultations are quite quick aren't they, and one issue you talk about here is not just one or two sessions or even more, but some quite detailed conversations, are not playing to a clinicians skill in many ways.

if the culture changed around so that the patients were used to expressing what they wanted. It could actually be transformative, and far more efficient.

One clinician said “the **medical profession are not prepared for patients having self management skills**. Co-ordinators have to go out to GP surgeries to get them to send patients. As if clinicians don't want to know that there is education programme for patients. GPs don't want to know. It's as if clinicians don't want to engage with patient self management support.

Another clinician with a **nursing background said about cocreating health training “we learned loads. This hadn't been part of our bread and butter. It is totally new to us and fairly revolutionary**. We are now balancing management of medical risks with the patient setting the agenda. We do still slip back into problem solving but we try to let patients take charge. Our current approach is very medicalised and we tend to concentrate on things we're concerned about as professionals, as there is risk involved. Using a **cocreating health approach has taken a lot of practice. It is not comfortable and we need support from each other**. Previously, we were not focussed on patient goals, but on management of risk factors. We are now focussed on achieving the patient's goals. Every patient has the opportunity to set their own goals. These can focus on risk factor management or quality of life, it's up to them.

Initially we were trying to do both work with the patient's agenda and using the medical model but we found this wasn't practical and was too much for patients. By working with the patient's agenda, this often brings up medical symptoms. We do need to be safe and realistic. **If the patient's agenda is very different, certain things need to wait. We have found out what is possible and we give ourselves permission to leave out things that we previously felt were important**.

A third clinician, a practising GP said “Secondary care clinicians in particular need to understand co-production and to interact with the whole patient rather than seeing an isolated, impersonal condition”.

A fourth clinician said that “there is **fear aversion in NHS and they feel they are not allowed to practise in a non-medical way** That is, they move away from the patient agenda to avoid criticism of not being thorough enough. The structures within the NHS in Wales can stop coproduction due to role definition and the dominance of the medical model”.

A fifth clinician said “I think you might have resistance from medics, doctors I suppose.

A seventh clinician said “**what we learned to do in medical school is a hell of a lot easier than managing patients. The patients come to us for the alleviation of suffering and we want to treat their diseases and they’re not the same thing.** And unfortunately treating diseases doesn’t alleviate a great deal of suffering. And lots of suffering isn’t about disease, and that mismatch is the crux of most unhappiness from doctors and patients

The role of the doctor is to alleviate suffering. My peers all practice in a different way to me. They have great strengths and they’re much better than me at operating, and much better than me at social organising and much better than me at uro-gynae, loads of things, **it takes all kinds to make a team.** I think they’re glad somebody practises in the way I do.

A ninth clinician said “I think whatever profession you’re from, maybe people who’ve got more experience of working with people with chronic conditions. They’re in a good place to think about self management, more so than people who’ve worked more acutely on the wards. I think OTs tend to think along those lines anyway, physios as well to a certain extent, and psychologists. I work with fantastic colleagues, but some of the nurses also deal with people who’ve got acute pain so they have to change roles quite quickly when they deliver the chronic pain programme, it really is a different approach for them.

A second senior leader said “Clinicians have said that patients want decisions to be made for them. But the evidence is that patients want to be engaged. The biggest barrier to people understanding and implementing the cocreating health framework is people feeling that ‘we do this already’. But when they go through the skills training they realise they don’t practice in a cocreating health way”.

A fifth senior leader with a medical background said “in private practice, there is the discussion of options , consistency of clinician, enough time spent in the consultation and a substantial proportion of patients choose not to have the operation that would have been beneficial to the surgeon. So there’s something about the NHS system with limited amount of time for discussion, limited ways of discussion which forces a particular type of practice.

Doctors’ practise is hugely variable. It will vary from individual to individual and specialty to specialty, and different in primary care to secondary care. I imagine GP’s would say they do it all the time. But I know they don’t

A sixth senior leader with a medical background said “We **need to somehow to get across the message that somehow this is different to what we already do**

A third clinician said “at university and in initial training, there was definitely a lot of terms of holistic care and person-centred care, but obviously there’s huge amounts of clinical work that you do and outcome measures, and time frames and expectations, so sometimes as you go into the clinical world then sometimes those things you’ve learned can sometimes be overtaken by those pressures.

1.4.2 Clinician Permission

To work in a cocreating health way, clinicians will need permission granting, from their employer, doctors, professional bodies to practise differently

One senior leader said “Physiotherapists need permission not to get it right first time”,

A second senior leader said “More junior staff will need to feel they have permission to talk to patients about changing their behaviours. Clinicians need permission to be able to suggest that patients go away, understand some of the issues before coming back to discuss the options We will need to give patients permission also”.

A clinician said “clinicians need permission to encourage other colleagues to use coproduction approaches. Even just keeping a record of the conversation with the patient is helpful in being less prescriptive and represents permission granting. **The value of the cocreating health training is in giving clinicians permission to practise in a cocreating health way**”.

A clinician with a therapy background said “What I found out of the training was, it wasn’t a massive change in my practice, it was almost permission to encourage others to do the same thing. That tool, that piece of paper, represents almost that permission granting.

1.4.3 Clinician Profession

In the way services are currently organised there is symbolic interactionism in that patients respond differently to doctors, nurses, therapists as they perceive their role differently. Therapists and to a lesser clinical nurse practitioners are more likely to change their practise to work in a cocreating health way. But other professionals will find it difficult to engage patients in cocreating health without support from doctors, who are seen as the person in charge by patients and other professions. Cocreating health needs long appointments which patients have with clinical nurse specialists and therapists, but not currently with doctors.

The majority of interviewees agreed with a policy lead who said “Different professionals will engage differently”.

A policy lead said “I think you’re going to get different professionals, different interactions at different points in this.

A clinician with a therapy background said **“patients respond differently to a physio than to a nurse who wants them to carry out an activity because they see nurses as carers more. Carers who will do to them, whereas therapy staff are more there to get them to do things for themselves. It’s absolutely classic where the nurses are unable to motivate the patient to walk. And I guess the patients also know that for the nurse it’s going to be quicker to take them on a steady stand to the toilet so they kind of know that if they say well I don’t feel good, the nurse will say well ok then lets take the steady. Whereas the physio, we don’t have that sort of.. no, we’re here to get you to perform.**

A second clinician with a therapy background said **“the groups that would take well to the framework will tend to be the nursing groups, the occupational therapy groups, the physiotherapy groups, the therapy type groups. I think they are the people who are more hands on at the coal face. I think the groups that would take less well would be the medical groups. They make the decisions, they do things, they do the operation or make the operational management decision and everybody underneath them sort of processes what they want. Patients see the consultants as the person in charge. And they do have that expectation, and it’s very difficult to change that unless the drive comes from the consultants.**

A third clinician with a therapy background said **“some of the nurses also deal with people who’ve got acute pain so they have to change roles quite quickly when they deliver the chronic pain programme, it really is a different approach for them.**

1.4.3.1 Doctors

Without training, clinicians may not have the skills or attitudes for cocreating health. Doctors are trained in a paternalistic way of working, and work within a paternalistic culture. It is difficult for doctors to put themselves in the place of someone without medical training since as they have expert knowledge, they believe they know best what is in the patients’ interest. There can be lack of equality in MDT working with doctors expertise and opinion and way of working valued more highly than nurses or therapists. Doctors need to see themselves as ‘a good doctor’ and are concerned that if they do not intervene medically to prevent illness they may face criticism from their

peers. Doctors are not all the same. Different specialties, for example physician, surgeon, radiologist have different skills in interacting with patients and some such as pathologists may never do so. Since they have a long term relationship with patients, GPs may be more likely to want to work in cocreating health way than surgeons. GPs may need to be given money to change to a cocreating health way of working. It is of prime importance that doctors grant permission for cocreating health, and do not actively oppose it. When under pressure from patients or time, doctors tend to prescribe or refer for tests or agree an intervention. It is said that 'nothing ends a consultation like a prescription-discussion takes longer'. In secondary care, it is very important that consultants are supportive of cocreating health as they have the power to prevent other clinicians working in this way.

A senior leader said **“Doctors need training and support to develop new skills and competencies. It is often assumed that doctors have the skills for cocreating health, but they don’t.”**

We shouldn't underestimate the requirement for doctors to develop these skills. There is a culture of paternalism within the medical profession. Formal Health services have taken aspects of self care into it. There is a reluctance to let go from patients and clinicians. It is difficult for older doctors trained in a paternalistic role to adopt a different way of working. Patients say 'what would you do doctor'? It is tempting in the limited time available within the consultation to maintain the current medical model.

A policy lead with a nursing background said **“particularly with medics, the position is that they know best, they have the scientific knowledge**

A third senior leader said “Doctors don't really listen to what patients tell them”.

A fourth senior leader, with a background in therapy said “I think the **challenge will be with the same professional groups as always. Doctors.**

There's certainly the question around **questioning their judgement, questioning their professional competence.**

A fifth senior leader working on the expert patient programme said “Over the years it’s been quite plain that **doctors feel they manage the patients and they don’t want interference in the way the patients feel about their condition.**

A senior leader with a therapy background said “Medical staff in England are more used to working in a more equal status of multi-disciplinary working. Whereas my observation in Wales is that it’s a much stronger medical model.

A senior leader with a medical background said “People always go on about the medico-legal aspect but there is also concern that peer review will say ‘you’ve done the wrong thing’. And it might be seen as being indefensible. If you have a large person and they have a stroke and what you did was tell them to put slightly less salt on their chips’. Well ‘Doctor, you know, that’s not much of a treatment. Call yourself a doctor’ ? But I do think people do say to patients ‘as part of reducing blood pressure you do need to eat less salt, lose some weight and smoke less’. But that doesn’t mean that they don’t not then give a prescription because that’s the bit they can directly influence.

They talk about all doctors as if they were the same, in the same way we treat all managers as if they were the same.

A neurologist would be someone who takes huge professional pleasure out of being very skilled in reaching a diagnosis and very often has very little to add, other than a very long name in Latin and they will be incredibly clever at saying its exactly that bit of neural pathway, or that bit of the brain that’s the problem but there’s no treatment, so there you go. So they’re motivated by the analytical detective bit, preferably using as few tests as possible, apart from their own hands and they’ll do the scan that confirms they were right. And so doctors are very different. A physician is someone who would reach a diagnosis, possibly having ordered quite a lot of tests that would either confirm or deny and then they’d do some more tests and then they would provide some treatment and see how you were getting on and then they might adjust the treatment .

And so, clearly, people are attracted to different types of practice,

so the challenge is that in medicine the training is pushing people into making a career choice, quite a fundamental career choice much earlier so almost at medical school you need to have decided whether you're going to be a surgeon, a physician or a gp whereas when I was training you might have thought well ive got plenty of time to choose what I want to do.

A senior leader with a nursing background said "Primary care when there was funding available did quite a lot in phase one of the shared decision making programme. They did statin prescribing, antibiotics in general, and one or two developed other approaches, again it was quite often driven by..if not by the practice nurse.

We found that general practice was interested when there was a bit of funding available. But not when it wasn't.

Quite often the debate and discussion goes on with the clinical nurse specialist who goes on to look after that person in the long term. The risk of this is that the clinicians in particular saw it as the nurses' project. And it wasn't until the medical director paid them a visit, to stress how important it was to the organisation, that the surgeons really came on board. I mean they acquiesced, they were sort of letting it happen as opposed to actively making it happen.

One clinician said "**the medical profession is not prepared to engage with patients in this different discipline of cocreating health. It is as if clinicians don't want to know that there is education programme for patients.** GPs don't want to know about patient self management". Another clinician, a practising GP said "GPs are likely to be better at putting the cocreating health framework into practise this than secondary care

Co-production and the cocreating health framework will fit better with GPs than hospital doctors.

Surgeons may find coproduction very difficult.

A clinician with a therapy background said **“I think you might have resistance from medics, doctors I suppose, Psychiatrists, people like that. And GPs are probably more amenable because they have to be listeners don’t they. Whereas surgeons are probably the least sympathetic**

Another clinician with a medical background said **“the consultants are the powerful players. Nothing will change unless the consultants want it to change because at the end of the day they have got ultimate control over that patient’s care because the buck stops with them. Unless you can change their thought processes it doesn’t matter about the multi-disciplinary team. People, staff and patients, will often think of the consultant as a strong person, the consultant themselves will often think of themselves as a strong person**

1.4.3.2 Nurses

It is helpful for nurses to have a framework to support their working with patients. Nurses are currently trained to become expert practitioners and this may discourage them from wanting to work in a cocreating health way. Nurses are trained to care for people, to do things for them and in their current practise may not support people to do things for themselves. Nurses are very busy in their daily work and may say that its quicker to do things for people but realisation that they’re not there for the rest of patient’s life may lead them to think of practising in a cocreating health way. Clinical nurse specialists and district nurses may find it easiest to co create health. Clinical nurse specialists can be competitive about number of people they are saving, rather than the number they have supported to manage own condition. Cocreating health would move CNS thinking from ‘I’ve got control over the patient’s condition ‘ to ‘the patient now has control over their own condition’. Nurses ‘do’ for people, therapists teach people how to do it for themselves. Nurses may see role just to get people out of hospital and to co create health will need to think about how they can better teach people to look after themselves.

Most nurses will need some kind of framework that steers them through the process. Nursing is still very much wedded to the notion of the expert practitioner.

Most young people come into nursing with the traditional notion that they're there to heal people or at least to care for them and caring for means doing for, normally. Its quite maternal, rather than paternal.

One of the first ever modern definitions of nursing, which dates back to the nineteen fifties is along the lines of 'the role of a nurse is to do for people when they can't do for themselves, but to encourage and facilitate them to look after themselves, when they can. So it's a kind of recovery model. Someone comes into hospital, first they need doing for, but then gradually, as they get better, the role of the nurse shifts and becomes a facilitator, helping them to identify their own problems and eventually discharge home.

A senior leader said "Clinical Nurse Specialists take patients through option grids and shared decision making. They evaluate people's knowledge before and after they have made their choices. Clinical Nurse Specialists were fundamental to the success of shared decision making as they do a lot of the patient discussions around choices. Clinical Nurse Specialists were able to move people from being uncertain about which option to take. In patients with major Head and Neck cancer, after diagnosis, their decision making was supported by a nurse. There is a perception that surgeons are more 'gung ho' and interested in the technical and clinical outcomes of surgery and not so interested in issues affecting patients' quality of life. On the other hand, Clinical Nurse Specialists look after patients in the long term, and organise the processes of treatment and care.

A second senior leader said "Nurses are more likely to use the cocreating health framework as they are with the patient more.

Another senior leader with a nursing background said "I'm in my mid forties, but nurses certainly of my generation, and I suspect slightly younger generation, when we entered into our nurse training as such, there was quite a high value placed on being busy, and caring for, and you still hear the language 'caring for' people. So really quite paternalistic. And I think that was sort of indoctrinated in us,. There are also **some incentives to 'doing for' so in caseloads, in specialist nurses, there is a struggle**

they have professionally, specialist nurses will say well I have my caseload is 120, and the next one will say well mine is 452! There's almost this competition about the wrong type of currency. So there is quite a seismic shift between an 'I'm doing, and I'm saving all of these people' which has actually been the philosophy, to more of a, almost like a life coach type of approach. And how do we tilt success to being 'well, Carol's mum now has got control over this', whereas previously the healthcare professional had control over this. So how do we get some sort of new currency by which practitioners can use that as a value for their own efforts? And of course people are very caring, and hopefully we have got people who want to make a difference, but make a difference by doing more and more and more. So actually it is fundamentally challenging to people to do less, but to get bigger impact I think, and having those challenging conversations. We're having to teach, often for the first time, a different value base where your success is reliant on how much they can do for themselves, not how much you can give.

A senior leader with a therapy background said "its getting that skill is that we have to help patients, we have to make them help themselves. Nurses feel very challenged by it, because they want to help. They want to do things, sometimes they will say 'oh but Mel, it's really quicker if I do it for them' than waiting for them to do it themselves, and then I take them back to say OK you're only with them for half an hour, what are they going to do with the rest of their half hours in their lifetime until you see them again in 6 months time. It's changing the way they think, and it's radically changed the way they think,.

A clinician with a medical background said "Nurses are far more likely to practice like me, generally far more holistic, unless they're pushed off their feet, midwives are tremendously holistic practitioners, they are professionals,

A clinician with a nursing background said "when I do meet patients I'm quite tentative in my approach because, remembering that I've been taught that my role is as a

training nurse. I'm a training nurse, that's all I have to do is to get that person onto dialysis. So, that's my role. It's engrained into me as a renal nurse. I've got to get this patient dialysing. That keeps the patient out of hospital. I certainly wasn't trained to work with the patients agenda. The role I was trained for at university and subsequently was to be a clinical expert who took charge.

1.4.3.3 Therapists

Many therapists are already practising a number of elements of the cocreating health framework and have that mindset. But some therapy professions such as physiotherapy and podiatry work in a way similar to medical model. Reflective learning and quality improvement are currently missing in the practise of many therapists as they don't have time to do this. Physiotherapists are not very reflective and tend to treat and then move on. Occupational therapists are trained in the biopsychosocial model but are constrained in their daily practise by the medical model. NHS structures can prevent therapists working in cocreation due to role definition and the medical model. Patients respond differently to different clinicians. Patients can seek to please doctors, by not asking them about the results of tests, but do ask therapists to explain these as nurses say they can't. Patients will complete activities with therapists that they refuse when asked to do so by nurses. The cocreating health framework will be easier to implement with mental health patients as they need to engage or they won't get better and in mental health services there is less pressure to work at the pace of the system rather than at the patient's pace.

One policy lead said "Some of therapies are fertile ground for coproduction as they are already closer to this way of thinking". A second policy lead said "The cocreating health framework is part of what OTs do already. There are differences in the way that the therapy professions practise for example OT and Arts might use a cocreating health model whereas physios and podiatrists generally use a medical model of Assess, Diagnose, Treat and Discharge, whilst OT's take a more holistic view. Speech and Language Therapists and physios have already started to change their model to give patients exercises to do at home". A third policy lead said "The people who understand the coproduction approach will be therapy professions, Health Visitors and

District Nurses – people who go into homes, talk to individuals about what they want for themselves”.

A policy lead with a therapy background said “The difference between podiatry and perhaps things like OT and things like arts therapy I suppose is that physio and podiatry work along the lines of more like of a medical model. A patient comes in and you diagnose and treat, hopefully cure and off they go. Occupational therapy and arts therapy are much more along the lines of a social model of care, which is taking a more holistic view. There are certain professions that I think are already doing this, certain professions that really need to perhaps embrace it a bit more. **The latter part, I thought, where you’re talking about reflective learning, quality improvement I think probably that is the bit that’s missing currently, because a lot of the time there’s not time to do it. If you look at the models of most of the services, actually OT probably not so much, there is a time slot to do it in, so to be able to fit this into a time slot as services are currently delivered I think would probably be quite difficult.**

A third senior leader said “**OT’s don’t practise the medical model, but we are constrained by it. OT’s use the biopsychosocial model. Physios work to a medical model, they tend to look at symptoms, for example outpatient physios**”.

Another senior leader with a therapy background said “Physios don’t reflect very well. it’s very much problem solved, done and dusted we move on. Sometimes people will say well, I’ve seen 12 patients today, and I’ll say yes, so what, so what if you hadn’t seen those patients today, what difference would it make?

A clinician said “OTs are very holistic and patient centred, not tick box. The OT model is to set the borders of what would be considered, guide the patient’s questions, start broad and funnel down. **NHS Structures can stop coproduction due to role definition and the medical model.**”

A clinician with a therapy background said “**I would talk through scans because doctors will often say to patients your scan showed you had a such and such stroke. The patient may not say to the doctor what does that mean, but they would say to us what does that mean and it would put us in a position where**

we're talking about those things. Oh, the mismatch in what patients say to doctors and what they say to everybody else is huge. Pain relief is my big bug bear because the doctor comes along and says how are you – 'oh, I'm fine' and then are you in any pain, no - because they're just sitting in a chair and they come into physio and we ask them to do things, and they are in pain. The doctor on our ward, dr tyreal is lovely and is very charming with patients and very caring, and they want to reciprocate that, they want to get better for him, so they will say things to the nursing staff and us – oh I don't feel very well and then how are you, oh fine, so I think it's not that they don't want to trouble them but they do respond to doctors very differently. And they respond to us very differently than they respond to the nursing staff, for example if I go to a patient and say right, we're going to walk now with your frame, they go and off they go, the nurses say that to them and they say oh no I can't. so I think it's not just doctors, I think every healthcare profession gets a different response. They know who the physios are, who the nurses are.

A fourth clinician with a therapy background said "You can't rush with mental health patients you have to have the time element. I think it's easier to implement in mental health. It would be easier to implement in the sense that you've got time. You can't rush the patient, you have to do in it their time and pace not your pace. Whereas I think in physical, the pressures outside make you do it at your pace, rather than the patients pace. It's got to be that way to a point, because we've got to have the turnover,

A fifth clinician with a therapy background said "I think there'll always be a slightly different approach anyway because we think of things differently because we're in different professions. I think sometimes OTs have a naturally – well, from the training, they think about client-centred approaches anyway, other professionals do to a certain extent.

A sixth clinician with a therapy background said "I think OTs have always said that we're very holistic, and when you look at holism, there are some professions who believe as long as you have a piece of paper with all of the boxes of all the different areas of life, and as long as you ask all of them then that's holistic. But an OTs view

of holistic is to ask for the person's priority, it's about meaning. So if someone identifies something themselves, and says this is what's bothering me, then that's their core concern, even if it may not be what would be bothering us as professionals. And then it's about negotiating that therapeutic contract is how you move forward.

1.5 Peer Expectations

Currently, needs assessment is predicated on what the system provides rather than what the patient may need. Peer expectations can be a barrier to cocreating health since the peer expectations of clinicians can be of expert, paternalistic practise. Nurses have peer expectation of caring, working as an expert practitioner. Doctors have a peer expectation of achieving a good result for the patient, being a good doctor, leading the team. There is also a Medico legal expectation that another practitioner seeing the same patient would have practised in a similar way. Peer expectations are set by the professional body, regulator, and employer. There can be a peer expectation to reduce variation, each patient having the same outcome, with the more patients treated in the same way, the greater the certainty of achieving a particular outcome. There are peer expectations of reaching 'moral' decisions that may not be those that the patient would choose.

A second policy lead said **“when professionals and health bodies and social care organisations do needs assessment it's predicated on the services they provide. Not perhaps what the patient requires.**

A third senior leader said **“there will be huge barriers, some of them we can identify, some of them must be really subtle, because otherwise we'd be further forward in this, it shouldn't take so much effort. But I think the barriers would be part professional, how to change that culture, there's also how to change the way that patients, the population view healthcare.**

I think **nursing is still very much wedded to the notion of the expert practitioner. As described back in the '80's by Patricia Bannerman.**

A policy lead with a medical background said **“if practice is challenged the powers of defence are would others have done the same in the same situation. And if in Wales we operate a certain style of consultation, a certain healthcare system and a certain set of values, and everybody understands that, actually I think that that then protects individuals.** I think if an individual were unilaterally to employ some of the prudent medicine or co-production methodology to describe and therefore in a sense offer less to people than their peers, there may be an element of risk which is why it's important we all move as a body. I think there are risks. Because I think people will refer someone to the GMC if they feel they've not been offered every possible option but I don't think the GMC would be interested in that.

And in England they've got an intrinsically anti co-production philosophy. Which is consumerism. So **England is locked into consumerism. So England passively accept and almost grow patient expectation.** The danger is having a different practice in Wales from England with the same regulator.

Cardiac surgeons believe they have to do a certain number of operations every year. These operations take a particular amount of time. So there is essentially a number of hours of operating they have to do a year to maintain their competence in their professional view. So if you start saying to them ‘we want you to spend less time operating and more time talking to people, they'll start saying ‘well that's no good because I only do fifty of these operations a year now, I wont be competent’

A policy lead with a nursing background said **“there's a legal aspect, but there's also a moral aspect. Some medics would say ‘that isn't my job. My job's to preserve life not to end life. And they might even say that ‘withdrawing treatment isn't my job. My job is to preserve life as far as possible’.** This is about role, it's about ethics, and if your ethics conflict with the role you're expected to do then you have to adjust your role, or get out. From a nursing perspective the ethical framework is quite vague, and we teach ethics but it's normally from the ontological perspective. Which is to say it's about duties, you know, the rules and of course, they're open to interpretation. That's the whole thing about

teaching ethics, you're not teaching a whole set of absolute rules that must be followed, you're trying to teach practitioners to come to these things themselves and to encourage them to make ethical decisions. If you're doing that, then you have to respect those ethical decisions.

1.6 Policy Expectations of Clinicians

Clinicians may need an incentive to shift to a cocreating health approach. Commissioning can be used to support change in practise. Cocreating health is consistent with the prudent healthcare agenda in Wales but not with consumerist health policies in England. There is a need to codesign policies and services with patients to ensure the right support is being offered. There is a need to align government policy, performance management of providers and training to implement cocreating health. There is a need to ensure that Government is consistently supporting cocreating health by setting out citizen responsibilities for their own health in addition to supporting their rights within health services. Widespread implementation of cocreating health will need consistent policy direction despite elections, changes of minister

One policy lead addressed the issues of motivation in implementing the framework “In the Welsh system there is the question of what motivates clinicians to do anything? In England and the US there are drivers from economic stimulation but we don't have this in Wales. We need to ask ‘what is the incentive to shift?’, ‘why would clinicians want to engage in coproduction?’ We need to tell people how to do it through the cocreating health framework but we need the correct environment for people to implement coproduction”.

A second policy lead said “So when I first read this I thought, ok this resonates with prudent healthcare and just so that you're aware the next stage of prudent healthcare is to establish some sort of principles. Some of which are not a million miles away from this, in a sense that it is a negotiated order in a sense, between provider and we call

them the consumer. The respective role of the professional and the respective role of the patient and where they fit within this co-creation framework.

A second policy lead for coproduction said “One lever is performance management and whether this is supported by managers. All need to be aligned for coproduction to work. We could redesign the NHS in Wales around a co-production approach. We need to consider how the cocreating health framework would fit in with this work. He went on to say “implementing coproduction will be a huge challenge. It means developing a completely different system on a huge scale. A 10 year timescale means at least 2 elections, with turnover of Ministers and civil servants”.

1.7 Requirements of Regulatory Frameworks

Professional regulators will not have an issue if a patient chooses a particular option that a clinician doesn't think is best for them but there is a need to record cocreating health decisions and rationale in patient records. If a patient doesn't want to take responsibility for managing their own condition, then the clinician needs to retain this responsibility. In some clinical situations there is a legal responsibility to complete certain objectives, which clinicians need to complete these to protect themselves.

A second senior leader said “The cocreating health framework will need to link with HCPC requirements. It will be important to document appropriately, to describe what a clinician is trying to do and this needs to be linked to outcomes that are clear and measurable. I don't see a problem in terms of professional regulation. We are guided by ‘Do no harm’. We are there for the patient. As long as they fully understand and we clearly document the discussion, that this is patient choice, then the patient is free to ignore our advice. Patients must decide. If we see a patient who wishes to choose a behaviour that is harmful to them, we still have a duty of care to guide them. The HCPC will be with us as long as we have fully advised the patient. This requires that we are clear, have good documentation that if a patient chooses certain behaviours these might be harmful.

A seventh senior leader with a therapy background said “As healthcare professionals we have those strict codes of documentation and I can imagine in many nursing circles

and maybe in therapies as well, how difficult it can be to find a consistent way of documenting that this is the approach we'll be taking. With the HCPC If you've documented things and you are clear then there are no problems.

An eighth senior leader with a nursing background said "I think it comes back to ensuring the patients are fully aware of the options, choices and risks. You then get into how do you document that, and that's another issue to a certain extent. And the beauty of the option grid to a certain extent was that you could annotate it, and if it was duplicate you can keep a copy. You're helping people to make a choice, documenting that in the notes is part of it. But if you've got a copy of the actual option grid you've annotated it with the discussion you've had and if it was duplicate you could keep a copy.

A clinician with a medical background said "**the tension would be if the patient doesn't want to take responsibility and then I think as a doctor you can't really hand over something the patients not prepared to do,**

A clinician with a nursing background said "**my work is target driven. I have to achieve that all the objectives are met. I have to make sure these are signed off for legal reasons, to protect the patient and myself. I have to follow the documentation. They have to meet those objectives for us, for safety reasons.**

1.8 Context

There are some situations when applying the full cocreating health framework may not be appropriate, such as when patients need acute care to save their life. In this context, however, clinician's practise would still be informed by review of individual outcome, audit, quality improvement. It will be important for clinicians to decide themselves which part of the framework to use in a particular context. The sicker people are, the more likely is that they will have things done to them, but clinicians can also work in cocreating health with families or carers of patient acting as advocates. Cocreating health is consistent with people supported to manage their own health at home, rather than being admitted to hospital. This needs secondary care providing

better support to GP's, and GPs working in a cocreating health way with patient to prevent exacerbation. Patients may be more able to co create health when they are more obviously in charge when in their own homes, rather than in clinician 'consulting' room. There may be difficulty in cocreating health in an inpatient setting. Clinicians engaged in cocreating health will need to ensure that patients have the appropriate understanding to be able to manage their own condition. This is difficult to achieve in inpatient setting, but can be done prior to elective interventions. Cocreating health is a challenge in MDT working unless all clinicians in the team are signed up to cocreating health approach and can see the chosen action plan in the patient's record. Cocreating health will need a seamless patient record that primary, community, secondary, social care and the patient has access to. Currently, it can be difficult to maintain a record that all clinicians can see, unless working in hospital. Currently clinicians have more conversations about behavioural choices in primary care than in secondary care. In the context of a system, both primary care, emergency care and inpatient care that is pushed to its limits from demand pressures from people with chronic conditions, it's going to be difficult to implement cocreating health that needs buy in and some additional time at least for a while. When seeing people in outpatients clinicians understand that they have the level of motivation, cognition and support to get them to the appointment, but this is different in inpatient settings. To implement the cocreating health framework there is a need to ensure that primary care, and other clinicians than doctors have access to diagnostic tests, specialist opinion etc so they can fully describe the patient's condition rather than send into secondary care. Decision support tools are helpful where there are limited range of presentations and options but not where this is more complex and there are unknowns. Cocreating health requires continuity of clinician, otherwise the interaction will cycle around the elements of the framework. The same health condition can have a different effect on different individuals, dependent on the context of their life. People can change their health status day to day, this is not a fixed condition, and changed circumstances will need a different discussion. Currently, people often don't know why their GP has referred them into secondary care. Cocreating health depends on clinicians establishing a long term relationship with patient, and the framework is less helpful if the patient interacts once with the clinician and is then discharged. Cocreating health will work well in paediatrics where clinicians have long term relationships with child and parents. The cocreating health framework will work better with GPs than secondary care clinicians

but GPs have 1500 people they are caring for, so will take some time to implement. If people are feeling very ill then they may not have the ability to enter into a discussion on self-managing their condition, in this situation they just want the clinician to take charge. If a patient can't speak or doesn't have mental capacity, or is a child then cocreating health may require family or carers to act as advocate. In acute care, patients may be in shock over a traumatic in their health and find it difficult to accept the new reality of the situation. Family members may want to care for their relative or see them being cared for, and may be uncomfortable with clinicians trying to get them to do things for themselves. Cocreating health is applicable to interacting with patients with cancer where clinicians focus on quality of patient's life.

A policy lead with a nursing background said "If it's not life threatening you know like that bleeding to death example. Smaller things, I don't think the time for reflection is necessarily available to you because if it's minor then you've just got to get on with it. It's something about **the magnitude of the intervention and the immediacy of your health status will be factors that will play into whether or not there is any breathing space to allow the person to reflect on the decision making. There is much more sense of control outside of the hospital and outside the consulting room. It's like 'whose patch are you on?'. If you're in the person's home, it's their patch so they're in the driving seat. If you come to see the doctor in his or her consulting room it's their patch so having a framework that actually allows you to frame the conversations when you're not in the patients home, because that is the most obvious place where they're in charge, they've invited you into their home. I don't think it would fit an emergency situation well without modification. It is more of a cold conversation, or more of an ongoing conversation. I didn't see assessments around patients' capacity or willingness to engage. So the preparation bit should perhaps also include whether this step in the process is appropriate, because the context may not be right, the person's abilities may not be right.**

The model you're trying to describe here is more about specific interventions and treatments. **I don't think that actually applies to the daily living support that a nurse would give as a package of care. I don't think it would work in an in-patient**

setting. You'd be having so many of these, how meaningful would it be, you wouldn't say I want you to think about the blanket bath and I'll come back in a bit when you've thought about what your role is in the blanket bath. It doesn't fit. I think would it would suit more for a treatment or an intervention. Rather than supporting daily activities which is the bread and butter of nursing.

A senior leader with a nursing background said "I've got questions in my head about which are the settings, and which are the types of patients where this level of interaction and this type of framework might best be most beneficial, because in my head I'm thinking when you're really quite unwell, are people more likely to say well over to you nurse, doctor, physio whatever, do what you've got to do, and is it when somebody's in a state of reasonable stability, when the environment is more right to have those partner conversations. That's not to say you know, the example you gave about somebody bleeding in the A&E department and life may be in the balance, that's a completely different set of circumstances to somebody who's trying to manage perhaps a number of lifestyle issues, their diabetes, their obesity, or whatever, sleep apnoea all those other things that are then happening.

I assume there is a more natural patient fitting environment where this is more successful. I suspect that the people, the nurses who might be better at this may be people working in the mental health field, I'd like to think. People working in the field of learning disabilities, and those working in rehabilitation whose aim should be about helping people to restore themselves after something has happened to them. Or recognising a disability and focusing on ability rather than disability.

A senior leader with a medical background said "GPs might be quite good at spotting patients who might be likely to benefit from a hip operation because of radiological and other measures and these are the patients they're sending to secondary care and they're not sending in the ones who wouldn't benefit. And therefore, the orthopod is just seeing patients after patient who would benefit from the operation, who fit the criteria for joint replacement. I think in primary care, they have conversations

about health behavioural choices relatively often. But ultimately they think they can best treat the patient with a tablet. They might say to a patient 'you should eat less salt' and the patient says 'but I like salt', and then they say-well, here's a blood pressure tablet, because otherwise they aren't fixing the blood pressure. You need some tests and some specialist stuff that I'm not allowed to organise or I can't, or it's outside my knowledge, so I'm sending you to a specialist.

A senior leader with a nursing background said "If you take secondary care, where someone's been taken from primary care quite often people are not entirely sure of why they're there. Head and neck surgery didn't really take as well, primarily because most of the options grids that were developed were found to be less.. I suppose they found the variety of presentations so great that whilst the principles of involving people in the decision making were sound, the actual delivery of it became more problematic, whereas in paediatric tonsillectomy it often did come down to 'you've been referred in from primary care, these are the options, you can have the tonsils removed or not,

I think if you're looking more at agreeing a plan, the next steps, reviewing and following up, it probably would work better where there is some continuity of clinician or continuity of record keeping in an appropriate way. If we're in this for the long game then a lot of our systems don't seem to be set up to facilitate that. In terms of seeing the same person, getting the same message, going back around the loop if you like. So a lot relies on that initial setting the course, doesn't it? And then it relies on follow up and review. I guess one of the challenges is even if you achieve the first part, how would you sustain that particularly across primary and secondary care. Especially within secondary care, if people are attending outpatients, I suppose it could and should be easier in primary care although again, a lot of people see the same GP time after time.

A senior leader with a therapy background said "Primary care are going to be vital in this. And longer term it's like everything, they've got the long-term relationship with the patient, while from a secondary care background - it's very

important when they're with us, but they'll probably see their GP five times for every time they come to a secondary care centre

A second senior leader with a therapy background said "I think also maybe for us is the **challenge of it's easier to implement this in an outpatient setting than it is in an inpatient setting but you're still talking with people about behavioural change very often in their treatment plan and they've got to own their treatment plans. The care plan, the treatment plan, that can be an imposed plan rather than a negotiating one. I suppose the sicker a patient is the more likely we are to do things to them.**

A senior leader engaged in the EPP said "context and relativity are important. In the sense of, when people have a condition that condition exists in the context of their life. So a basic condition will have a different impact depending on the life that it is impacting, and this is very important as well with chronic conditions – they're variable, not fixed, so just because someone presents as depressed doesn't mean they are a depressed person. They may have a low day, whereas that's not the norm for them.

A third senior leader said "**when people are referred in from primary care they may not understand why they have been referred into secondary care, what their condition is or what they might get from the interaction.**

A fourth senior leader said "We are able to implement co-creating health in some areas but not others. For example we can't use a cocreating health approach in orthopaedics as we are only seeing these patients for a short time. But in cancer rehab we can use this approach more. We can also use the approach in managing patients with long term conditions and reablement staff are using an approach of 'how do you want to live your life, how can we get you back to doing what you want to do'. In mental health services, a cocreating health approach works well as the client needs to work with you and is a waste of time if the patient won't engage. The cocreating health approach doesn't work well on acute sites due to time pressures as there is a push to get patients through

the system. A cocreating health approach will work in paediatrics where we work with parent with child over a very long time. There are pockets of using a cocreating health approach such as in the perinatal service where they look after mums who have had babies or expectant mothers who have mental health problems. A cocreating health approach is also used in forensic psychiatry as people are there longer, giving clinicians a chance to build relationships with patients.

A clinician with a medical background said “The average GP has got 1250 – 1500 patients, so the idea of delivering that to the population, you see them probably six times a year so it’s more of a drop feed than a huge thing on day one.

A clinician with a nursing background said “**now all of us will meet the patients in the pre-assessment. But we do follow them up all the way through. Sometimes I can meet them at home, or in the hospital, before, during, after surgery and beyond in training. As far as possible we try to see our own patient all the way through, unless there is annual leave. And when this happens we try to make sure that a colleague will come in with us in the appointment so that they can take over when we’re on leave and they’ll know what’s happening. So the patient is handed over.**

A senior leader with a medical background said “I wonder if there is a **place for the framework in primary care, before you even get to the consultant. And it would be easier to address it in primary care because you’re cutting people off, and helping people to have those discussions before they even come into secondary care in many instances. So I think there’ll be a huge potential again it would work well for the common conditions, not so well for the rare. And there has to be.. People need sound clinical judgement, because what it does imply is that you know what’s wrong with the patient, and on lots of occasions it’s not that clear until well into a pathway. So where there is clarity, it would work well. and I think it would work as well in primary care as it would in secondary care.**

I do think the primary care end is really important. Not just keeping them on board but exploring how far they can.. They may be able to make these changes more quickly than hospital based services because they're in direct contact with their patients on a regular basis. Particularly the patients with chronic diseases will be consulting, will have a relationship, will be responsive,

A clinician with a therapy background said "Some of my patients are really not very well, you know, and they just want me to come in and wrap them up

A second clinician with a therapy background said "I find working in the community often you can get family involved, which tends to bring things more – obviously you're in their home so it's very centred around them. It is less passive than say on the ward where you turn up at the patient's bedside, you are there to do something for them. So I find it easier to motivate people to do things for themselves when they are in their own homes. There's certain areas where you can't help but adopt that, especially in certain areas like acute care. There are such high pressures for bed space and things, you do kind of have to, especially with physio, you have your ward list and it's just tick, tick, tick who have you seen, who can be discharged. Obviously in terms of communicating, I don't think I would ever lose the person-centred style there, but yes in terms of taking a bit more time with patients I think sometimes that's definitely lost particularly in the acute settings. .

A third clinician with a therapy background said "it might apply quite nicely to an outpatient or a clinic type context, but it's hard to see how it fits so neatly into what we have here. Many of our patients have severe communication issues and I'm just talking about this ward, because this is where I work. I'm sure the same issues apply on other wards where the patients are admitted and remain for more than a day or so. So we're not talking about planned surgery or anything, we're talking about complicated people. So quite often we're dealing with people who are at the worst point of their entire lives, and their families, and their families are often in a state of shock/bereavement, they're grieving for a relative who they have lost in the form that they knew them and were used to. And they're getting used to this new relative who is now severely disabled or who

has characteristics which they're unfamiliar with. Frameworks and patterns and policies and all of those sort of ideas where you map out what you think patients are going to do, don't take into account the variety and deviations we see every day with every patient.

It comes back to that idea of patients agenda doesn't quite fit so well in this context. If the patient is unable to speak for example then it's rather difficult to establish what their agenda is. Sometimes we're dealing with people who are extremely elderly and the agenda isn't just their agenda it's their family's agenda as well. So I think we do have to lead the conversations in the direction it's needed to go in. to a certain extent. People are often cognitively impaired they may say that every day, and you'll go through explaining to them the same thing every day.. That isn't going to happen because and you may be having that conversation with their relatives as well. Who are grieving, the relatives are grieving, the patient is cognitively impaired and you're having a two way conversation.

A clinician with a therapy background said "If I'm seeing outpatients, they are people that can get themselves to this department that have a level of cognition and a level of drive that brings them to the department. Even though they have different expectations, you can open the discussions and set the scene and you can use that work and treatment of co-creating health, you can engage and you can offer that service. Part of my work is on the trauma wards. That is with people who didn't plan to come in, who don't really want to be in, some of them harbour a deal of anger about what's happened to them and therefore even if they've got a good level of cognition they're not at a place where you can engage them very easily. And so that group of patients you can work with them, using all these techniques, however it takes a great deal of time to engage and set the scene and discuss, and explain that to them.

There's another group of patients who come in and they don't have any cognition and you do need to get them to a level of independence as fast as they can, but there's no way that you can use that co-creating health framework with them. That is not possible. You have to lead those people, rather than engage them

and have a partnership with them. And often you can utilise those techniques with carers or family. You can't utilise them directly with the patient.

If we're trying to do it for people that are already in the hospital. We're starting at the wrong point. We might find a few quick fixes, and we could change a few bits of our system, tweak a few of the processes. We might have a new outcome for a good proportion of the ology's, or a good proportion of the population, but we can't change it all if we think we're going to do it within the hospitals. It's got to go out into the community.

One clinician said "I think cancer professionals, and I think certainly the specialist nurses who I spend most of my time communicating with, I think the philosophy is very different, and quality of life is very high on the agenda. So I think within cancer care, this model is quite comfortable.

Another clinician with a therapy background said "In Outpatients you've got the luxury of a little bit more time with the patients. When you're on the wards it's a faster turnover. Most of my patients, because I do hand-splinting my appointments allow an hour, so I have the luxury of the time to do things like this. If you're in a fast service like the acute medicine or whatever, it's going to be more difficult because of the rate that you need to be doing things. You can't rush with mental health patients you have to have the time element. I think it's easier to implement in mental health. It would be easier to implement in the sense that you've got time. You can't rush the patient, you have to do in it their time and pace not your pace. Whereas I think in physical, the pressures outside make you do it at your pace, rather than the patients pace. It's got to be that way to a point, because we've got to have the turnover.

1.9 Management of Clinical Risk

The healthcare system is risk averse and cocreating health carries inherent risks. Cocreating health will need clinicians to be trained to discuss risk issues with patients. Option grids can be helpful in discussing risks with patients. Patients are currently not used to being told in detail about complications, or possibility of death or that an

operation may have a poor outcome. It is very difficult to get patients discharged from hospital due to risk averseness from clinicians with a high threshold to discharge. Systems can burden clinicians with weight of assessments of inpatients that will prevent cocreation. The cocreating health framework has very different expectations of nurses than they are used to. There is a lack of public debate on risk of medical treatments. Clinicians need to balance clinical risks against working with patient's agenda. Clinicians can feel that risks are being managed by filling out assessment forms, rather than working with patients on managing risks and achieving benefits. Some patients find involvement in managing risks to be difficult and want to delegate this to clinicians. Clinicians can feel that they risk being hung out to dry when things go wrong and will need the support of the system if working in cocreation.

One policy advisor said “There is **risk aversion in the Welsh healthcare system. There is a perceived need to cover all angles rather than only perform tests for red flags**”. A second policy lead said “there are no medico legal issues in implementing the cocreating health framework, but clinicians may have the perception of this being risky. If an individual clinician uses a co-production approach giving patients less direct support than their peers, this carries inherent risks. At one level, implementation of coproduction is a risky strategy as it is about individual interactions,

One senior leader said “Sometimes it is right to say there are options, some safer than others. We need to help doctors convey information about risk. We need to combine discussions about preference with ensuring that patients understand their risk and benefits where they don't have medical training.

A second senior leader said “In making decisions about Tonsillectomy it came down to the options of tonsil removal or not. Use of option grids raised the awareness of the small risk of death under General Anaesthetic

Another senior leader with a medical background said “I think it's also difficult to know, sometimes that is the right thing to do, sometimes it is right, to make is very clear there are options but that some are safer than others and to support doctors to know how to convey information about risk,

A senior leader with a nursing background said **“the co-creating health sets an entirely different expectation on nurses for example, where they might be concerned about managing risk, they might be concerned about professional regulatory issues that they haven’t done everything they’re supposed to do.** Let me give you some examples to illustrate exactly why I think that is so. Somebody comes into a hospital, they’ve been unwell, in our community, hospitals are there to try to get them ready to go home. Then we’ll make them do a stairs assessment, they must pass all these tests before they’re allowed home. And there is a very real case from where I worked previously, the nurses and physios were desperately trying to get this lady to walk up the stairs, cos she actually did live in a two storey house but it emerged after some time that actually the lady had been up and down the stairs on her bottom for sort of 15 years previously. But the nurse and physio felt that it would be an unsafe discharge if they were to let her go home. If a nurse or perhaps another professional, but if I speak for nursing if we’re not seen to have done everything and make this safe, then we will be failing

One clinician said **“Skills in risk assessment and risk analysis are in short supply. Clinicians don’t have time to include patients in clinical risk assessment and risk analysis. There is no proper public debate on the risk of medical treatment.”**

Another clinician with a nursing background said **“we need to balance medical risk and decision making with agenda setting. We had been medicalised and tended to concentrate on things that professionals might be concerned about, as there is risk involved. In the past,** we were not focussed on patient goals but on risk factor management. We do need to be safe and realistic. If the patient’s agenda is very different, we need to wait. We still address medical issues and risks”.

A third clinician said **“Some patients can manage risk, some don’t want to. Some patients can put up with uncertainty. The NHS is not great at managing risk and protecting those who manage risk when things go wrong. I am troubled that when systems fail sometimes doctors get hung out to dry. We need to ask the basis on which decisions were made on when something goes wrong. In co-production, we need to ask ‘How big a safety net do you want?’ We need to get the balance right”.**

A fourth clinician said **“there is risk aversion in NHS and we are not allowed to practise in a non-medical way. People move away from the patient’s agenda to avoid criticism of not being thorough enough. “**

A clinician with a therapy background said “the clinician would obviously want the patient to reduce any risk and do things like maybe alcohol intake if that’s too high, eat a healthy diet, take exercise. Some clinicians would probably feel under pressure to get those outcomes for maybe lots of patients they don’t always want to change. Maybe they know there are risks but maybe they don’t consider them in a serious way.

A second clinician with a therapy background said “it’s more to do with the risk aversion. Because you’ll find that people will move away from the patient agenda if they think that there’s going to be some kind of criticism for the fact that they’ve not been thorough enough. So you’ll find that you can teach junior therapists to set a patients agenda but you’ve then got other members of the MDT demanding that they be able to provide certain amounts of information that weren’t part of that agenda setting. Then you’ll find that they immediately default back to ‘well, what if I don’t know this, then I’ll get in trouble so I’ll just do what I do’.

2 System Factors

2.1 Pace-Complexity

Clinicians say that it is easier and quicker to tell people what to do, but this doesn’t necessarily lead to good outcomes. Short appointment times make it difficult to implement cocreating health, this needs an appointment of at least thirty minutes, but in primary care and secondary care, doctors have about 10 minutes. Engaging in meaningful conversations about health behavioural change takes at least an hour. An appointment to meaningfully review outcomes and decide on the way forward takes at least thirty minutes. The cocreating health framework suggests multiple interactions between patients and clinicians. A cocreating health interaction between clinicians and patients with multiple chronic conditions will take longer than current appointments. We could reduce time in face to face interaction by patient preparation before hand by

sending them option grids, questionnaires, information, asking them to think about how they want to live their lives. Because of the pressure in hospitals, secondary care clinicians prioritise their time to deal with the immediate care priorities. It will be easier for nurses and therapists to implement cocreating health as they have longer interactions with patients. Longer appointment times in private practice means that clinicians are implementing aspects of cocreating health in private practice that they can't in the NHS due to time, so the barrier to cocreating health may be more organisational than cultural. Another time pressure is that some clinicians, such as surgeons must do a certain number of operations each year to be considered competent, so they would have concerns if asked to spend more time interacting with patients and less time operating. If clinicians don't spend time interacting with people, they can just keep returning to see the clinician because their health issue is unresolved. Time is wasted in the current system with patients being referred from one specialist in secondary care to another, being cycled through clinics, not listened to, with the outcome they want not achieved. Clinicians may consider that time spent interacting with the patient is time wasted that could have been used in treating them. Clinicians may rely on patients thinking they have all the solutions, so want to spend only a short time with the clinician being given the answers. In the current system, when under time pressure, GP's refer more to secondary care and prescribe more, just to end the consultation. There is a challenge in getting clinicians to change their interactions with patients as they are currently highly overloaded. To resolve this will require space and time to implement the cocreating health framework and some work diverted away from them such as psychological therapies, walk in clinics to therapies and nurses. Clinicians who work in a cocreating health way found that although the initial appointment took longer, the patient subsequently returned to clinic less frequently, saving time in the long run. Working with the patient's agenda is a more efficient use of time. Initially, whilst learning how to co create health the interaction with patients takes longer, but as clinicians become more comfortable with it, this reduces. But when under time pressure they tend to revert to the medical model. There is less time available for cocreating health in inpatient settings than in outpatients. Systems can be currently constructed to give each patient a set number of sessions, rather than the number appropriate for their needs. There is a recognition that current systems don't use clinician time effectively, with much time wasted. If moving to different system then managers may need to plan for fewer patients being seen

initially, with longer term gains. This has to be understood and accepted by Health Economies for the implementation of cocreating health.

All interviewees suggested that the current amounts of time set aside for patient-clinician interaction would make implementation of the cocreating health framework challenging. All interviewees spoke of the current time limited consultations as a significant challenge in implementing the cocreating health framework. One policy lead said “Within the later parts of the framework, reflective learning and Quality Improvement aspects are missing currently in many professions practice as they don’t have the time to do it. Most professions find it difficult to fit everything into the time slot available the way services are currently delivered. Coaching is an interaction taking an hour or more. This is not going to be introduced in the NHS as it would be considered a luxury”

A second policy lead said “given pressures on the service and the system there are questions whether the cocreating health framework is a luxury. It describes multiple engagements between professional and consumer. There is a question about the feasibility of the cocreating health framework, especially in Primary Care where the consultation currently lasts 7-10 mins. I think the questions I’ve got are the feasibility of employing it especially within primary care. Where you’ve got your 7 minutes, 10 minutes if you’re lucky. And within the pressures and demands that the service faces.

. In patients with Co-morbidities, who require several appointments, the cocreating health framework may be a way forward. The NHS could explore **changing the appointment systems for patients with multiple chronic conditions**. In primary care they could dedicate sessions to facilitate more involved conversation with patients

A fourth policy lead with a medical background said “GP’s to use the framework they would need longer appointment for better communication. And probably less of them. So a longer appointment gives them a chance to share information, listen to the patient, in a sense engage in shared decision making. It’s also about time management. I’ve got x minutes to see you and I’ve got to get to the core of this quickly and therefore there’s an issue about someone has to manage the situation. You can’t

let it drift around. In its most extreme form that would be the old..... where the patient wasn't allowed a seat. Because you put vast numbers in, and you just had to come in, stand, and then it was easier to manoeuvre them out again.

A fifth policy lead with a nursing background said "I think, inevitably it will take longer to use this framework. Inevitably, you can't do this in ten minutes. I think if this model were implemented in a GP surgery, rather than a hospital setting, it wouldn't have to happen all at once, it could be a gradual process. In nursing, there may not be the opportunity to sit down and talk with the patient for half an hour and actually go through this, but it could be an ongoing thing that is addressed through the first few days of their admission

One senior leader said "GPs now have 10 minute appointments GPs need thirty minute appointments. **Ten minutes is not enough to do medication reviews, risk assessment and co-ordinate care. The GP champions in Swansea noticed that in thirty minutes with the patient they could get to the heart of the matter. GPs need to spend at least thirty minutes in consultations to engage patients fully and to understand their condition.** Thirty minute appointments for GPs will be crucial in implementing the cocreating health model. It takes time to establish a true partnership between the clinician and the patient. It is tempting in the limited time currently set aside for the appointment to maintain the current medical model. Doctors need to be able to convey information and knowledge and ensure that patients have understood this. It is easier for doctors to say what they think rather than working in partnership with patients. The biggest challenge for Primary Care is their workload currently and anything requiring even additional thinking is challenging. To implement a cocreating health model it will be necessary to do the ground work including offloading unnecessary bureaucracy from primary care. We need to look at the roles in the Primary Care team. Other members of the team could do some of the roles that GPs are doing. Those things simple and easy for GPs to do, another member of the team should be doing".

A second senior leader said "it **is easier when under time pressure to tell people what to do, but the outcome of this may not be effective. We need to structure consultations for more negotiation. Clinicians need permission to be able to**

suggest that patients go away, understand some of the issues before coming back to discuss options.

A third senior leader said “. We know that time invested up front pays off down the line. In Primary care they have shown that repeat attendances are reduced by clinicians spending more time with patients in the initial consultation”.

A fourth senior leader said “OT’s **only have time to deal with the immediate priorities.** They can’t deal with the ways people want to do things. Because of the time pressures, OTs don’t have time to do rehabilitation any more. We don’t address the patient’s issues, we just try to get them out of hospital. Because we haven’t addressed their issues, they come straight back in again.

A fifth senior leader said “I think that surely what we’re trying to do is not to have the most effective and efficient use of clinicians time, what we’re trying to do is give people the knowledge, and the understanding and the education for them to manage their own condition

A sixth senior leader said “Some consultations are quite quick aren’t they, and one issue you talk about here is not just one or two sessions or even more, but **some quite detailed conversations, are not playing to a clinicians skill in many ways.** Its lots of information giving, asking where the patient is. It could be made quite slick actually, if the culture changed around so that the patients were used to expressing what they wanted. It could actually be transformative, and far more efficient.

A seventh clinical leader with a therapy background said “I think that with **nurses and therapy/health sciences profession. Because they’re with patients longer, they tend to be able to get into a deeper conversation** with patients. That may be pre or post operative or part of their stay. What you’re asking medics to do and at the moment they get twelve to fifteen minutes, you’re asking them to do a lot.

An eighth senior leader with a medical background said “**There are two things implicit in private practice. It implies that there are longer consultations and**

this allows discussion. Secondly it does by and large imply that most patients would have two interfaces with the orthopaedic surgeon and there is absolutely not the capacity to do that currently in the NHS. So in private practice, there is the discussion of options, consistency of clinician, enough time spent in the consultation and a substantial proportion of patients choose not to have the operation that would have been beneficial to the surgeon. So there's something about the NHS system with limited amount of time for discussion, limited ways of discussion which forces a particular type of practice.

If you took cardiac surgery for example, the cardiac surgeons believe they have to do a certain number of operations every year. These operations take a particular amount of time. So there is essentially a number of hours of operating they have to do a year to maintain their competence in their professional view. So if you start saying to them 'we want you to spend less time operating and more time talking to people, they'll start saying 'well that's no good because I only do fifty of these operations a year now, I won't be competent'. If the GP had an option grid that they could share with the patient which described the options in secondary care the advantage is that you're then left with possibly only having one consultation in secondary care and GPs would no doubt say that many of these patients have many consultations in primary care and they are only referring the ones where things have been going on for months.

A ninth senior leader with a therapy background said "Every clinician says it's easier to tell people what to do. I know it's easier to tell people what to do but it may not have an effective outcome.

A tenth senior leader with a therapy background said "Before this service was established, patients would wait for a long time to have their 15 minute or 10 minute slot and there wasn't a resolution of the issues, people were well meaning but they were just processing them through the clinic and seeing them again and again and not actually treating them.. and not doing anything for them.

Patients feel devastated going from one appointment to another. Because nobody is treating or listening to the problem that they actually have

An eleventh senior leader with a background in nursing said “There is an element that people think time spent in discussion is time wasted ...

A senior leader said “**can we afford a 3-6 month downturn to get the benefit further on. and understand in which stage of the 4 stage RT pathway.. It may happen here, but you’re going to see benefits here. Unless you do it, moving from a discussion, document plan into an implementation phase, there’s nothing wrong with saying in January to March we’re going to have a dip and the dip is going to be like this, so the organisation can plan appropriately, and put something in place to smooth that dip out. Operational delivery is around understanding pinch points, understanding obstacles and what are the option appraisals for those obstacles and see if there are ways around it. And if you have great, and if you haven’t there are points in time where you’ve got to accept the dip. It’s the longer term gain.**

One clinician said “. Patients have the perception that the clinician has all the answers, that there are simple solutions. This is a farce but it is a consistent mindset. Some clinicians rely on that methodology and don’t set aside time to explain.

Another clinician with a medical background said “When you’re under real pressure, you prescribe more, you refer more.

A fourth clinician with a medical background said “you can’t tell people who are already horribly overloaded with keeping their heads above water, to also reflect on what’s dragging them down. If they did, it would pay dividends - but when? You’ve got to keep swimming. You can’t stop or you’ll sink.

A third clinician with a therapy background said “we have time pressures, you go in with a set agenda, you know try and go in and do it as quick and as streamlined as possible, and then with waiting lists and things it’s sometimes difficult to try and be completely holistic. in the long term **if it means that a separate referral isn’t sent in to our service, then you really we’re saving time.** Initial assessments have taken

a little bit longer, but I've found in terms of goal setting and follow ups I've found that there's less to do then.

A fourth clinician with a therapy background said “ ‘oh, **when I'm rushing I haven't got time, I go back to my old techniques**’, we all said it, we all did it.

A fifth clinician with a therapy background said “you have to take time yourself to learn the other way. You have to be given that time,

A seventh clinician with a therapy background said “working with the patient's agenda is a more efficient use of time.

A senior leader said “systems are structured around linear/simple clinical scenarios”:

A third senior leader said “**In Australia the research on ‘ask 3 questions’ showed that consultations could be shortened if there is a structure or preparation with time in the consultation used more productively.**

A clinician with a therapy background said “**There's a lot of wasted time here.** A tremendous amount. And patients don't want to be here. Generally speaking they shouldn't be in hospital, they're not having medical care, and they should be elsewhere

A second clinician with a medical background said “I've spent far too long with patients. But I think it's efficient, I hardly follow anybody up, I see them and I see them properly and I don't do much follow up, it's much easier to see people back in 6 months, without really digging into ‘give them the tablets’.

A third clinician with a medical background said “what's really important is that you need that to engage patients fully, and you can't do that within 10 minutes, and you need to make sure they fully understand their conditions, that they have a great understanding of them, that they know how to access information, that there is true

partnership in all the decisions that are made, that takes time. and you can't do that very quickly or easily.

2.2 Political Dimension

Cocreating health requires political and policy support as it challenges both the power of powerful clinicians and patient expectations of being fixed. There is a risk that patients will think that cocreating health is about saving money, denying them services. Cocreating health is easier to implement where you have an integrated health system. The welfare state has created a culture of entitlement and people may feel that the purpose of cocreating health is to deny them access to a treatment they value. For cocreating health to be implemented it needs to be accepted by politicians across all parties, public services, citizens and the public. People in poorer communities have less experience in planning their lives, in making decisions and have lower expectations of their lives. If implementing cocreating health leads initially to an increase in waiting times, this has to be accepted by politicians and policy makers.

One policy lead said **“There’s going to be flack from the public about it because nobody likes change. In Wales, co-creation will be easier than it would be in England. We have a government and Minister who are signed up, prepared to be vocal, and to respond to challenge. This is about vision. To institute any change, need a vision to hang the change into. We now have the best opportunity to do this. The Minister is totally signed up. But nobody likes change and we will expect flack from the public.** There is much more collaboration and co-operation in Wales than elsewhere. Professional bodies could put a spoke in the wheels when rolling out the framework, but they have good collaboration with Welsh Government officials. In Wales, professionals have good access to Welsh Government officials. This is done in a different hierarchal style than in England. In Wales, there is an element of stability through formation of the LHBs. We are not due for election for 3 years and this gives an opportunity to follow things through. In England, organisations change every couple of years and people never get to finish projects”.

A senior leader with a medical background said **“because of the financial context people will think we’re doing it to save money.**

A second senior leader with a medical background said “The structure of health services in Wales should be an advantage, it really should because we’re providing the care that we’re commissioning.

A fourth senior leader said “The **Health Board structure is helpful as it enables an integrated service to be provided. The fact that Health Boards are integrated organisations is recognised as good across the UK. There is a challenge in England due to fragmentation of the system that causes issues in providing good care. In Wales, there is better integration with community, primary, secondary and Local Authority OTs. Can discuss issues between different clinical teams, social care, consultations, link with Professional Body Network across wards for example Mental Health, Paediatrics, Emergency Department.**

Another senior leader said “the expectation of the welfare state, in that I’ve paid my stamp and therefore I’m entitled to there’s an issue where we need politicians and public services and patients aligned and not having differences between them about what public services are about.

A clinician with a medical background said “In poorer areas, **expectations are lower, taking control is poorer. It’s really lifting people’s expectations** but we have people round the corner who own a shop and they say we don’t open for Christmas day, if we did they’d come in because they’ve forgotten to shop. It’s **this daily lack of planning, reactive – you know, when I haven’t got any money I go down social. And it’s lifting that expectation, it may be not be as easy to apply universally as perhaps politicians might like to think.**

A clinician with a therapy background said **“to be contextually informed of your illness you have to feel good about yourself, you usually have to have a good circle of friends, don’t you, if you’re a certain age, employment**

2.3 Organisational Change

Implementing cocreating health requires organisational change. In particular, cocreating health needs a continuity of relationships, which is particularly challenging in secondary care. Cocreating health will need primary care clinicians to refer to secondary care for assessment, without giving patients expectation of having a particular treatment. Healthcare systems are very complex and have significant inertia, preventing change. Clinicians in private practice have better ability to influence organisational change including the arrangements to see their patients than in NHS practice. NHS managers consider that clinicians are inefficient if they have multiple interactions with their patients, see them without providing interventions or have long appointment times. To ensure management support for cocreating health there is a need to demonstrate the improvements in both patient care and cost effectiveness. Cocreating health will require restructure of primary care to reduce the bureaucratic load, to get other clinicians to take on tasks currently performed by GP's, to hold chronic condition clinics that consider multiple physical and mental health conditions within a single interaction, rather than multiple appointments for single conditions.

Many interviewees considered that implementing the cocreating health framework would require organisational change to support individuals changing their clinical practice. One policy lead said "There is an issue of visibility, across the UK, not just in Wales around rehabilitation. Less importance is given to what happens after a crisis. Most of therapy is delivered after the acute crisis. If money was invested in the community services this aspect might be forgotten. There is a resource deficit for patient rehabilitation. Another issue is how organisations are set up. Health Boards are under pressure to deliver certain things. The problem is that to deliver preventative services they would need to stop what doing currently – and do this. If the outcome model is that for every case, clinicians either achieve agreed outcomes, partially achieve, or don't achieve, we could redesign the NHS in Wales around a co-production approach. The other thing which comes to mind is the notion of linking this to needs assessment. Because when professionals and health bodies and social care organisations do needs assessment its predicated on the services they provide. Not perhaps what the patient requires. So this person needs XYZ whereas the patient sees it as ABC and the organisation doesn't even provide ABC. So they had XYZ even though...

A policy lead with a medical background said “I suppose the one aspect of prudent healthcare that in a sense lies over and above this is the way we should set the system up. I’m thinking now about primary care. Because what I think we want to do is to support GPs to work with patients to manage their own situations, without necessarily escalating them into hospitals. I think GPs need support, often from specialists, but that shouldn’t mean necessarily pushing them into hospital or definitively on to the next point on the escalator. I think GPs need to be supported by the sort of approaches to the primary secondary care interface that a number of forward thinking departments are already employing. So for instance when I was in Bridgend we allowed the GPs to order any cardiac tests. And then we wrote a letter back in which we gave advice, and in which we tried to by some educational content. And I decided to avoid seeing patients in clinic. It takes a certain discipline to do that, but that’s the type of thing. So it means GPs can have access to the investigations, they can have access to the advice, they get developed and the patient stays with them. We all need to work with the GPs to help them. So they need I think to manage chronic conditions. In a way separately. And that is QOFF recently announced that GPs can check blood pressure, diabetes, cholesterol as kind of separate streams. Obviously they’re all long term conditions, if you manage them all together then in a sense you can collapse down that resource around the patient and use it better. I suppose there’s always the question of whether the GP is always the person who has to do this work. GPs are expensive but on the other hand productive.

A senior leader said “a new model for Primary Care is needed to manage long term conditions. We need to shift from an episodic approach towards anticipatory or planned care. We need to incorporate care planning for patients with long term conditions into GP IT systems such as care planning modules within clinical record Design and fund primary care estate to ensure it is fit for the future. This will require Community Network development with collaboration at all levels. We must embed an every contact counts philosophy, review workload in primary care and align with workforce capacity and skills, reducing unnecessary bureaucracy. A second senior leader said “a big challenge is ensuring continuity of the relationship between the clinician and the patient. If a plan is agreed between a patient and a clinician, you need

the same clinician to review the patient and follow them up. This works better if there is continuity of clinician and record keeping in a long term relationship”.

Another senior leader with a therapies background said “I think the big challenge lies in continuity potentially, between the clinician and the patient, I think if you’re looking more at agreeing a plan, the next steps, reviewing and following up, it probably would work better where there is some continuity of clinician or continuity of record keeping in an appropriate way. If we’re in this for the long game then a lot of our systems don’t seem to be set up to facilitate that.

I guess one of the challenges is even if you achieve the first part, how would you sustain that particularly across primary and secondary care. Especially within secondary care,

A senior leader with a medical background said “To make the cocreating health framework happen would require a wholesale change in our approach. It would require a different conversation in primary care. It would require GPs to say that they are sending patients up to the hospital to get their advice, which I think they often would do, but not to raise the expectation that the outcome is treatment. But very often that is the patients expected outcome because the GP says ‘I’ve done everything I can.

Also we have follow ups and new ratios, well this would stuff that up at a stroke. There’s a sort of system issue in implementing cocreating health and the message clinicians get is follow up bad, new good. You’re inefficient if you do lots of follow up patients.

Another senior leader with a medical background said “one of the things we need to be doing in primary care is remodelling so we offload the unnecessary bureaucracy, we look at what the roles within primary care are and where they should best be used, because I don’t think they’re used necessarily appropriately at the moment, I think our GPs are doing things that others could be doing, I think the role of the practice manager is key and needs to be developed. In terms of structuring the systems and clinics and things that work in primary care. For instance patients are coming up for a COPD clinic, they’ve come up for a diabetic clinic, they’ll come up for a heart failure

clinic, if we had co morbidity clinics then actually the patient would just be able to come, and then you would be able to do a co production approach that's truly holistic and meeting all the needs of that patient, in one go, rather than having to attend lots of different appointments and not get that whole system approach. I think that actually if someone were to sit in on **general practice, I think you would find that 80-90% of patients are complex** in that way, most of them have got not just health needs but social needs, problems with employment, problems with families, all of that.

2.4 Infrastructure

All interviewees were clear that implementing the cocreating health framework would require a supporting infrastructure. Part of this is the contractual arrangements in primary care. Cocreating health requires an IT infrastructure giving all clinicians and patient access, need PCs available to clinicians and patients. We will need to engage managers in creating the infrastructure to support cocreating health. Electronic decision support tools are helpful but paper based option grids are an easy way to start engaging patients in discussion and documenting the outcome of these discussions. We need to develop an IT infrastructure that is part of the work of clinicians, not extra to it.

All interviewees were clear that implementing the cocreating health framework would require a supporting infrastructure. Part of this is the contractual arrangements in primary care. One policy lead said "Currently, key aspects of the cocreating health framework are undelivered. The reasons for this are partly in gaining access to records. It is difficult for clinicians to access notes unless they work in a hospital. There are issues in primary care about who gets the notes etc. This is partly down to IT issues. But there are also cultural issues such as who owns the patient's notes. The Professional is not the sole source of information to guide the patient in their decision making".

A senior leader said "to provide excellent care planning and self-management Support, we need to provide clinicians with appropriate training and access to telehealth and

other care technologies. We will need to integrate planning with resource flows, align commissioning priorities with population needs so that financial flows reflect the complexity of patient management. We also need to incentivise working across organisational boundaries and redesign funding models to facilitate co-ordinated care for example creating pooled budgets with health, local authorities and the voluntary sector. In particular, we will need IT systems to enable data sharing including data on self management capability & social care”.

A senior leader with a nursing background said “if you can make it easier for people to follow the process, it works. **If patients come in with an ‘ask three questions’ card, if they go into a setting where an option grid is available**, doctors, surgeons wouldn’t put that infrastructure in place but a good GP or GP practice manager was often the person who made it happen because they would manage both the patient as the NT surgery and their doctors.

Clinicians say that they don’t have the right materials to support coproduction but constructing option grids is easy. They provide a structure that can be quickly put in place.

It was also considered important that records were seamless across boundaries. A third senior leader said “we need to know what tools GPs need to work in co-production including joint record keeping. We need to make cocreating health an integral part of the systems, part of the day job and not additional work. There will be data protection issues. In terms of joint record keeping, doctors will need to think about how much they share and how much they keep to themselves, particularly with vulnerable patients. Some information may be judged by doctors not to be in the best interest of patients to understand. Shared records already exist in maternity and diabetes care. If doctors rely on patients carrying the records there may be issues if they forget to bring them

A senior leader with a medical background said “, if you make the documentation and paperwork an integral part of the system, so that this is something that is in the day job for doctors, and we’re not adding to their workload, what we’re doing is just making sure that things that you capture are captured within a care planning framework, it’s

not additional work it becomes a day job, and it also supports practitioners to think about it, co production, in a logical way, just as you have a framework for assessment of patients in a clinical setting, you take a history, a diagnosis, do an examination, do the investigation, all to make the diagnosis, in co production there must be similar stages that we will need to teach our clinicians to go through to make sure that every stage is covered off, and we need the tools embedded in primary care systems to support that approach. And to enable GPs to do it within the very restricted timescales that they've got when they see patients.

An important part of the information infrastructure was considered to be patients holding their own records. One clinician said “there has been an information revolution in the past ten years. But the public are technophobic and can't use the internet”. There is an absence of shared resources and patients don't have access. Patients need to be empowered with sources of good information.” A third clinician said “tools to support cocreating health need to be embedded in the IT systems. You need to become involved in influencing GP system suppliers to embed the cocreating health framework within the support system. You need to get the software in use in Primary Care changed to support cocreating health”

3 Patient Factors

3.1 Patient Expectations of Clinicians

Patients can have the expectation that everything will be done for them, that clinicians will fix them and that when they interact with a clinician they need to come away with a prescription, a referral or a treatment. This patient expectation of treatment, of being fixed is driving Health Service development. People want more, specialised, treatment from expert clinicians. People can have unrealistic expectations of being fixed and this can be set up in primary care before referral to secondary care. People come into hospital with the expectation of being fixed but without an understanding of what that means. Patients can have the expectation that clinicians have all the answers and can apply a treatment that acts as a magic wand to cure them, and can become frustrated if this expectation isn't met. Clinicians having a conversation with patients about what they can do for themselves may be against their expectations. To make the NHS work

we need patients to accept that they have responsibilities for managing their own health and well being as well as rights to treatment. Patients have the expectation that doctors are in charge of their health and unless doctors say otherwise, this isn't going to change. There will be a proportion of patients in the current system who are willing to engage in cocreating health, another proportion who are willing to consider it and a small proportion who would not engage, wanting only to be fixed. Cocreating health needs to change the expectations of individuals, their families and community by educating people about how to look after their own health, that of their immediate family and the wider community. Patients don't have an expectation that there are preference sensitive options in their care and don't come prepared to engage in such discussion. Some patients are challenged by the lack of certainty in being presented with options by clinicians. Some patients want to transfer their problem to the clinician, hoping they will provide the holy grail of a cure without behavioural change and when this isn't offered, feel that the clinician is at fault. Patients who have been acutely unwell often have unrealistic goals and then the clinician has to balance a conversation about realistic expectations with ensuring that their motivation remains high to achieve lesser goals. When patients come into hospital, they expect not to have to do anything for themselves and this is reinforced by hospital rules and the behaviour of staff. Patients expect that all of their healthcare will be free, so they don't expect to pay for things that improve their health such as eating healthily, exercising or paying for treatments. People have the expectation that, having paid their taxes, that the NHS will fix them. In poorer areas people have lower expectations of themselves including less ability to manage their own health and poor planning skills, so need to increase people's expectations of themselves whilst reducing their reliance on clinicians 'fixing' them. Patients have the expectation that any treatment will be effective and without risk and don't expect that clinicians will discuss this with them. During the interaction there is the expectation that the patient will listen to what the clinician has to say and not say much themselves. It may be that people feel that when they are in hospital or in NHS premises, they should do what they are told but when clinicians are working in people's homes they are more likely to engage in managing their own condition as it is their turf. Patient's expectations can be changed by contact with other patients with the same condition. If they don't gain a cure through medical intervention, patients can come to the realisation that they need to be engaged in managing their own health. Patients can be deferential to doctors, wanting someone with more knowledge to take

charge of their health and well being.

One policy lead said “Patients say ‘they’re doing everything for me’ .There is an expectation around the welfare state, a socialist approach where people expect that everything will be done for them: For example. If you see doctor and don’t come away with a prescription don’t feel that have had a good time with him. It is a big change for clinicians to say ‘there are things you need to do for yourself.’ People expect the ‘Nanny State’ and this did deliver for a long time. There is the expectation in people that will have every treatment possible in hospital.

There is an expectation amongst patients in Wales that things will be done to them and for them irrespective of whether these meet their needs. As long as they come away with intervention such as medication they will feel as though they have got a good deal”. A third policy lead said “People feel better if they are having something done to them. There are difficulties if comparison is made with England where funding is being supplied to meet consumer demand for intervention. The public feel that if something is wrong, something can be done about it, but this may not be true.

A second policy lead said “the culture of previous generations has been not to challenge, not to question, not to really engage with the doctor, because what the doctor said went. If the doctor said you take these tablets three times a day, you take those tablets three times a day. It’s the sort of Doctor Finlay’s case book type culture. That has changed now, but I think what we’ve got now is the expectation that things will be done to you and for you. Irrespective of whether they actually meet any inherent needs. As long as you come out with a prescription, or as long as you come out with some tablets or medication, you’ve got a deal. In a chronic pain setting patients perhaps have an expectation that there is a treatment that will work for them and then when the treatments don’t work they get the sense of frustration, anxiety and psychological distress.

A third policy lead said “I was at a meeting in England this week and they talked about their drivers. And the biggest driver was patient expectation. And they anticipated this growing because of the internet. If patient expectation does continue to increase as

they anticipate, they won't be able to afford to meet it. The distributed sources of learning and information for the public tend to be **English. And that is all about consumerism and that is all about we'll give you whatever you want. The English system and the English rhetoric still supports the escalator as being excellent. I think it's more than that though, the English system in a sense has only come in since the 90s but the expectation of welfare benefit has been around since '48. and I would have thought that that expectation – that I've paid my stamp, this is the national service for me when I need it is a much deeper social phenomenon and probably even stronger in Wales because of the labour tradition.** at the moment I think people want more. They want everything possible, and they want the best, and the more specialised it is, and the more technical it is, often it's seen to be better.

A second policy lead with a nursing background said “And there are **some people who don't want to engage in the way you outlined. They just want to go to the doctor and have the doctor tell them what to do, or have the therapist tell them what to do. I say I don't think this model will fit everybody because they won't want to engage in that way, they'll just want you to sign a sicknote, or give me the pill, I don't want to know why you expect me to do stuff. I suppose for me it's where the locus of control sits. For some people they will externalise it, they'll say no, no it's the doctor's job to fix me, it's the NHS's job to provide me with services. If you're asking me to take exercise, or lose weight or stop smoking before my operation. Some of them say no, I'm sick, you're supposed to fix me, it's my right to have services. So there's a little bit of, you have to have willingness on the patients part to play the game.**

Another senior leader said “there's this expectation that it's the NHS responsibility to do something which will fix me and I think that's quite pervasive

A senior leader with a medical background said “the problem with cosmetic surgery is that people have unreasonable expectations. **People become dissatisfied because they had unrealistic expectations.** Their expectations hadn't been set well for them. The expectation in secondary care is set up in primary care and by what they've heard from their colleagues and the TV

We need to have a different conversation with patients about the things they can do for themselves. Is that going to be an easy conversation for clinicians to have? It may be against the patient's expectations and the clinician's expectations. I think we need to get better at it.

The whole language around the 'consultation' is I'm coming to you as a patient and you're giving me your opinion 'I went to see the specialist, I went up the doctors', 'he said 'it was the worst he'd ever seen' 'but he thought he could put me right'. 'I need to go under the knife'. That's the conversation, or at least what people take out of it

Another senior leader with a medical background said **"when I went to Sweden it was absolutely obvious that they took responsibility for their health, they saw it as equally important to the care and support resource that they got from the NHS, their part in it was equally important and I think if we talk about barriers, I think the taxation system where people feel that they've paid their taxes and they're going to get their money's worth that a big part of that is clinicians doing the work, as opposed to them having to think about is something we're going to have to have a national debate about. And what really do those taxes pay for, and what is it that citizens are going to have to do, accept is their part in this as well.**

Another senior leader with a medical background said **"we need to change that patient expectation from going into a service where they expect to have things done and they expect someone is acting in their best interest at all times. To something where they are part of the solution, and they are part of the dialogue, and they can influence..**

A clinician with a therapy background said **"I think the patients see the consultants as the person in charge. And they do have that expectation, and it's very difficult to change that unless the drive comes from the consultants.**

2 thirds of the patients would expect you, and you can be any member of a healthcare team, expect you to do something for them. One third of the patients would say that's fantastic, thank you very much for telling me, what can I do for myself?

Within that 2 thirds group I think that there will be a proportion of patients who will think do you know what, I've never thought of it like that before but yeah, I suppose I could do that. And then there will be a proportion of that group that says no, you owe me something, I pay my taxes, I'm here and you need to do for me now

you need that can we call it community education, because it's when they're outside of the hospital that you need to have robust ways of teaching patients about responsibility for their own health so that they have a different expectation, a different view on health care, of how they look after themselves in the community and whether they need to step across the threshold of a hospital. A different expectation of what happens in the hospital as well. And that's where it starts, somewhere before hospital, it's right out there in schools, in community settings, in family settings, it's out there and that's a huge undertaking.

A senior leader with a therapy background said "people come to hospitals to make them better. And there's no understanding of what 'better' is on many occasions. We don't have that conversation.

Another senior leader with a therapy background said "patients have this expectation of an instant cure that you can do an operation or something, wave a magic wand. When I say there isn't a magic wand they get quite angry. Because obviously we as the medical community should know more about this condition, and why isn't there a cure?

A senior leader with a nursing background said "a lot of patients I've spoken to have expressed surprise that there would even be options to consider, never mind have the ability to understand the way we currently present them. So conditioning probably started in our mind probably when people entered the

beginning of the consultation process, they need to be made very clear that we are wanting to help people make the right decisions for them by engaging in some active part of the consultation. I think you still go in expecting a solution, and the solution is in the hands of the person who's got more knowledge.

One clinician said "patients have the perception that the clinician has all the answers and that there are simple solutions to their health problems. This is a farce, but it is a consistent mindset amongst patients. Patients can have a comfort blanket dependency".

The expectation of patients varies a lot but as I say I think **some are really challenged by the idea that you don't tell them what to do. And some are will cope with it. It's a bit like coping with uncertainty, some people cope better with uncertainty and some people can manage risk, a lot of the high demand patients will not or do not want to manage risk.**

The other thing I suppose you should mention is **transference, the patient comes in to see the doctor with a problem, they give the problem to the doctor, they go out feeling better, the doctors going to solve it, and the doctor ends up worrying what he's going to do about it.** I think that transference is something some patients prefer and will find it difficult. **Many patients have looked for the Holy Grail and I don't know many have found it. The Holy Grail is getting completely better. Resolving their problem completely. The Holy Grail is getting completely better without making any behavioural changes. If only you could find out what was wrong.**

Another clinician with a medical background said ". Patients have an expectation for example that I'll fix them? They come and see me, and I'll fix them. Why else would they bother coming. Of course there are many reasons for coming, it can be validating an unwilling reason to get on with life, and handing over responsibility, so.. I can't do this because of my bad leg' as soon as patients start personalising their ailments you've got a problem. The role is to alleviate suffering. People need to come to an understanding that they have an ability to affect their condition themselves

A clinician with a therapy background said “if you say to most of the patients on the ward what are your goals, most of them would say I want to walk again, I want to talk again, I want to eat normal food etc. and for us, mostly that ain’t gonna happen. So there’s a balance between how much you have to guide them to come up with realistic goals or achievable goals and allowing them to express what their wishes are. I guess patients become quite conditioned to the medical model

When patients come into hospital they are historically used to being ‘done to’ and that, to a huge extent, particularly older patients, they continue to expect that. And possibly I’m sure we do still reinforce that as well to a large extent when we say to people you mustn’t get up and walk on your own because you’re going to fall, so make sure you press the buzzer and then wait, that’s very medical isn’t it.

A clinician said “patients have the perception that the clinician has all the answers and that there are simple solutions to their health problems. This is a farce, but it is a consistent mindset amongst patients.

“GP’s working in a poor area know that self help that costs anything won’t work. Free prescriptions are an enabler.

In poorer areas, people’s expectations are lower, and so their ability to take control of their own lives is lower. In these areas there is lower empowerment and people live on a day to day basis and have no experience in planning their lives on a long term basis. To make cocreating health work we will need to lift people’s expectations of their own lives out of daily lack of planning and a reactive mindset.

Patients need to be told when they may not survive a particular operation, that an intervention may not work, that it may give better outcomes for them to change their health behaviours rather than have an operation or medication. But in general, doctors don’t have this discussion with patients, instead they rush to treatment. Patients may not want to have open conversations about risks of treatments, Like gamblers they don’t want to hear who’s lost (died during an operation or for whom treatment wasn’t

successful), instead they want to know about the patients for whom intervention by the doctor was successful (ie the ones who won).

A senior leader said “. Taxation is an issue as people feel as if should get their money’s worth and that clinicians are paid to do the work, not patients. There is a need to have a National conversation in Wales about citizen responsibility”.

A third senior leader said “The expectation of both patients and clinicians is that clinicians will talk, and patients will listen and if there is silence this is uncomfortable”.

A second clinician with a therapy background said **“I find working in the community often you can get family involved, which tends to bring things more – obviously you’re in their home so it’s very centred around them. It is less passive than say on the ward where you turn up at the patient’s bedside, you are there to do something for them. So I find it easier to motivate people to do things for themselves when they are in their own homes.**

Another clinician with a therapy background said “I think maybe some people think we’ve got a magic wand and that we can cure their pain, and they’ve got that hope, they hope that things can change things for them and that their pain will go away, but during the course of the programme, they’re with us for 8 weeks, most of them realise that that’s not the case, that that’s not going to happen. But, quite often their relationship with the pain changes, and we see that that will hopefully happen well, to make them more accepting of the pain. Some patients have the expectation that we’ll fix them. Some of these are more difficult to engage in self management of their condition. If they continue with that fixed idea throughout the 8 weeks, sometimes they may leave the programme if they find it helpful then, some of them struggle with that but we use group dynamics I feel in an effective way, and if some within the group realise that their pain isn’t going to be fixed, and maybe they’ve started the group not knowing that that’s what a group is about, I think that that influences some of the people who were expecting the magic wand approach.

Sometimes there is no answer, there is no medical cure, that's when some patients are still looking for those answers, those cures and find it really difficult to accept that there won't be a quick and easy answer and the solution is for them to put a bit of work into their own health. That takes discipline and time and patience.

One policy lead said "The issue is in patients taking responsibility – they have deference to doctors. There is an expectation that GPs will deal with all minor problems. The population feels that there is something there that you can have and this is deep rooted in the UK system.

A senior leader with a nursing background said "I think you still go in expecting a solution, and the solution is in the hands of the person who's got more knowledge.

A policy lead said "the culture of previous generations has been not to challenge, not to question, not to really engage with the doctor, because what the doctor said went. If the doctor said you take these tablets three times a day, you take those tablets three times a day.

3.2 Patient Activation

3.2.2 Patient Engagement

Engaging patients in cocreating health requires a transformational change, but patients and clinicians may not welcome this, preferring to maintain the status quo. Patients need training to understand risks, how to consider options and to interact more effectively with clinicians. Patients need to think how they want their lives to be, what support they have to achieve this, and lastly what gaps are there that the health service can fill, rather than formal health services being the first place they go to.

A second policy lead said "the idea in the cocreating health framework that outcomes should be determined by the patient from what they want is a very healthy starting point but different from where clinicians may be currently. The **current imbalance in power undermines the responsibility of patients to manage their own health**".

One senior leader said **“we need a transformational change to the way we care to become proactive, holistic, preventative and patient centred. This assumes an active role for patients with a shift to a partnership model and support for self-management”**.

A second senior leader said **“there is a reluctance to let go of the current model from patients and clinicians. Patients say –‘what would you do doctor’?”** A third said **“patients may feel that they need permission to take responsibility”**. Another said **“to make the cocreating health framework a reality, we need patients to want to be engaged and this requires public awareness”**

One clinician said **“patients need to be empowered and to have sources of good information. At the moment, clinicians don’t include patients in clinical risk assessment and risk analysis. This gives patients the perception that the clinician has all the answers and that there are simple solutions.** The EPP works with patients with long term health condition and encourages self empowerment. When graduates interact with the health service they are more proactive. They come prepared with a lot of questions and know to participate, to take part. **The EPP provides people with a four stage formula of prepare, ask questions, repeat answers to ensure accuracy of communication and take action on what is agreed. In this way, people fall into empowerment through repetition.**

A second clinician said that he understood coproduction as **“What do you (as a patient) want to do differently? What do you want your life to be? How can friends/family/community help you to get there? Don’t ask for a doctor as the first port of call, rather formal health services should be used to fill in the gaps when other sources exhausted. The ‘How’ of coproduction is : what can an individual do to deliver this? For example, ‘What do you want your life to be?’ What friends/family support service is available? Formal health services should be seen as enablers to fill in gaps where needed.**

3.2.3 Patient’s Ability to Understand Their Condition

For cocreating health, clinicians need to be able to assess the patient's ability to understand and manage their own health. Patients can be given too much information that they don't understand and conflicting information by different clinicians. Patients need support from clinicians to understand information about them, to understand numerical information and statistics in the context of their own lives. Patients may not want to hear about unsuccessful treatments, thinking that this will never happen to them. Once patients are educated in their condition, they can manage their own health better.

A senior leader said **“Clinicians need to assess the capability of patients to engage including their level of health literacy if they are to provide support to patients to work as partners. Patient without health literacy can fall behind in our systems.”**

Another senior leader said “patients can be confused with too much information and can be given conflicting information by different clinicians.

A senior leader with a medical background said “I think the challenge will be what suits a patient of one social class or level of intellect and literacy, will be very different from those who are at the other end of the scale and I think that's something we need to recognise, that perhaps there will be different approaches, depending on experience of health literacy for patients.

One clinician said **“Patients need more support to access information and to understand medical jargon within medical reports. They also need better understanding of numbers and statistics. This information isn't yes/no and to put this in context patients need interpretation skills”**. A second clinician said “patients need to be told when they may not survive a particular operation, that an intervention may not work, that it may give better outcomes for them to change their health behaviours rather than have an operation or medication. But in general, doctors don't have this discussion with patients, instead they rush to treatment. **Patients may not want to have open conversations about risks of treatments, Like gamblers they don't want to hear who's lost (died during an operation or for whom treatment wasn't successful), instead they want to know about the patients for whom intervention by the doctor was successful (that is the ones who won)”**.

A second clinician with a therapy background said **“when you’ve got the education of the patients on board, that’s your first stepping stone. Because they then come in with a different expectation. They think I know about my new knee, I know about my new hip, I’m more informed, I know how I’ve got to prepare myself for going in, I know that if I do this well, the way they’re telling me, I’m likely to be out in a short space of time, therefore I need to ensure that the environment I’m coming out into is suitable. What support do I need, they’ve set up the support because they know they need it in a week’s time. Do I need to ask my family to take some time off work to help me, I need somebody to collect me, I’d better fill my fridge with some easy food.**

3.2.4 Patient’s Health Behaviours

For cocreating health, the NHS needs to organise itself to support people to remain well, rather than just seeing them when they are sick. People can be focussed on buying food that is cheap, rather than food that is good for them. One challenge to cocreating health is that currently the population has poor health behaviours and these are getting worse. In primary care, clinicians have conversations with patients but they mostly try to fix a problem with medication rather than addressing the health behaviours. Cocreating health will mean a change towards patients accepting that following a conversation with clinicians they may have to change their health behaviours. Cocreating health will mean that the organisation of health services will need to change to supporting people to achieve an outcome through changing health behaviours rather than a secondary care intervention. To co create health, clinicians will need training to assess a patient’s readiness for behavioural change, to understand why they aren’t ready to change and to not give up on a patient changing at some point. Patients may have very little awareness of their own bodies and clinicians may wish to promote this understanding. In cocreating health, it is important to use the right language with patients to prevent them disengaging from behavioural change. It can be challenging for clinicians to accept that patients may not want to change their health behaviours despite the bad effect this is having on their health. It can be very challenging for some people to reflect on their own health behaviours and realise that their health maybe poor because of the life choices they have made, rather than a fault of the healthcare system. People may well know what is making them

unhealthy but lack motivation to change, although pregnancy is highly motivating towards women making health life choices.

A second policy lead said **one area that lends itself to this is cardiac disease where interventions are expensive and are dependent on patient smoking habits. We should use interventions for lifestyle. The Incentive for the population is ‘why would you let yourself get ill?’** A third said **“clinicians need to focus on the wellness of the patient. The NHS needs to focus on maintaining independent living of patients rather than creating dependence. The NHS needs to work with patients to make them proud of what they can do for themselves”**.

A senior leader said” In essence, we’d be equipping our workforce who come into contact with service users regularly with basic health promotion and prevention skills. We need to bring in messages of prevention and health promotion. In Sweden, each person has a personal role, responsibilities to look after their health-we need the Welsh people to think this way”

. A second senior leader said “People do find getting food cheaper to be important for them and this makes it hard for people to make healthy eating decision. For example, there are buy one get one free offers. We need to support people to identify value in food terms. There are few advocates for fruit and vegetables.

A second senior leader said **“we have conversations all the time about how we’ve got to change the mindset of the public, in my experience the public are nowhere near that,**

A senior leader with a medical background said “I think **in primary care, they have conversations about health behaviour choices relatively often. But ultimately they think they can best treat the patient with a tablet. They might say to a patient ‘you should eat less salt’ and the patient says ‘but I like salt’, and then they say-well, here’s a blood pressure tablet, because otherwise they aren’t fixing the blood pressure. The support we provide to help people stop smoking, lose weight, take more exercise is very patchy.**

We need more support to make health behaviour choices and that needs to be seen as equally as likely an outcome from seeing the doctor, who may send you off down to the gym, the gardening club.

One clinician said “there is a need for patients to engage in health behaviour changes but that they may not be offered support to implement alternatives to medical interventions. For example, health services are more able to operate on someone with knee pain rather than providing support to help them lose weight”.

A clinician with a therapy background said “It’s the patients that have low mood, that’s gone under the radar, particularly and they’re just not ready yet. You need to come back and you need to give them time, and you need to keep exploring when they’re going to be ready and not just ignore them and think oh well they’re not engaging, that’s it. It’s just keep going until you find a level where there’s some kind of carry over, some kind of change happening that you can make your move.

A third clinician with a therapy background said “many of these patients have not felt their body for years, they are not aware of their size and by actually getting them to massage over their big stomachs, big legs, whatever, suddenly they think, my gosh - is that me? This is me. It’s all about yes, this is your body - I can help you deal with your body, but ultimately it’s your body. 80% will take it on the responsibility for managing their condition no problem at all, they will accept that skin care, moving their body – we don’t talk about exercise anymore, because exercise to patients means going to a gym, so we just move your body. Language is really important, skincare, moving their body, wearing the compression gloves, and being aware, self management of obesity and so on. It’s the 20% that just can’t get it, and maybe it’s that they can’t get it now. But that’s not to say that they won’t get it 6 months to a year down the line. And what we have found is that these patients, who are non-compliant, eventually start coming back to us, 6 months to a year down the line. And they’ve taken on some of the things we’ve said, but they’re not ready for it.. The longer you know a speciality, then you step back because otherwise it’s as if you’re killing

yourself trying to help everybody when people won't take on the responsibility themselves. So you go through the anger, the disbelief that people won't take on what you're saying, and eventually you accept that you know what, some things in life are more important for those people, and they probably will never take on what you're saying. Their life may well be sitting in front of the television, they don't want to move, they will continue to eat to get to obesity and we can sometimes not help that because they're not willing to let themselves be helped.

A fifth clinician with a therapy background said "to have patients think and reflect about if an intervention has gone good, bad or indifferent. And then why. And if the not good bit is actually because the hospital didn't deliver an outpatient appointment in a timely fashion, well then that's something that the hospital has to address. But if it's because as a patient I didn't do my exercises.. It's quite difficult to get them to take that responsibility, of looking inward on them, to reflect on themselves. It's quite difficult to get us all to do that. We're all really good at putting out there in the public domain the bits of us that we're really happy with. We've all got little places inside of us that we know we're not very good at and we don't look at those places very much.

A clinician with a medical background said "it's such a heart sink, the idea of getting people to lose weight, or stop smoking even when they're pregnant and they have a lot of extra impetus to make changes, it's very difficult indeed. There's no way I can do very much without the patients engagement in their own health. All I can do is facilitate. It's a bit less obvious when you're operating on people. That's more old school. But a lot of operating doesn't solve anything, and even if it does strike at the heart of the pathology, it doesn't make the person better. People need to come to an understanding that they have an ability to affect their condition themselves, it's a good time to be promoting change in pregnancy. Most pregnant women are very open to the idea that change will help the baby but it's still very difficult, I make people cry all the time.

We still have about 27% or thereabouts of people smoking in the population in some areas. I smoke too..I understand why people don't quit, I would never finish a course of antibiotics, I smoke and I expect to die of various problems, or cancer and I would

rather do that than quit quite frankly. I think there's lots of ways of looking at health, and decisions that one justifies or doesn't justify and prefers to look away from that I entirely understand. I talk all the blooming time about behavioural changes but I try my best to let it come from them of course. People know damn well. Big fat women with polycystic ovaries are not unaware and if I sit there and say it's because of your weight they say 'oh, everybody says everything's because of my weight. So I wouldn't introduce these subjects because it's so unhelpful. Once you have people saying I think it might be my weight or I have tried to lose weight, or all the other sheepish ways that they introduce this difficulty, then you can ask what have you tried to do before, and use the tools I've been given – what's the likelihood that you might change, one to three words, where does the three come from. What might work, and I think I have tremendous success with weight loss and healthy behaviours in diabetes clinics, and I can't replicate that in gynae with the polycystic ovaries girls for nearly the same proportion of people, because pregnancy is highly motivating.

3.2.5 Patient Self-Efficacy

At the policy level, there is an understanding that the NHS needs to change towards supporting people to better manage their own health and well being. Supporting patient self-efficacy is well established in mental health services. The needs of a patient's family for them to be cared for might be in conflict with the patient's wishes to manage their own health with family support. In chronic conditions, patients go through stages of believing that they can be cured, but when they realise that there is no cure, they may welcome support to help them manage their condition. Nursing originally meant caring for people when they couldn't do so for themselves and when they could, supporting them to do this. In cocreating health, patients with chronic conditions need to be engaged in developing management plans as full, active partners from the first interaction with clinicians. Through consistency of relationship, clinicians can develop the confidence of patients to manage their own conditions. When clinicians have a fully informed discussion with patients this can lead to them choosing not to have interventions that they would have otherwise felt were valuable but denied to them. When clinicians are honest with patients that there is no cure for their chronic condition, eighty per cent of patients will engage in self-management. Of the twenty per cent of patients who are unwilling to engage, about half will become engaged in self management when they've had time to reflect, leaving around ten per

cent of people who will continue to believe that there is a cure that doesn't involve them in making health behaviour changes. That ten per cent who refuse to engage might be discharged by the service because they are unlikely to gain benefit and very likely to not attend appointments. People in lower socioeconomic groups are less likely to engage in self management or to make health behavioural changes. Some of this may be due to lack of resources or choosing to spend their resources on poor health choices. Patient education programmes such as EPP are important in patient self-efficacy, but these may need to be bespoke for particular conditions. Patient education programmes such as EPP are important to help people understand how to better live with their condition. Part of this is ensuring that patients understand when they should self-manage and when they need support from a clinician. Another part of patient education is ensuring that patients know how to best interact with clinicians. Patients look to clinicians to alleviate their suffering but the clinician can only facilitate the patient to do this. By giving patients challenging goals, clinicians can support their self-efficacy, particularly if the patient has family support. The ability of patients to manage their own health is highly dependent on the support network they have from family and friends. Older people living on their own with little family support face great challenges in managing their own health. Patients need small, achievable goals in order to manage their own health. Clinicians are important in giving patients the confidence to manage their own health. Patient self efficacy requires knowledge, will and action.

One policy lead said “ **“coproduction means asking patients how clinicians can them to make changes in their own life” ; “as clinicians we need to understand that its not our life-we have to find a way to support people to be in charge of their own life” ; “the NHS needs to focus on maintaining independent living of patients rather than creating dependence” ; “the NHS needs to work with patients to make them proud of what they can do for themselves “.**

A policy lead with a nursing background said **“these attitudes have been espoused in mental health nursing for a lot longer. There is the recovery movement in mental health nursing, which is very much around, what is it that you need? To what extent is the family involved? to what extent are their needs taken into**

account. Because, of course, the patient's needs might conflict with what the family need is. For example, the patient may feel that they need to be nursed at home, if they're a mental health patient or end stage terminal illness, the family may have different ideas. I suspect that with chronic conditions most patients that have had these for some time will probably have got over that phase and realised that there is no fix, as such. And might welcome a bit more involvement. If its presented as 'this is something you're going to have to learn to live with, you're the person that going to have to live with it, therefore you've got to tell us how best you can live with this and its our role to facilitate that process. with chronic conditions, the journey through chronic illness is probably a gradual realisation that by its very nature, by definition, there is no cure for this. And I'm sure that **when most patients first present, they're not aware that it's a chronic condition probably and they have an expectation they will be fixed. The typical trajectory would be that the medical team tries several things, none of them really effective and there's this growing awareness in the patient..ahhh..There is no cure. So I guess once a patient is well into that journey, then this message is probably exactly what they want to hear. Basically, this is something you need to learn to live with, to adjust, you need to adjust your own life, how can we help you do that?** What do you think you need? A lot of chronic conditions end up being social problems rather than medical problems.

One of the first ever modern definitions of nursing, which dates back to the nineteen fifties is along the lines of 'the role of a nurse is to do for people when they cant do for themselves, but to encourage and facilitate them to look after themselves, when they can. So it's a kind of recovery model. Someone comes into hospital, first they need doing for, but then gradually, as they get better, the role of the nurse shifts and becomes a facilitator, helping them to identify their own problems and eventually discharge home. And I think with the move to community care, we will be even further down that route. Right from the outset, the assessment should be focussed on recovery, rather than just the illness, thinking 'what is this patient going to need in the long term '?

One senior leader said "the management of patients with long term conditions needs to shift to a partnership model in which action plans are developed and implemented together

A third senior leader said **“conditioning of patients to engage starts at the start of consultation process. We need to make it immediately clear that they’re being asked to be active in the consultation”**.

A senior leader with a nursing background said **“confidence has only grown through a period of knowing the same person and having that relationship that means I think you’re not going to drop me here or leave me too much on my own if I need you but you’re giving me more space within which I can operate within my own parameters and I know (and I’m speaking for my mother now), I know that I can do this, and this but if I’m feeling like this then I can take the next step and I can start the antibiotics, or do whatever. And actually we do all sorts, you know – we’ll do your leg dressing, we’ll check your diabetes, we’ll give you your medication, do you really focus on social isolation. Actually if we could unlock some of that with people, then the other things that need to be done become far more diminished**

A senior leader with a therapy background said **“when the GP could then have a discussion with the patient about the recurrence rate for ganglions and actually that the evidence is indicating that this was a surgery of limited value, actually the GPs found it very helpful to have this discussion with the patient to help them make an informed decision about what to do. And actually the patients mostly said thanks very much don’t bother to refer me. And meant that it was appropriate care, and the GPs found it very helpful to guide with the patients why they had taken the choice with the patient that they did. Rather than just say no, I’m not going to refer you. Actually having some visual, actually that is a visual decision making tool in a pathway type form, with evidence base and patient information was very useful too.**

Another senior leader with a therapy background said “one of the biggest issues for me is getting patients involved in their care and they have to be hand in hand with us, we can only facilitate. That is a problem we are facing whereby patients with this chronic illness have had their condition for such a long time they want somebody to come in and wave this magic wand and there is no such thing. We are actually upfront with patients about that. But I think where we’re at is that patients have to take responsibility. 80% will take on responsibility for self

managing. It's the 20% that just can't get it, and maybe it's that they can't get it now. But that's not to say that they won't get it 6 months to a year down the line. And what we have found is that these patients who are non-compliant eventually start coming back to us, 6 months to a year down the line. And they've taken on some of the things we've said, but they're not ready for it. Of that 20% about half would begin to make changes. The remaining 10% still don't want to know, and that's their choice. From our point of view, we say well we've given you all the skills that you can manage, we cannot do any more for you and we're discharging you, but if you want to come back then we will see you again. And I think that's important that people know we are not this everlasting service, we have to help the people that really want to be helped.

In terms of those 10% of patients that won't take control and therefore they're not going to get better, I think if I talk about it from my point of view and experience. I used to always want to try and make that patient take on what I wanted them to do. But I think the longer you're in a service, and the longer you know a speciality, then you step back because otherwise it's as if you're killing yourself trying to help everybody when people won't take on the responsibility themselves. So you go through the anger, the disbelief that people won't take on what you're saying, and eventually you accept that you know what, some things in life are more important for those people, and they probably will never take on what you're saying. Their life may well be sitting in front of the television, they don't want to move, they will continue to eat to get to obesity and we can sometimes not help that because they're not willing to let themselves be helped. So we see patients, and what we say to the patient is we'll come in and say here is the bucket, I want you to wash your legs. The nurse will come in, fill the bucket, get down on the floor and she will wash the patients' legs for them. The OT will come in and say you need to wash your legs, now what aid can I give you to help you wash your legs. The 20% of patients who don't want to engage are the people that will DNA, they will actually not turn up and they will be discharged. So we are missing that 20% and what we will find is that that 20% are the ones that will be in and out of hospital and they will be costing the most in the NHS. The lower classes find it much harder to engage. Now whether that's because their lifestyle is different, they don't think of healthy eating, they don't

go to gyms, they don't do public health messages. And if you think about the head and neck cancer group which we deal a lot with we've often said, to get those patients to engage with us we'd be much better going to the pub at lunchtime, because we'll see a lot of them there together, we'll probably get a message over. We haven't done that, I need to say. If we got a lot of them together and said right, we're going to be in this pub, I bet you they would turn up. They do smoke, they do drink more, they don't know about healthy living – it's hard to get five fruit and veg let alone the 7 they've now recommended. So it is harder. But a lot of these people don't have money, and the money they have they spend differently. And it is a harder group to treat. Some people plan over a longer time scale, and some people live very much day to day...

If you're looking from a financial point of view they live day by day as to when they're going to get their money as to what they're going to do that day. And we know patients like that – they couldn't possibly come and see us on Thursday because that's when they get their money.

With lymphoedema we've got our own model of the EPP, we've got a living with lymphoedema accredited ...(?) unit. So it's teaching patients to manage their condition so they do become experts in their condition,

A senior leader engaged in the EPP said “there is a difference between knowing about the condition, and knowing how you can live with the condition and what the EPP programs can show is how to live with the condition. Because not only do you get the long term condition, but you get the symptoms – what we call our symptom cycle, like the pain, like the stress and anxiety, the difficult emotions, the depression, the poor sleep, the tense muscles because there's a lot more with a condition than taking the medication. But knowing how that symptom comes about and all the different tools that we show them and the techniques over 6 weeks.

Clinicians recognising that people are in a different cycle and need different types of support is the core of enabling that patient to self manage, because there are things that I know I can do, there are times when I know, no – I need

my medical teams help here. So we're not instead of, it's about us working together.

A clinician said “when graduates interact with the health service they are more proactive, more aware of NHS limitations and of communicating with clinicians. They know to participate, how to take part. CBT is an effective social care provision that enables people to manage their own health”.

A second clinician with a medical background said “the patient has to play a role in alleviating their own suffering, there's no way I can do very much without that. All I can do is facilitate.

A clinician with a therapy background said **“some patients just love to be told what to do and they do it. I had one in today, his wife's had a stroke, and whatever I tell him to do he'll do it, anything, because he just wants the best for her. I don't need to do that with them, because I'll just say I want her to practice this, this and this week, and he'll do it. Every day, ‘how many times a day?’ and that's all they do want from me, I think. They don't want any.. And it's good because they didn't think she would walk on the ward, and she's walking now, so it's been really nice. We've got a goal that we didn't think was achievable.**

A second clinician with a therapy background said “The engagement of patients in managing their own condition varies, some patients who are – and I don't want to stereotype, who are living alone, who are elderly, their priorities are very much getting through from day to day. Some patients who have a good support network, who do have the cognitive ability they want to read around things, they want to learn, they want to know, and often they engage a lot better but I suppose each person is at a different level so it's making sure that you sort of stage your intervention at the right point for each patient.

unless it's something as simple as ‘I would like to walk’ we may have to break it down to initially well you may have to get down to sitting tolerance., then we need to work

on this, then we need to work on that.. So it could be staged from an initial idea from them but we might need to break it down into manageable pieces.

A fifth clinician with a therapy background said **“you’ve got to instil confidence in them as well.** Some people say ‘I can’t do that’ and you’ve got to give them confidence to do it.

A sixth clinician with a therapy background said “if you’ve had a family situation where you’ve been looking after a relative who’s quite a challenging relative maybe with dementia, and then for some reason somebody else is looking after them, they’re in a safe place, in a hospital environment, fairly regularly those families, they might not be aware of it, but they’re very grateful, of the break, it’s not a conscious decision and therefore they’re not always receptive to you empowering them to go and look and see what they can do in partnership.

An eighth clinician with a therapy background said **“I. It’s an important part of our service that patients carry out actions themselves to help themselves because for patients with acute and chronic pain, there is no medical cure and we emphasise this when they first come in, when they first come in to an information day, we state clearly that this is a self management group and we hope they can maybe make helpful changes if there are any that they can make.**

Self management fitted really well with our service, because we put a lot of emphasis on acceptance, and we use approaches like mindfulness and also things like the solution focused techniques and motivational interview

Eighty or ninety percent of patients become engaged in managing their condition. I think maybe all of them have the potential to engage in self management but maybe 80 to 90 percent actually do it. Maybe about 10% go away thinking the times not right for them to change. Maybe we’ve just planted the seeds, and maybe that’s enough for the time being. I think a lot of people change during the programme, a high percentage. The 10% who have the potential to change but haven’t shown any signs of it we see 4 months later. I suppose everyone’s got a different story but I think some of them have made

lots of changes within that 4 months and maybe that's about accepting the things they can and can't do realistically.

With something I heard recently as well, about this triangle of knowledge, action and will. I think that maybe self management is really looking at the will. The knowledge can be acquired from various places, and then it's up to the patient to carry those things out, in terms of the action, but I think the key thing is looking at the motivation. How motivated the person is, and looking at whether there are ways of increasing that.

3.3 Patient Characteristics

3.3.2 Patient Socioeconomic Circumstances

The ability of patients to self manage their condition may be related to socioeconomic circumstances. Clinicians often come from higher socioeconomic groups and need to understand that patients with less access to resources may not be so able to engage in cocreating health. Free prescriptions are helpful in providing access to healthcare but move patients away from cocreating health. Patients in better socioeconomic circumstances may be able to contribute to cocreating their own health in managing their condition in non-medical ways. They are also likely to have better health literacy and are better prepared for the cocreating health conversation, feeling more empowered to have cocreating health conversations with clinicians. Cocreating health may need clinicians to engage with people from lower socioeconomic groups differently and in different places.

A senior leader with a medical background said “. If you look at the Public Health bandings and you correlate this with attendances at secondary care, at hospitals with deprivation, people turn up at hospitals more. Culturally we've still got people who go to hospitals for treatment.

Another senior leader with a medical background said “the education or socio-economic status of the patient in private practice varies with NHS practice and can engender a different conversation.

A senior leader with a therapy background said “There is an effect of on socio-economic status and education

A second senior leader with a therapy background said “as healthcare professionals that we are wealthy in Wales and it can I think really skew our view of what’s possible for people, or what’s not easy, but what’s viable – we think it’s very easy I think to change our health habits and our patterns of behaviour.

A clinician with a medical background said **“if you work in a poor area, self help, that costs anything is probably not on. Free prescriptions are an enabler. But it does medicalise what would normally be a pharmaceutical area. I think the whole principle, it’s a mindset first. And then following on from the mindset is how do you deliver it? In poorer areas, expectations are lower, ability to take control lower, lower empowerment – people live on a day to day basis and have no experience in planning their lives on a long term basis. To make cocreating health work we will need to lift people’s expectations of their own lives. Some people have a daily lack of planning and are reactive. Unless we to lift expectations there will be difficulty in applying co-production universally**

A clinician with a therapy background said “In terms of patients who are in a better financial situation, I have patients who privately fund equipments and things, even if you’ve maybe had a discussion where you think maybe it’s not quite appropriate, or you try to sort of talk around funding and stores levels maybe that’s not appropriate, they will go above and beyond to purchase something themselves.

The people in better socio-economic areas with family support they will be encouraged to read around things more, or again they will have the educational background where they want to know more. I’d say again, from more of the lower areas you get more of the passive, willing to take advice but expecting it to be given to them.

A second clinician with a therapy background said **“There are difference between socio-economic groups in how people engage. The lower classes find it much harder. Now whether that’s because their lifestyle is different, they don’t think of healthy eating, they don’t go to gyms, they don’t do public health messages.**

if you think about the head and neck cancer group which we deal a lot with we've often said, to get those patients to engage with us we'd be much better going to the pub at lunchtime, because we'll see a lot of them there together, we'll probably get a message over.

3.4 Power Relationships

Some clinicians may see cocreating health as a challenge to their power and autonomy. Some clinicians reinforce their power by choosing to sit behind a desk or in their choice of clothes, whilst patients may not even be offered a seat or are in hospital gowns or partially clothed. Clinicians may also use non-verbal behaviour in reinforcing their power over patients, even before they start their interaction. To co create health, clinicians need confidence to equalise the power relationship with patients. Clinicians can feel a weight of responsibility from patients to be powerful, to take charge of their health. Clinicians should be aware that the interaction is of greater importance to the patient than to them. Patients start the interaction with clinicians in a position of very little power. Hospital doctors consider themselves as very powerful within healthcare. Hospital doctors may consider that the more patients they have coming to see them, the more powerful they are and this might make them less interested in cocreating health as this would reduce the number of times a patient would come to their clinic. Although clinicians consider they have power derived from their expertise, they may not be able to articulate the reasons for their opinion and the cocreating health framework will cause them to reflect on this. The cocreating health framework reduces the power imbalance by acknowledging the expert power of the patient. Deferring to the power of the authority is particularly strong in older people and this may prevent them from cocreating health. Clinicians can reinforce their power by controlling the duration of the interaction and by interrupting patients. Many clinicians may wish to maintain the power imbalance over patients. To co create health, patients need access to better sources of information to improve their knowledge, reducing the gap in expert power with clinicians. The power imbalance reduces the ability of patients to co create health. Application of the current medical model reinforces the power imbalance between clinicians and patients whilst the cocreating health framework makes this more equal. The assumed role of clinicians in telling people what to do and the implied role of patients to listen and not contribute

reinforces the power imbalance. Clinicians can struggle to interact with empowered articulate patients because they are not trained to do so, because this is unusual and because the system is not organised to facilitate this. Healthcare has developed a paternalistic culture that has taken away many of the responsibilities of patients to manage their own health and changing to cocreating health will be challenging for both patients and clinicians. Clinicians will need training in empowering patients to co create health. The power is with clinicians because they are the decision makers. Both patients and clinicians may not want the current imbalance of power, but if patients feel they have had good treatment then they tacitly accept the power imbalance, even if they haven't had good outcomes. Patients with chronic conditions may have more expert power and be more willing to co create health. The interaction between patient and clinician can shape the power balance and this includes the rationale for the discussion, which may be overtly a patient seeking an expert clinician opinion. The imbalance in power can be partly addressed by the patient having an advocate with them during the interaction. The reflective element of the cocreating health framework would help clinicians to consider whether there is an unintended imbalance in power. Educating patients and in particular their understanding that a clinician may not be able to offer a cure for a chronic condition will help to address the power imbalance and engage them in cocreating health. The power imbalance can come from learnt roles of 'clinician' and 'patient'. Some therapy professions have changed their interaction with patients to acknowledge the sharing of expertise and power. Clinicians frequently choose not to refer patients to educated patient programmes because they want to maintain their expert power. Clinicians can feel exposed if the power relationship is more equal, and this may be more of a challenge for professions such as surgeons. The imbalance in power between patients and clinicians can become a co-dependent relationship.

One policy lead said **“I don't know of any health professional who wouldn't say that the cocreating health framework is a good thing. But some will see it as a threat to their autonomy. Others are already in a position of power, and would say that they don't need others to tell them what to do.**

A policy lead with a medical background said “A simple point, and it’s an old chestnut is the position at which you sit around a desk. I always sat on the same side of the desk as the patient, at the same level as the patient, with the patient

For a lot of clinicians, power is something they like to preserve. I think it takes a certain confidence and openness to allow yourself to be at the same level as the patient

a lot of clinicians think that the pressure on them in terms of the number of patients, and that the expectation of them is dealing with a lot of people, means not so much that they have the power but that they have almost the responsibility in the situation, to take the lead, and keep the show on the road

But the clinician has to recognise the importance of that consultation to each patient. But it’s a more important consultation for the patient than it is for the doctor.

You bring people into your clinic in a sense as supplicants for your information, wisdom and your advice,

If you’re a hospital doctor you tend to think you’re the main player, the larger the body of patients that have your name attached to them as their consultant, the greater your power and influence. Often only in your own mind, but that’s how a lot of colleagues will see it. They will keep a lot of people under their wing unnecessarily.

There’s huge amounts of non verbal behaviour in the relationship between professional and the public that would need to be taken into account if you tried this dramatic and comprehensive shift.

A policy lead with a nursing background said “I think **nursing is still very much wedded to the notion of the expert practitioner**. As described back in the ‘80’s by Patricia Bannerman and people like that. You know, the expert can’t actually articulate

their expert decisions. So you walk into a situation and you just know what to do. You can't properly articulate it. But nevertheless you just have a gut feeling of doing the right thing.

You're saying that the patient is the expert in what they need as an individual and the clinician's job is to help and facilitate them to discover, and turn into action what they need.

A third policy lead said **"the attitude of previous generations was not to challenge, not to engage in their own health but to do what the doctor says.**

I would say that things have probably changed, but if you go back to earlier generations, the 'Doctor' was perceived as some sort of deity in the community. And that's less so now, but the culture of previous generations has been not to challenge, not to question, not to really engage with the doctor, because what the doctor said went. If the doctor said you take these tablets three times a day, you take those tablets three times a day.

A fourth policy lead said **"Doctors tend to interrupt patients. They have got X minutes for the consultation and have to get to the point quickly. Patients never interrupt doctors. To speed through the appointment, patients may not be allowed a seat and will have to stand up during consultation. Many doctors want to be in control during the consultation.**

There is an unequal power relationship between patients and clinicians. The clinician's position in sitting behind a desk emphasises the difference in power. Doctors and patients should sit on the same side, at the same level. The fact that desks are set up in opposition is symbolic. The evidence is that relationships between patients and clinicians are better if they are both sat on the same side of the desk. This is a sign of respect and says 'I'm in the same place as you, just another person trying to help you'. Patients may not be able to interact with doctors wearing suits as this emphasises the 'class' differences. The non-verbal behaviour in the relationship between professionals and the public needs to be taken into account if radical and comprehensive changes are to be made. For many clinicians, this power relationship is something they want

to preserve. It takes confidence and openness from clinicians to have a more equal relationship with patients.

There is a need to resolve the asymmetry of power and information, that there is a need to get good information into the hands of the public to enable them to have an equal discussion with clinicians.

The current imbalance in power undermines the responsibility of patients to manage their own health. Patients in the clinic have the role of supplicants for treatment and advice.

A fourth policy lead said “coproduction is about power.

One senior leader said “It is not conscious decision of doctors to have power, this is a consequence of the traditional medical model”. A second senior leader said “there is an issue around the power relationship between patients and clinicians. Some clinicians assume that their role is to tell people what to do and some patients feel their role is to listen and acquiesce. For example, in a consultation, patients can be on edge of couch or partially dressed with the clinician behind the desk, in a suit. This reinforces the power relationship. The expectation of both patients and clinicians is that clinicians will talk, and patients will listen and if there is silence this is uncomfortable for both”.

A senior leader with a medical background said “I think clinicians struggle with very empowered, articulate patients. And actually, that’s not universal. I think some clinicians do. Because it’s un-nerving, not because they resent it, it’s un-nerving. It’s out of the ordinary. The whole culture of medicine is paternalistic. I don’t think it’s necessarily because doctors set out this way. I think the whole system is set up to be paternalistic. So a patient comes in and says ‘ive got these problems and I was hoping you can sort it out. And I’m here expecting you to tell me what you’re going to do to me to sort it out. ‘And the doctor kind of responds to that in a way and goes ‘yeah, I can sort that out for you. Ive got a solution for that.’ The whole language around the ‘consultation’ is I’m coming to you as a patient and you’re giving me your opinion. ‘I went to see the specialist, I went up the doctors’, ‘he said ‘it was the worst he’d ever seen’ ‘but he thought he could put me right’. ‘I need to go under the knife’.

A senior leader with a medical background said “I think we’ve developed a culture of paternalism, I think that health has taken many aspects of self care into itself that means we will now need to do an active process of then passing that back to patients. So I think that reluctance to let go of that comes from both patients and professionals. I think it’s also difficult for some groups of doctors, particularly older ones who’ve trained in a paternalistic role, that’s what they feel is good and also of course from a patient perspective they very often ask what would you do doctor,

We will need to support and train doctors in how to cope with addressing that in a different way, because it’s very tempting, particularly with limited time, to give the answer. And how you help doctors to have more of a counselling, coaching approach. That doesn’t just give the answers, and in fact if you do that which impedes patients from taking ownership and keeps the system as it is, I don’t think it’s very often through a conscious desire to have power, I think it’s the traditional medical model and I think we need to look at what the evidence shows is effective ways of changing that culture both from a professional and from a patient perspective.

A second senior leader with a medical background said “the power relationship between the patient and the clinician needs to be reversed doesn’t it. Simplistically I would say the power is with the consultant because you only get what the doctor offers, and it might be what the GP says as well as the consultant, but you only get what they offer. And yes, patients can ask, and they can push and some patients may get more out of what a single doctor can offer than others do, get more intensive care, whatever but at the end of day the doctor decides what they offer. So the power in effect is there.

The current power relationship, isn’t comfortable for the patient and the clinician.

If the patient feels they’ve had really good care, they’ll feel quite relaxed about this, and actually have confidence and feel they’ve been treated well. I do know family and

friends who've gone through the system in Wales and elsewhere who've had good outcomes and have felt they've been managed really well and have got no comment, no critical comments whatsoever. As a doctor, I think some of my friends have had pretty poor outcomes, but they think they've had wonderful outcomes and they think they've got no criticisms, and I wouldn't dream of undermining that. And conversely people could have very good outcomes and think they've had a bad experience. So some of this is about how they've been listened to and respected on the way, isn't it. And there's also that the patient has a hand in their own recovery as well.

A policy lead with a nursing background said **“there'll be an imbalance in power depending on how expert the patient is in understanding the condition, so chronic conditions the patients are on more equal footing with the doctors, depending on how often or not they see the therapist or senior nurse or senior health professional, because they get to learn how to manage it.**

The model would help and try to address the power imbalance because you're almost inviting the patient to take the driving seat. So I do think that it would suggest to me that the model itself would be helpful in framing the conversations, which actually puts more power back to the patient. There has to still be a degree of willingness on both sides to allow that power to shift from one to the other. Because obviously they've come to see a health professional for expert advice, so the expertise in itself is a power thing. It's a powerful thing to have knowledge, knowledge is power is where the saying comes from.

There would be an educational element for the professional to understand that the way that they shape the conversation actually will change the dynamic of the conversation. And some people won't want the dynamic of the conversation changed. Because they will say you've come to see me, I'm a world famous neurosurgeon and you want to hear my advice, I'll give you my advice.

I do think there should be something about engaging with other family members or other decision makers. You think of a pregnant woman coming in for decisions about where she wants to give birth, her partner, her mother, her best friend who's going to be the birth partner might want to be part of the

conversation.

Reflection wouldn't necessarily mean that they are putting the power where the patient is, because they might reflect on how they took charge. So where reflection is useful it doesn't necessarily direct actions. You have to sign up to a way of thinking and behaving. It's supportive for sure to think how effective was I in enabling the patient to take charge or whatever, but they have to have thought that's the way we're going to practice. It won't make them practice in that way.

A senior leader with a nursing background said ". **My mother herself, she's got copd and I've seen quite a shift over the last couple of years very much deferential to the GP which still remains, and to the nurse in the beginning. So I think there is something about training and supporting people to do that, and to have those slightly more challenging personal conversations, and perhaps being a bit more vulnerable in acknowledging what we can and can't do with a magic wand, you know**

A second senior leader with a nursing background said "Some clinicians think it's their role to tell patients what to do, and a lot of patients do feel their role is to listen, and if not to do it, at least to listen and acquiesce.

I remember going to a clinic with my father, I went in with him because his hearing wasn't brilliant, he sat on the edge of the examination couch, I'm stood up and you think you know, that's not the setting to have a discussion in, and the power was there because the guy is stood up, and you think that's not conducive to the 'lets look at an option grid lets sit down and.. So now I know why we are constrained by our environments. I'm convinced that the impression of power is you behind a desk or you in an inappropriate setting,

A senior leader with a therapy background said "I think the power imbalance is always in the background. And what you're talking about here is that we've done something

for thirty years and the **public go and see their doctor and what the doctor does is give them something.**

You'll never divorce power out of the NHS. It is what it is. There's power on a number of different levels. There's hierarchical power, personal power, expert power. I think it is something that will have to be worked through. I think we are in a very privileged position as healthcare professionals. And there are not many professions with that standing.

A second senior leader with a therapy background said **"early in my career we had a set of language which was about my patient, and I have always stood against that. That was the medical model and I remember many a time taking a dietician up who would say my patient, 'they're not my patient' they're not your patient, they're their own people and that's very much the medical model. I don't hear that being said very much anymore come to think about it and I would like to think that we have changed.**

A senior leader engaged in the EPP said **"Doctors feel that they manage the patients and they don't want interference in the way the patients feel about their condition.**

Clinicians of all types, doctors, nurses, feel that it's their job to manage the patient. **The majority would say they found it difficult because 'we manage you', you listen to us and you do as we say.**

A clinician with a medical background said **"By implementing the framework it's inevitable that there would be transfer of power from the clinician to the patient.**

GP trainees, they come in and there's nothing to shelter behind. You're on a one to one basis with the patient, sometimes on their territory, in home visits and whatever, and you haven't got the white coat, you haven't got the team to protect you. You're just exposed and that can be quite challenging.

So I think a lot of clinicians shelter behind the power. And it will be quite challenging for them, whereas others are used to working with patients and

families, and they will find it easier. I can imagine some surgeons would find it extremely challenging.

One clinician said “there is a power relationship between patients and clinicians. We need both patients and clinicians to address this as it is currently a co-dependent relationship. Patients have a dependency which is like a comfort blanket. The downside of this is that this co-dependency is like substance misuse or an eating disorder. There is an overwhelming need to address the dependency of both patients and clinicians. Clinicians are under great stress due to coping with the dependent relationship.

A clinician with a therapy background said “patients know what your role is from how you dress. So they know doctor t is a senior doctor, they know that from his age, he wears a tie, he always has an ironed shirt, maybe some of the younger doctors don’t look quite so formal etc. So they respond differently to a senior doctor and a junior doctor.

A second clinician with a therapy background said “the patients see the consultants as the person with power.

4 Support Factors

The previous factors determined intent to co create health, but the actual cocreating health behaviours where intent became action was found to be dependent on :

4.1 Patient Training

The EPP programme prepares patients for cocreating health through providing them with knowledge, empowerment and problem solving skills. Clinicians are not generally supportive of the EPP programme. Although the benefits of patient education are known by some clinicians, there is a lack of capacity to offer this routinely. Ninety per cent of patients who complete the EPP programme are able to engage in cocreating health.

A clinician engaged in the EPP said “we only work with patients with long term health condition. The course is delivered using CBT and the purpose of the course is to empower patient to participate in own health care. The CBT works through repetition of action planning and repetition of problem solving. Patients are taken through a range of issues with long term conditions as a peer support group. At the end of a week session we need to make it clear to participants that problem solving solutions have been constructed by them. This enforces self empowerment. Patients are more prepared to work with clash of cultures, they know to participate, to take part in the consultation. They are prepared using a four stage formula, which is prepare, ask questions, repeat the answers to ensure accuracy of communication and take action by acting on what is agreed. Through this training, people fall into empowerment through repetition.

We get more referrals from dentists and the private sector than GPs. We find that our co-ordinators have to go out to GP surgeries to get them to send patients. It is as if clinicians don't want to know that there is an education programme available for patients.

A second clinician engaged with the EPP said “There is resistance from doctors and nurses to sending patients on the expert patient programme. When patients have a consultation they are not sure what to do. We need to change the attitudes of both doctors and patients to long term conditions. There are very few referrals from GPs to the expert patient programme. Doctors don't like patients to consider themselves as ‘expert’.

A clinician with a background in therapy said “**we offer a patient self management course, but a very low number, less than ten per cent of people with lymphoedema go on these courses at the moment.** We've got 8500 patients in Wales with lymphoedema, I would say less than 500. Probably a couple of hundred have been on the course. The whole lot, eight thousand five hundred would benefit from the course.

A senior leader engaged with the EPP said “I think a lot of people change during the programme, a high percentage. The ten percent who have the potential to change but haven’t shown any signs of it we see four months later. I suppose everyone’s got a different story but I think some of them have made lots of changes within that four months and maybe that’s about accepting the things they can and can’t do realistically.

4.2 Leadership Support

Leadership provided by senior clinicians will be required to implement the cocreating health framework. Leadership is required to generate enthusiasm for change and to show the way. The cocreating health framework will need champions who are opinion leaders for its implementation. The cocreating health framework requires leadership and passion at every level of management and clinical leadership.

A policy lead said “there are not enough role models to drive behaviour. We need communities and leaders to be engaged. In particular, we need to know how to create a cadre of senior clinicians who can be on board to create leadership, drive, assurance and to encourage co-production behaviour”.

The power of leadership was described by a second policy lead “Enthusiasm and knowledge will engage people. If they say – we need to change, and we know how this can happen, and explain how this will help you then people are very positive about a change.”.

A third policy lead for coproduction said “we need champions on a public platform who have had high quality leadership training to include a systems-thinking perspective.”

A fifth policy lead said “If you can get buy in at that level.. Then you need some champions don’t you. Promote it

A third policy lead said “I do think we need to get the clinician alongside us,

A senior leader with a therapy background said “you also need to have your personal responsibilities, and I think your personal responsibility of being passionate, being

motivated, being caring, dealing with people as you want to be dealt with – that has to be there. And what worked a year ago, might not work now. And don't be afraid of failure, because failure is actually a learning experience, and from my experiences, ok if somebody shuts the door on you not only might find a window open but you might find a patio door which is actually better than the door, and that's the way I've always worked. And some things that we've done don't work and it's so what, it didn't work. You've got to have leaders, you've got to have a passion, you've got to be aware of change, you've got to pull people with you.

4.3 Clinical Framework to support Cocreating Health

Interviewees were asked to comment on the framework and its implementation.

The cocreating health framework is considered comprehensive but needs to be described in language that demonstrates it is different from current practise and encourages its adoption. Implementation of the framework should be phased and will require tools to embed it in practise. Implementation will require a jointly owned management plan. To co create health, clinicians will need training to develop some additional skills such as self management support. For clinicians to support the cocreating health framework it will require them to have ownership of it through being involved in its development. An evidence base is required to demonstrate the efficacy of adopting the cocreating health framework, that it adds value to patient outcomes and can be incorporated into the daily work of clinicians rather than being an 'add on'. We need to carefully plan implementation of the cocreating health framework in the recognition that if this is not done well, it will be some years before we can try again. Implementation of the cocreating health framework could deliver a better agency relationship which is currently partial due to clinicians having incomplete information. The cocreating health framework is a very different model than that currently practised by doctors and nurses. Improvement resource is directed towards high priority issues and there may not be resource to spend in supporting widespread implementation of the cocreating health framework. The cocreating health framework may be implemented independently by a number of enthusiastic teams. E-learning can be used to spread cocreating health more widely. Cocreating health will fundamentally

challenge the innate desire of nurses to care for people. The cocreating health framework presents a very different conceptual model to current thinking. Patients will need to understand the benefits they may realise from engaging in cocreating health. The cocreating health framework will fundamentally change the relationship between patients and clinicians. The cocreating health framework is fundamentally about establishing relationships and trust between patients and clinicians through a consistent interaction over time. The support of leaders for the cocreating health framework will give clinicians permission to be engaged in person centred care.

A clinician “considered that the Cocreating Health Framework is very comprehensive”. She also said that the **challenges in GPs implementing the framework included “how to phase the implementation”, and that “the framework needs to be described succinctly in language in which GPs can engage. You need to communicate a message that cocreating health is different to the current model of practise” and that “Implementation will require tools to support it”**. In her view, **cocreating health has two linked requirements, namely : “Firstly, a case planning approach where everyone has a clear understanding of the needs of their condition; who’s involved, joint self management, ownership, when need to seek help”. Secondly, “doctors need to be taught how to provide patients with self management support skills and how to provide patients with appropriate information”**. She also considered that “in order to implement widespread change to a cocreating health approach we need to : **Involve clinicians in the design of the cocreating health Framework ; Use appropriate language that will engage doctors ; Ensure that implementing cocreating health will have an added value ; Ensure doctors will convey the message about the cocreating health framework to colleagues”** She felt that we need to understand from GPs : **“What do they need to implement cocreating health ; How to make the cocreating health framework fit for purpose ; How to ensure that the cocreating health framework facilitates consultation rather than adds to workload”**. She expressed concern that “if we get the implementation of cocreating health wrong it will be two to three years before we can try again” and that “we need to decide how to spend time, effort and resource in implementing the cocreating health framework”.

A policy lead said “I think the framework is moving towards a better agency relationship, if that is what is required. Because the nature and complexity of health and social care the consumer, the patient is unable to acquire all of the knowledge to be able to make an informed judgement and an informed decision. That’s where the agent comes in. To provide that context, to provide that Rather than provide partial information and indeed make recommendations. That is a seismic shift for some professionals.

A policy lead with a background in nursing said “**the framework entails quite a significant shift in attitudes, philosophy, from this idea of the practitioner, particularly the doctor, acting as the expert. Because this isn’t an expert role at all, is it ? This is a facilitating role. A coaching role. This isn’t an add on at the end. Because this involves a change of attitude and a change of perception as to what the nurses’ role is.**

A second senior leader said “we are working with service improvement teams to embed shared decision making in pathways. But this may stop as improvement resource is targeted at unscheduled care. The e-learning challenge is getting people to find time to do this and we may need an incentive. The way to do this is to work with individual clinical teams and use students. E-learning is scaleable in terms of access.

A senior leader with a nursing background said “So how do we get some sort of new currency by which practitioners can use that as a value for their own efforts. And of course people are very caring, and hopefully we have got people who want to make a difference, but make a difference by doing more and more and more. So actually it is **fundamentally challenging to people to do less**, but to get bigger impact I think, and having those challenging conversations

A senior leader with a therapy background said “taking the patient on a journey that they haven’t been on before and there’s something around shared understanding. This to me **creates a very different thinking model than we have now.**

Most interviewees pointed to the importance of the cocreating health framework of having realisable benefits to engage people in embedding the framework into practise. One policy lead said “there is an opportunity to make co-production work in the healthcare system. Austerity may force coproduction as a systems issue. If we can get this right, coproduction may attract European funding. There is currently an issue of over and under treatment. In the focus on waste, harm and variation, cocreating health adds weight as there is variation in over-provision. The ultimate test is whether the cocreating health framework will provide outcomes valued by patients and clinicians. There is a need to appropriate the tools that others have, to use outcomes and performance management to serve the purposes of co-production. We need to address the gaps by reducing unit costs, reducing demand by implementing public health measures and increase supply using self care, mobilising the population around their own health”.

A senior leader said “you will need to involve patients in the implementation of the cocreating health framework. You need to be able to describe to patients what is the essence that gives added value that they don’t have at the moment from the current medical model. You need to understand from GPs what do they need to do to implement cocreating health, how to make the cocreating health framework fit for purpose and how to ensure that the cocreating health framework facilitates consultation rather than adds to workload”.

One policy lead said “one **challenge for coproduction is changing the relationship between patients and clinicians**”.

A senior leader with a nursing background said “My sense of it **is the framework allows a number of contacts, and I think that’s about the relationship building and the trust. Actually the building of the relationship over time allows the individual to become more evenly balanced with the professional.**

confidence has only grown through a period of knowing the same person and having that relationship that means I think you’re not going to drop me here or leave me too much on my own if I need you but you’re giving me more space

within which I can operate within my own parameters and I know (and I'm speaking for my mother now), I know that I can do this, and this but if I'm feeling like this then I can take the next step and I can start the antibiotics, or do whatever. So I think there's some important things in here. One is about the **continuity of seeing the same person and building the trust**.

A senior leader said "we need to see **co-creating health as a continuum rather than isolated entities and to link back to a relationship centred approach**".

A clinician with a therapy background said "**some patients are on the ward for such a long time that you build up quite close relationships with them, you end up knowing them very very well, and inevitably a dynamic builds up where they know what kind of person you are, and you have a rapport**".

A second clinician with a therapy background said "the **cocreating health framework gives the permission to return, and to use a more patient centred approach**".

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5 Controls

Factors that negatively influenced intention to co create health were contentment with current ways of working and the mistaken perception that this practise is consistent

with cocreating health. System factors acting as controls included the way interactions with patients are currently organised and perceived lack of time to engage in longer interactions. Patient factors acting as controls included patient's perceived lack of willingness to engage. Infrastructure controls were particularly centred around the lack of shareable electronic patient records. Clinician factors acting as controls included the perception of risk to patients of being offered and choosing an option uncomfortable to clinicians, and most importantly the current power relationships.

One policy lead said **“There are currently issues with unnecessary referrals, treatment, tests - need to get wasteful processes out of the Welsh healthcare system. There is risk aversion in the Welsh healthcare system. There is a perceived need to cover all angles rather than only perform tests for red flags.** The cocreating health framework is encouraging”. A second policy lead said “the research shows that if we give people a cooling off period after being offered surgery then twenty to thirty per cent will say no. There is an issue of over and under treatment with waste, harm and variation. There is variation in over-provision. The management structure can help with this. For example NICE guidance around do not do list, Interventions not normally undertaken. **There is variation in production and clinicians have different thresholds. At the moment people want more, more intervention and feel better if they have something done to them. In England, funding is being supplied to meet consumer demand for intervention. In Wales there is an expectation that GPs will deal with all minor problems. The population feels that there is something there that they can have and this is deep rooted in the UK system”**

A policy lead with a medical background said “We tend to just give the intervention, and a bit of advice, and hope that the lifestyle change will follow the intervention but actually we should use the intervention as a motivator for lifestyle change. And actually Cwm Taff is starting to do some work with their cardiologist. So some of the steps the minister has outlined, they were looking at NICE guidance around not doing stuff as much as doing stuff. Looking at the interventions not normally funded, are we rigorous about those? I think we should look at variation and in a sense look at variation to understand to what extent variation is over production as much as production. I think that we'll **find there's a different threshold within different specialities and**

circumstances. But at the heart of it is about these individual clinical decisions. It is clinicians who put people up the escalator. It's about what you need isn't it. It's about providing what you need but no more. At the moment in the middle of secondary care.. Say you've got somebody who needs cardiac specialist intervention in the community they have to come into secondary care. Chances are they'll spend time in hospital with the attendant costs and risks. And they may get a bunch of investigations and other procedures or whatever and then their need is identified and they get specialist care. All of that potentially has been a waste of money and time and against their interests. If somehow we can speed that up and cut out this muddle here then that is proportionate and it's prudent. Just identify the need and let them have it. The NHS needs to focus on maintaining the independent living of patients rather than creating dependence by intervention”.

A senior leader said “Physios have an information base to support people where referral to a doctor is not warranted, for example giving advice on self-management in patients with upper limb issues. **When GPs are unsure of whether surgery would be beneficial it would help if they could discuss this with a secondary care clinician rather than referring in to the hospital”.**

A clinician with a medical background said “My view is that **part of the model is wrong that we use, cos my view of healthcare is you start off with the GP and hit a problem and maybe you need to investigate, so it's a series of whys whereas I think in hospital it's seen as a ladder. The trouble is when you get to the top of a ladder it's a long way down. So if you go to the top of a ladder, and the top of the ladder says you need some psychological help well then it's a long way down back on to the GP. so what I'd like to see is you talk to the patient, you prescribe something, that doesn't work you go to the next level which is to investigate it. It comes back to the GP, put it in context, discuss it again. Goes up again, you need to see a MCAS, that doesn't work, you might find something, you go up again, but you keep working back to the GP to put it back in perspective. And I think colleagues who do the clever stuff need to start getting hold of putting it in the perspective of the patients life. It's not the condition, it's the patient with the condition. And I think that is where secondary specialist care your intervention comes in and it's putting it into that context.**