THE ROLE OF CONTEXT AND PROFESSIONAL AGENCY IN THE SPREAD OF HEALTHCARE INNOVATION

An exploratory study of healthcare professionals' views of diabetes self-management and the X-PERT Programme

by Josephine Go Jefferies

2012

A dissertation presented in part consideration for the degree of Master of Research

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Abstract

This study explores the views of a network of healthcare professionals who, in addition to their main clinical roles and related professional training duties, are also trained patient educators (Educators) delivering a structured education (SE) programme to adults with diabetes. The author engages with literature on self-management and institutional change in healthcare and closely considers factors affecting implementation of self-management and structured education. The research aims to show the mental framing that Educators use when considering self-management, and the implications for the spread of self-management diffusion at the micro-organisational level. It does this by analysing Educators' beliefs and attitudes to diabetes self-management and SE, and then situates their responses using theoretical frameworks to identify and explain institutional change processes taking place. Echoing Coulter's (2012) findings from her study into leadership and patient engagement, my study shows that healthcare professionals hold positive views about being an Educator chiefly as it allows them to acquire new knowledge and skills, which allows them to improve professional effectiveness and patient outcomes. This can be interpreted as new cultural-cognitive and normative elements creating a new institutional logic at the micro-organisational level. Being an Educator also allows them to mitigate effects of poor practice elsewhere in the diabetes care network resulting in better patient outcomes; they do this through exploiting micro-institutional affordances in a highly structured institution like the NHS. This enactment can be interpreted as forming new regulative elements. The study makes a novel contribution to the literature on self-management by addressing the views of healthcare professionals and healthcare innovation by showing how their engagement means self-management is becoming institutionalised.

Acknowledgements

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List of Abbreviations

ANT	Actor-Network Theory
BMI	Body Mass Index
CCG	Clinical Commissioning Groups
CCM	Chronic Care Model
CG	Clinical Guidelines
CHD	Coronary Heart Disease
DH	Department of Health
DSN	Diabetes Specialist Nurse
EBM	Evidence-based medicine
GP	General Practitioner
HbA1c	Glycosylated Haemoglobin molecule (blood glucose test)
LES	Local Enhanced Service
LTC	Long-Term Conditions
NHS	National Health Service
NICE	National Institute for Health and Clinical Excellence
NPM	New Public Management
PCC	Patient-centred care
PCT	Primary Care Trust
PN	Practice Nurse
QISMET	Quality Institute for Self-Management Education and Training
QOF	Quality and Outcomes Framework
RBR	Repertoire-Building Research
RCT	Randomised Control Trial
SE	Structured Education
WHO	World Health Organization

Chapter 1: Introduction

This dissertation presents empirical research into the diffusion of healthcare innovation by exploring the spread of diabetes self-management approaches through structured education programmes. The cost of caring for long-term conditions (LTC) is approximately 70 per cent of NHS spending (Coulter, 2012) and is forecast to increase. The self-management approach increases patient empowerment and engagement in their healthcare. Through self-management education programmes patients are taught to manage the symptoms of LTC and thereby contain utilisation of healthcare resources. In several international contexts the provision of self-management education has been integrated into strategies for improving quality of healthcare in order to meet the needs of rising demand for LTC care. Structured education (SE) was introduced in the UK to assist healthcare commissioners to identify self-management education programmes that conform to quality criteria and also to distinguish it from traditional forms of patient education efforts. SE consists of theory-driven, evidence-based organised group learning experiences focusing on the acquisition of relevant therapeutic and health promoting behaviours by patients and their carers.

This chapter explains the importance of the research topic and summarises the theoretical perspectives that informed the research design.

1.1 Why this study is important

This study addresses one of the biggest global challenges to healthcare: chronic disease. A chronic disease is a long-term incurable condition with typically slow progression that requires daily care. Non-communicable conditions[1] and mental disorders accounted for 47% of the burden of disease in 2002 and are projected to increase to 60% by the year 2020 (Epping-Jordan et al., 2004). In the UK the cost of LTC care is disproportionately large and forecast to increase: 15 million patients or less than a quarter of the total population accounted for 75% of the NHS budget in 2009 (Cruickshank et al., 2010). Addressing LTC is especially important in light of demographic trends forecasting a rise in prevalence by 2020 due to the ageing baby-boomer generation maturing into a lifestage with increased incidence of chronic disease (Bodenheimer et al., 2002).

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[1] A non-exhaustive list of examples of non-communicable chronic disease include: coronary heart disease, cardiovascular disease, hypertension, chronic obstructive pulmonary disease, asthma, diabetes, stroke, kidney disease, blindness, rheumatoid arthritis, cancer, HIV/AIDS and mental health problems.

This study analyses the views of healthcare professionals working in diabetes care. Diabetes mellitus is characterised by the body's inability to effectively produce insulin resulting in intolerance to blood glucose. If uncontrolled it is a debilitating illness and significantly increases the risk of developing other serious comorbidities including painful chronic infections, blindness, heart and kidney disease, and limb amputation. Diabetes is a healthcare priority because incidence and prevalence are growing globally. People can be born with a condition of glucose intolerance (Type 1), or they can develop it, usually as a result of prolonged exposure to risky health behaviours (Type 2). The negative economic and social impacts of illness and permanent disability from diabetes can lead to loss of earnings for individuals and their households. Across all categories of national economic development, poor diabetes management contributes to poverty and is exacerbated by social factors such as poor health literacy, engaging in risky health behaviours, poor diet, and poor access to quality health care.

My research focuses on the contribution that quality of healthcare makes to diabetes management. It does this by studying the implementation of UK policy requiring all newly diagnosed diabetes patients to access SE and seeing whether the driving principles behind policy encouraging patient self-management are becoming institutionalised in terms of attitudes, beliefs, behaviours and routines in a sample of healthcare professionals.

1.2 Theoretical approach

Extant literature on self-management and SE does not identify factors and processes that influence self-management institutionalisation from the perspective of healthcare professionals who are SE Educators. My study explores the mental framing that Educators employ when considering self-management and SE because it influences the generation and mobilisation of ideas and meaning by actors in social movements. Because so little is known about SE Educators as a group, my approach to the research topic and research questions is exploratory. The two-fold aims of this research are 1) to identify the mental framing and 2) to understand the way it influences the institutionalisation of self-management and SE.

My approach is based on sociological theory where individual actors are considered according to their agency or actions at a micro-level within larger scale social structures, and micro-level structures involved in human interaction (Ritzer & Goodman, 2004). Giddens (1984) elaborated on the interdependence of agency and structure: by engaging in human practices, individuals adapt their consciousness of social conditions and thereby their actions, according to changes in their understanding of the social structure. The reproduced social practices and relations between actors make up structures that can be seen as constraining as well as enabling.

The Educators are healthcare professionals. Professional agency is a perspective focusing on members of the professions[2]: Schon (1991) argues that the way professionals engage as agents with structure is attributable to their privileged status within social structures. According to Schon professional agency results in routines and practices that foster a sense of security and sustain their status and freedom to operate in relative autonomy. Conceptualising the changing role of professionals in society, Scott (2008b) studied the leading role of professionals as a collective entity in preserving institutions that: create normative pressures and prescribe behaviour; operate on a cultural-cognitive level by conferring value on the knowledge they own and through which distinguish between legitimate and illegitimate forms of knowledge; as well as exerting coercive authority. Like Schon, Scott suggests that professions adhere to institutions but use them in different ways; he shows the network effects of professionals to govern each other through professional associations are powerful and transcend national structures.

The link between agency theory and institutional theory can be understood through studying individual behaviours, as interpersonal micro-level exchanges, and how collectively individual behaviours can cause macro-level change in structures. One way of interrogating this extension from individual action to group behaviours is through network theory. Network theorists moved the focus from the perspective of individuals and instead studied the relationships and patterns of ties that link individuals. Network actors can be individuals, groups, societies or corporate entities. The bonds between actors are usually studied according to whether they are strong or weak ties and what this typology implies for explaining or predicting actor behaviour which influences structures (Ritzer & Goodman, 2004). The influence of strong or weak ties has been interpreted by network theorists as influencing agency insofar as they manifest as constraining or enabling structures. My study considers the spread of self-management and SE according to influence of networks on Educator behaviours. It examines the role of context in professional agency by considering the influence of network structures and agency freedom on Educators' mental framing and self-management institutionalisation. The study

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[2] Schon (1991) included teachers, lawyers, health professionals and architects in this classification because of their years of training and technical knowledge.

has practical implications for those interested in the spread of self-management and specifically X-PERT structured education.

This research joins a large pool of literature studying self-management as well as the agency of professionals to promote or inhibit innovation (see examples: Chreim et al., 2012; Dopson et al., 2008; Ferlie et al., 2005; Mascia & Cicchetti, 2011; McWilliam et al., 2008; Scott, 2008b; Scott et al., 2000). Institutional theory is commonly used to explain the processes by which innovation becomes institutionalised. This is problematised by the lack of a clear definition for when an innovation becomes institutionalised (Bridges et al., 2007). DiMaggio and Powell (1983) describe characteristics of the institutionalisation process, or 'structuration', at the organisational field level[3]. They argue that structuration is observable by the extent to which coherent structures or patterns of interaction occur, such as:

> *increasing interaction rates, amount of shared information, mutual awareness and shared governance arrangements* … the process by which an orderly social structure is constructed over time by the *interactions of a shifting set of collective and individual actor*s (Scott et al., 2000, pp. 26-7) (my emphasis).

Institutionalisation can also be identified using Scott's (1995) Pillars Framework that suggests changes in the regulative, normative and cultural-cognitive elements that are present in all institutions are indications of institutionalisation.[4]

1.2.1 New approaches to considering the role of context

The study considers the highly complex healthcare context (Dopson et al., 2008). My understanding of how the data relates to the role of context is informed by van Dijk et al.'s (2011) study of radical innovation diffusion through legitimacy crises in

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[3] 'Fields only exist to the extent that they are institutionally defined. The process of institutional definition, or 'structuration,' consists of four parts: an increase in the extent of interaction among organizations in the field; the emergence of sharply defined interorganizational structures of domination and patterns of coalition; an increase in the information load with which organizations in a field must contend; and the development of a mutual awareness among participants in a set of organizations that they are involved in a common enterprise.' (DiMaggio & Powell, 1983, p.65)

[4] As Scott (2004) suggests, the pillars framework is useful for considering institutional change by assessing structures that underlie enduring and stable institutions. Scott et al. (2000, p. 168) assert that '[all] institutions incorporate one or more of the three pillars' (regulative, normative and cultural-cognitive structures) in varying combinations. Institutional forms differ in the priority accorded one or another element, and institutional scholars vary in the attention granted to the elements.'

technology companies. They focus on configurational interstices in Scott's pillars framework. Their paper added to my processual understanding of Giddens' (1984) structuration concept. In particular van Dijk et al. describe micro-institutional affordances that include a temporal dimension (which I understand to be agency enactment opportunities) as a contextually important factor in innovation diffusion. I found this a useful conceptualisation of context – as time and institutional circumstance – and innovation diffusion being dependent on the identification of a path of least resistance for actors to exercise their agency opportunistically. These configurational interstices allow institutional actors to attract allies and support for changing behavioural templates, especially when attempting to resolve legitimacy crises. Legitimacy crises, over what an organisation does or should do, occur as a result of disagreement over the advantages of an innovation over the prevailing model or institutional logics in a given context.

1.2.2 Professional agency

The research considers personal and professional motivations for becoming an Educator to promote change through self-management and SE. This has implications for understanding why busy healthcare professionals decide firstly to take on more work and secondly to adopt changes to practice that challenge long-established ontological assumptions. Such assumptions have been described as the basis of a privileged position in society for professionals: including having the right to tell patients what to do based on their superior knowledge, and being entrusted to practice in relative autonomy (Schon, 1991). Two examples of shifts showing what is at stake include changes to the notion of *what healthcare professionals do* and *what they believe their role to be.*

Professional self-interest has been a theme in healthcare studies in terms of identity-formation through Bourdieu's habitus (McDonald, 2009) or self-governance of professional associations (Scott, 2008b) and these in their own way can be construed as interpretations of the role of context on agency. Schon's (1991) reflective practitioner provides a slightly different view of context and agency. His work outlines an approach to professional development that embraces a maverick route to identity formation. It sees practical deviation from the strictures of institutional logics (which he refers to as knowledge-in-practice) in a highly structured field[5] as the most appropriate means to developing good clinical practice. He suggests highly skilled professionals are more equipped than others to translate these knowledge-challenging experimental departures to positive effect. Therefore the healthcare professional's role and actions are determined by the way that they contend with and transgress the constraints in their context. Ironically the duty of a professional to exercise her abilities correctly by working against accepted practice is presented by Schon as an established medical professional institutional logic. He asserts that expert professional skills bring privilege and autonomy to deviate from knowledge-in-practice. Therefore this destructuration process from constantly challenging knowledge-in-practice paradoxically conforms to dominant cultural-cognitive, regulative and normative elements; these institutional logics confirm what professionals are and do. For the purposes of this study, I wish to emphasise first that he asserts a normative expectation of deviation from institutional logics, and second that he illustrates that there is, and should be, a degree of play between parallel institutional logics that co-exist. They may be competing or rivalrous in nature, but in practice they are not depicted as destabilising the entire institutional framework that they are part of.

However, this normative reading of what a professional should do or be does not illuminate whether a professional will be motivated in context to take up a competing or rivalrous stance, especially when professionals are incentivised to conform to standardised guidelines and established knowledge-in-practice. Any individual impetus from personal motivations can be clouded or overtaken by the highly politicised external environment (e.g. over the future shape of healthcare), as can the reception of clear signals of normative behaviour (i.e. what should professionals ideally be doing to improve healthcare). Therefore I do not engage with the subject of how professionals are enacting their agency at the general level of institutional fields. Instead I consider how they are responding in their local contexts. I suggest that it is a less intimidating to subject professional decisions and reputations to scrutiny (and thereby to justify the legitimacy of their actions and behaviours) if there are fewer information asymmetries at the local level. To verify

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[5] 'The more highly structured the field, the less impetus or room there is for disconnected and distinctive actors. The less structured the field, the more latitude and stimulation there is for autonomy and innovation at the organizational level. It is a bellwether of the state of the wider healthcare field that we currently observe such vigorous organizational experimentation and exploration.' (Scott et al., 2000, p.362).

that this is true I am interested in finding out how Educators act as a result of their mental framing.

Sen's (1982) Capability Approach to human development economics addresses this idea of contextualised action. He relativises previously accepted standard measures of quality of life (e.g. prosperity and wellbeing) to the most relevant local context. He asserts that better understanding of personal fulfilment and wellbeing is reached by assessing the operation of functionings, capability and freedom. Functionings are the things that people can do within their context, and capability is the opportunity to exercise those functionings. An individual will attain fulfilment when they achieve capability to act in their local context, and wellbeing when they are aware of their freedom to act in their local context.

This applies to institutional theory as far as institutional constraints affect the way professionals conduct themselves, and the extent to which they feel free to exercise their capabilities within a local context -- without necessarily exploding the entire fabric of wider institutional structures. By this I mean they may consider and calculate the value of challenging local constraints but wider implications of this decision to act are not considered as part of the equation.

These theoretical frameworks nuance my understanding of professional agency within a highly institutionalised structure and add a new perspective to the current thinking around professionals' motivations to change accepted practice and their choice to work outside their comfort zone in a way that directly challenges their authority and previously held assumptions.

1.2.3 A theory-driven understanding of the case study context

My study considers a highly institutionalised NHS context (Scott et al., 2000) organised according to a model of medical professionalism (Giamo, 2002) and which has been subject to near constant innovation – either through the efforts of policymakers and strategic leaders, or else from continuous incursions by new research resulting in changes to standards of healthcare and treatment guidelines. Therefore healthcare can be viewed as being forever midstream in a change process. I bound my study as observing downstream developments resulting from the 10-year modernisation plan for the NHS announced in 1997 by the newly elected Labour government (DH, 1997). Modernisation in this sense meant challenging the dominance of medical professionalism by changing to a model of continuing care across integrated services that involved activation of constituents in the wider community (Ferlie, et al., 2005; Harrison, et al., 1992). As the change process has been of long duration, consequently the task of pinpointing the extent to which certain institutional logics still can be said to endure and in what form is complex because of the emergence of bundles of ideas for innovations and various change agents engaging in divergent activities in a non-linear fashion (Van de Ven et al., 1999).

Recent studies of healthcare innovation diffusion consider network effects on the behaviour of classes or grouped job roles (Battilana & Casciaro, 2012; Mascia & Cicchetti, 2011). Their work reminds me to make explicit the network that I am analysing in order to increase comparability of my findings. One aspect of the study context that made the data rich with complexity was the mix of professionals in the sample, and the fact that the network seems to be born from the self-management innovation, resulting in a nascent semi-formal professional network as a relevant unit of analysis, or context. This network's most striking characteristic is its orientation, which lies across the traditional professional categories and associations that are normally the subject of professional agency analysis in healthcare. Figure 1 depicts the variety of professions belonging to the group of self-management educators under analysis.

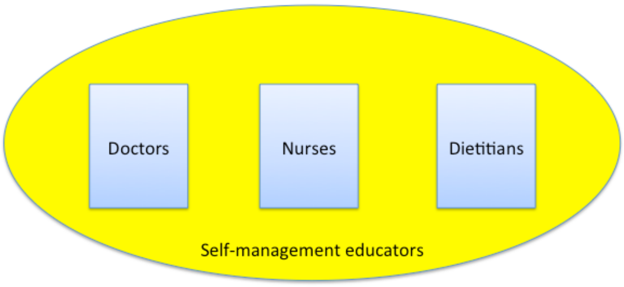

Figure 1: Self-management educators: a multiprofessional group

In their study of the nonspread of innovation due to professionalism Ferlie et al. (2005) make reference to this type of multiprofessional care team grouping, but only in terms of negative correlation to innovation diffusion, when compared to uniprofessional teams, who tend to agree together to adopt or reject an evidence-based medicine (EBM) innovation. Furthermore, I explore the validity of their assumptions to my study, especially those regarding the basis of cultural-cognitive epistemes and the influence of research cultures as an explanation for blocking innovations that contradict institutional logics.

Peckham (2003) describes the highly institutionalised NHS system. A particular institutional logic is the division of labour according to hierarchies of patient need and medical specialism. However, the nature of my network almost ignores this ordering and Educators come from all divisions without regard to service context or specialism. Figure 2 shows how the clinical roles are spread between Primary, Secondary and Community healthcare jobs, and also how the self-management educator group lies transverse across the current labour division of health service delivery contexts.

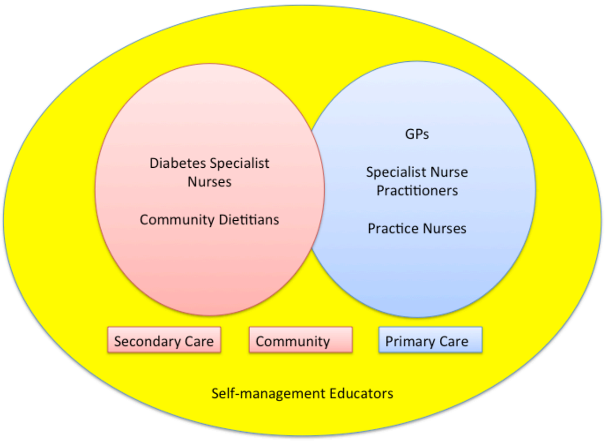

Figure 2: Self-management educators and the organisation of their clinical roles to healthcare settings

I develop my argument about the role of context in institutional change by discussing the combination of *cross-cutting* (as in cross-role and cross-hierarchy) *interpersonal dynamics as context* that play a role in whether to take part in self-management diffusion and why. I will discuss the purpose of a new type of multiprofessional network of Educators is a) to negotiate around institutionalised regulative functions that fail to engender good clinical practice and b) to establish new shared governance mechanisms to replace them.

1.3 Initiating the study

The opportunity for primary research emerged after a presentation on a digital portal for patients with long-term conditions (LTC) at the NHS Innovations conference in November 2011. The NHS project board accepted my offer of research and meetings were held in January and February 2012. I wrote a research protocol and in 18 weeks secured key NHS stakeholder support and ethical approval for the project. Key support came from the NHS PCT Self-Care Programmes Manager and the creator of the X-PERT Programme first by allowing me to observe a biannual X-PERT Educators' Update Conference and to introduce myself and the project to the cohort of potential participants; and second by emailing my recruitment advertisement (see Appendix 1) direct to potential participants.

This study focuses on one of the nationally approved SE programmes: the X-PERT Programme. X-PERT was designed by nutritionist and dietitian Dr Trudi Deakin and is based on theories of empowerment and discovery learning. In 2006 Deakin co-authored a paper reporting the results of a RCT that showed evidence of effectiveness at 14 months: adults with Type 2 diabetes who had participated in the X-PERT Programme had 'improved glycaemic control, reduced total cholesterol level, body weight, BMI and waist circumference, reduced requirement for diabetes medication, increased consumption of fruit and vegetables, enjoyment of food, knowledge of diabetes, self-empowerment, self-management skills and treatment satisfaction' (Deakin et al., 2006, p. 944).

X-PERT Educators must be qualified healthcare professionals who undergo specific training on course content, course delivery and core principles of self-management and the X-PERT approach. The design of the programme delivery is highly standardised; this means the programme can be transported to different contexts and minimises as much as possible variation attributable to the quality or motivation of the Educator (therapist effect).

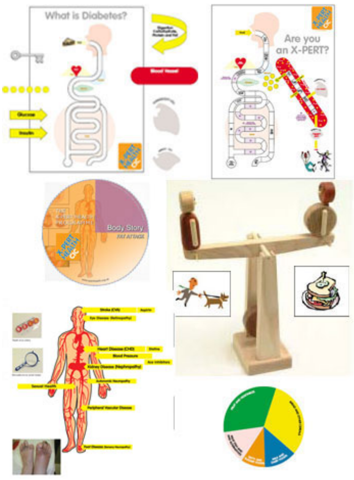

Figure 3: Examples of X-PERT visual learning tools (adapted from www.xperthealth.org.uk (Deakin, 2012))

Branded teaching tools are visual and interactive (see Figure 3) and patients who attend get a substantial handbook that serves as a teaching and reference tool. Educators receive regular updates, are quality assured, and data on patient outcomes from their Health Profiles are monitored on a proprietary X-PERT database for audit purposes. In order to conform to NICE key criteria for SE programmes, X-PERT has a written curriculum, visual aids, 'train the trainers' course, an evaluation scheme and quality assurance programme.

1.4 Research questions

The research questions are:

- *What is the mental framing of self-management and SE used by Educators?*
- *Is self-management becoming institutionalised?*
- *How is this happening?*

Chapter 2 discusses the background and policy context to the study and sets out factors that might influence Educators' mental framing. Chapter 3 presents the literature review in two parts: first reviewing what is known about self-management and SE; and second reviewing the literature on spread of innovation in healthcare organisations. Chapter 4 details my methodological approach. Chapter 5 presents my findings and discussion. Chapter 6 presents the study's conclusions, implications and limitations.

Chapter 2: Background and Policy Context

2.1 Introduction

This chapter explains environmental issues influencing the study context and thereby the mental framing by Educators. It covers market factors calling for radical healthcare system reform as well as pressure from the NHS management hierarchy to implement widespread organisational change. I show that the argument for organisational reform due to increased demand for healthcare is evident, especially in light of current economic shrinkage, but that the benefits of the proposed reform are contested and that this problematises normative pressure for healthcare professionals to support organisational change through encouraging patient self-management. I also discuss existing institutionalised barriers to self-management. These include poor patient education and the inadequacy of 1:1 consultations, which show a need for specific resolution using change agents like the Educators in this study.

2.2 The Chronic Care Model (CCM)

Chronic disease is the leading cause of mortality in the world representing 63% of all deaths. One quarter of the 36 million people who died from chronic disease in 2008 was under 60. Ninety per cent of these premature deaths occurred in low-and middle-income countries (WHO, 2011). It is unsurprising therefore that the World Health Organization (WHO) has been promoting appropriate models of healthcare in order to improve chronic disease care. Epping-Jordan et al. (2004) collaborated on a study adapting the Chronic Care Model (CCM), a conceptual framework first developed by Wagner et al. in 1999, into the Innovative Care for Chronic Conditions (ICCC) framework. Apart from improvements in quality of care for chronic conditions within primary care, the envisioned system relies on a combination of informed activated patients (Greene & Hibbard, 2012) and prepared proactive healthcare teams, with interactions that are both more productive and satisfying, leading to improved outcomes for patients in terms of activities of daily life functions as well as clinical outcomes (see Figure 4).

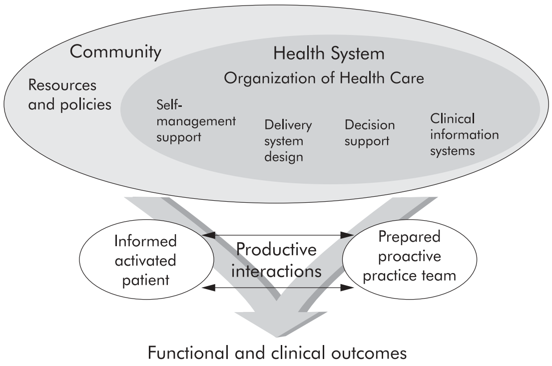

Figure 4: Wagner et al.’s (1998) Chronic Care Model (adapted from Epping-Jordan et al., 2003, p. 300)

The authors argue in favour of transformation of healthcare systems from the provider-led model to an integrated model that promotes patient-centred care (PCC). By 2003 more than 1000 American healthcare organisations based their service improvements on the CCM framework, resulting in positive patient outcomes (Bodenheimer et al., 2002).

A review of frameworks for care of people with LTC conducted by Singh and Ham (2006) confirmed that there is insufficient evidence concerning which of the components of the CCM framework model is effective and that comparison with other models is hampered by a lack of similarly developed conceptual models and published evaluations of them. There is evidence that self-management significantly improved processes and outcomes, and may improve patient and staff satisfaction, quality of care and clinical outcomes as well as reduce resource use in some cases but the quality of evidence tends to be from observational studies of small scope, rather than randomised control trials (RCT) (Singh & Ham, 2006, p.7).

In 2007 the DH clarified its strategic intentions using the widely adapted Kaiser Permanente Pyramid of Care (see Figure 5), which clearly embeds the concept of patient self-management and the need for its support and management into health system planning.

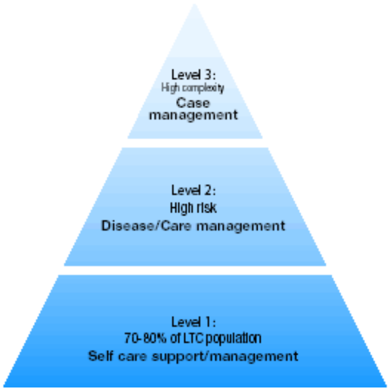

Figure 5: An operating model for the division of labour in chronic disease healthcare (source: NHS Supporting Long Term Conditions) (DH, 2007)

The disadvantages of the older model included a tendency to limit access to healthcare due to physical centralisation of healthcare expertise. This weakness became more apparent due to demand for daily care being a characteristic of chronic disease management.

Epping-Jordan et al. identified key areas for improvement in healthcare design based on findings from a study of five different healthcare systems. They include: 1) *poor provision of advice on health risk behaviours* and 2) *failure to ask patients for their ideas or opinions about treatment*. In other words they criticised patient education that fails to meet the needs of patients, as well as healthcare professionals' didactic interactions with patients. The latter implies that poor treatment adherence by patients was a response to prescriptive approaches which are ineffectual because the one-way discussions that healthcare professionals held with their patients did not take into account the practical circumstances of the patient that would play a huge part in treatment compliance or non-compliance. In summary, improvements in these two factors of healthcare provision: relevant information provision and a consultative approach to possible treatments would increase the ability of patients to manage their conditions better.

Advocates of the PCC model suggest that improvements would come from changes to

- access to local healthcare services,
- *provision of quality healthcare advice that is suited to patient needs,*
- *levels of patient engagement.*

Strategies to improve the delivery of quality advice and information to diabetes patients is evident in NICE Clinical Guidance 87 (NICE, 2009) requiring provision of structured patient education to Type 2 diabetes patients. In 2001 the National Standard Framework for Diabetes highlighted the role of structured education and its purpose[6] to underpin Standard 3, which enshrines the principles of diabetes self-management:

> **Standard 3**: All children, young people and adults with diabetes will receive a service which encourages partnership in decision-making, supports them in managing their diabetes and helps them to adopt and maintain a healthy lifestyle. This will be reflected in an agreed and shared care plan in an appropriate format and language. Where appropriate, parents and carers should be fully engaged in this process (DH, 2010, pp.14-15).

Roll out of the NICE Guidance resulted in the current commissioning requirement to provide structured education to all newly diagnosed Type 2 diabetics.

2.3 Self-management and shift among types of institutional actors

The self-management approach is a component in transformative models of healthcare provision that focus on the development of ambulatory or community-based services to help patients to self-manage, thereby diverting the majority of LTC care away from the more resource intensive acute care setting. Hospitals become less central as 'managers and planners embed medical care provision in wider and more differentiated care networks' (Scott et al., 2000, p.353). The NHS and Social Care LTC Model (2007) shown in Figure 6 shows sharing of responsibility within teams in social care (usually provision of local government

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[6] 'Structured patient education plays an important role in enabling people with diabetes to manage their diabetes on a day-to-day basis. The first recommendation in NICE CG87 is that every person with diabetes should be offered structured education.' (DH, 2010, p.14).

and Third Sector), and clearly identifies in the last column the designated role of patients to become empowered and informed.

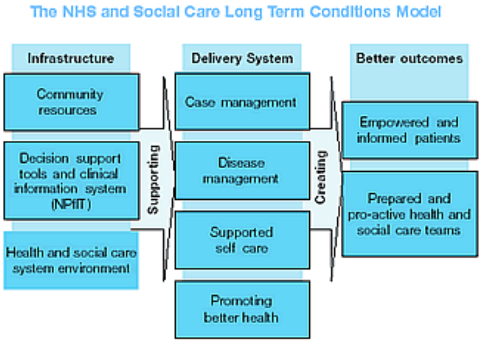

Figure 6: Health and social care for chronic diseases in the UK (DH, 2007)

Institutional actors are 'carriers of specific constellations of interests and logics of action' (Scott et al., 2000, p.351). The actors may exist already in a different sector or may, as in this case, be the redeployment of existing actors to new functions and new constellations of interest and logics of action. Some examples of redeployment into new institutional actors in my case study are:

a) Elevation of lower skilled healthcare workers to undertake work previously done by more highly trained health care professionals
b) Deskilling through higher skilled healthcare professionals doing clerical work
c) Reskilling of highly trained healthcare professionals as qualified Educators with new specialist knowledge and skills (e.g. dietetics, motivational coaching, group teaching, pedagogy for adult learning)
d) Upskilling of patients to actively participate in the management of their chronic diseases.

'Patient activation' as described by Greene and Hibbard (2012) leads to better patient outcomes such as improved treatment adherence, due to involving patients in agreeing care plans with healthcare professionals, and making shared decision-making a key part of on-going management and treatment. But what steps are required in order to engage patients in their own healthcare and what are the consequences of patient engagement on the relationship between patients and healthcare professionals?

This process of patient transformation into effective self-managers is partially aided by new and revamped information governance systems involving process and technology innovations allowing symptom monitoring and health record keeping to take place at a distance from the healthcare setting by new types of institutional actors (e.g. patients, their families and carers). New levels of information-sharing result in a new type of actor and holder of knowledge; informed patients will have a different relationship with traditional holders of knowledge (i.e. healthcare professionals).

2.4 Patient education and clinical consultations

Patients require education to engage. Training patients is not new: from public health campaigns to increase health literacy to traditional patient education, i.e. the provision of information about the disease and its treatment, and teaching technical skills, such as blood glucose testing and injection of insulin. This type of education is usually conducted via short face-to-face appointments with a doctor or nurse accompanied by a leaflet (authored by a health service organisation, charity or pharmaceutical company) to take home and read, occasionally enhanced through provision of a one-off short group education course on a relevant topic.

The quality of this traditional patient education, however, has been the subject of self-management studies that have shown that the provision of information alone is not sufficient to trigger behaviour change in patients (Lorig & Holman, 1993) and self-management programmes that incorporate elements of motivational coaching and the creation of self-efficacy, as identified in Bandura's (1986) sociocognitive theory of behaviour change, are much more effective at increasing patients' knowledge and skills. Self-efficacy can be developed through opportunities to practise newly acquired knowledge and skills in appropriate situations in order to build a patient's confidence and competence in a particular area, leading to increased levels of empowerment and motivation.

If it is difficult to develop self-efficacy in those with little experience or knowledge, it is magnified if the patient is depressed, in denial, anxious or angry. It is common for patients with chronic diseases to suffer from the emotional sequelae resulting in mental health issues. Managing depression has implications for good patient self-management. In a systematic review by Wilson and Childs (2002) the brevity of the 1:1 consultation was identified as inadequate to meet the growing expectations and demands of health promotion and chronic disease management due to effects of poor quality communication. They conclude that pressures for brevity often meant patients' psychosocial problems were being missed altogether or if recognised were not being dealt with. In assessing the degree of patient-centredness of doctor appointments, they looked at studies measuring rate and quality of prescriptions, taking patient history, levels of doctor stress, and the spontaneous offer of active and passive counselling during the appointment. These were all affected by length of consultations. Finally, they show that seeing patients more frequently does not compensate for deficiencies.

This section indicates that existing health service design, (i.e. patient interactions characterised by information-only patient education and brief 1:1 consultations), prevents assimilation of self-management education into existing practice, highlighting the need for quite radical reform in terms of service redesign as well as incentives to change attitudes and behaviours.

2.5 Self-management and institutionalising PCC

Patient self-management is an approach to healthcare that centres on patients' (and their families') ability to use their knowledge and skills for good management of their LTC in partnership with and given appropriate support from healthcare professionals. The building blocks of patient self-management include developing confidence and competence in a number of areas:

- What is the disease, what are the symptoms, how does it affect the body
- What treatments are available and how they work
- What they can do to avoid illness and complications
- How to follow a medical treatment plan, including learning technical skills (e.g. measuring and monitoring vital signs, what the parameters are to achieve optimal control their condition, storage of medicines, injection sites and use of sharps, etc.), and understanding the importance of a healthy lifestyle (e.g. appropriate diet, physical activity, weight control, not smoking, regular check-ups, social, financial and emotional support available, etc.) on the progression of their disease
- Where to find help if they experience any problems

The patient self-management approach aims to increase patient autonomy. This is different to the older medical model of healthcare professionals exerting their *droit de seigneur* justified by their expert medical knowledge over passive patients in prescribing treatments (Schon, 1991). What Schon describes as the prevailing 'knowledge-in-practice', also known within institutional theory as institutional logic, was the healthcare professional's focus on the malady or disease rather than the patient, known as the medical model. Engel's (1977) biopsychosocial model of healthcare controverted the medical model by recognising that the patient and context were key factors in the progression and successful treatment of disease. This change of perspective on disease treatment also brought changes to the relationship between healthcare professionals and patients, often described as taking a holistic approach to healthcare.

The healthcare service model of PCC is a further development of the holistic biopsychosocial model of care in that the needs of the patient are allowed in part to dictate what healthcare organisations should be delivering. In line with New Public Management (NPM) approaches that import techniques from the private sector to improve the performance of public sector services, PCC can be seen as a customer-focused strategy: focus delivery on what the customer needs, and reduce costs from unnecessary operations. Although there is a body of literature criticising the fundamental assumptions of the application of NPM to healthcare, including whether it is appropriate to treat patients as customers, especially in the UK NHS model (Aberbach & Christensen, 2005), elements of the PCC strategy and with it the biopsychosocial model have gained traction in US and UK healthcare organisations (Bodenheimer et al., 2002).

Developing healthcare provision modelled on PCC requires mapping the demand for services. The cost of chronic disease care in the UK is disproportionately large. Chronic diseases are non-curable, long-term, slow-progression diseases that require daily care; using highly specialist and centralised resources (i.e. staff, equipment, and accommodation in a costly acute care setting) for daily blood tests for glucose monitoring is neither sensible nor feasible. Strategies for demand management were the subject of UK health reform, which reassigned the completion of such tasks into the community healthcare setting (DH, 1997). The community setting includes GP surgeries in primary care, third sector services, care homes, and patients' homes. The lever of change is by increasing the incidence and quality of patient self-management and ensuring healthcare services are configured to support it.

2.6 Changing relationships between patients and healthcare professionals

Patient self-management usually involves patients taking ownership of the disease and accepting responsibility for changing risky health behaviours in conjunction with support as required from healthcare professionals. Evidence suggests that long-term benefits may require on-going collaboration between patients and professionals (Glasgow et al., 2002; Norris et al., 2002). This micro-level change in the quality of interaction between patients and professionals, chiefly by putting the weight of responsibility for disease management squarely onto the shoulders of patients, conforms to macro-level strategic responses to managing demand for chronic disease care: divert patients away from the acute hospital setting and move their care into the cheaper community setting.

How should the shifting of responsibility for managing chronic conditions from hospitals to patients' homes be viewed? A critical view asserts that it is morally irresponsible to make medical expertise more inaccessible and that patient outcomes are being sacrificed to unreasonable expectations of patients' ability to cope especially given they are unwell and lack medical expertise. It is also a realistic view given assessments published in health policy documents describing people with a LTC spending the vast majority of their lives managing their health on their own in the community, meaning they are lay experts on their condition and how it affects their lives, and therefore efforts should focus on improving patients' knowledge and skills (DH, 2001; NICE, 2003).

The latter view can be seen as consistent with some major shifts in cultural beliefs within healthcare internationally. First is the shift from the preoccupation with quality – with healthcare professionals as arbiters – toward an emphasis on equity of access to healthcare partly due to increased public spending in previously non-Socialised healthcare (such as US Medicare and Medicaid provision described by Scott et al., 2000, p.349). Second is the shift in responsibility observed in neoliberal governments by Rose (2007), who describes movement away from the State providing the majority of key functions in society toward an emphasis on individual responsibility in the political and increasingly biomedical spheres. The transformation of healthcare services involves extramural change through the empowerment of patients and the community (Anderson & Funnell, 2000). By encouraging a greater proportion of patients with chronic diseases to manage their conditions better, it is argued that demand for chronic disease care, and especially demand for emergency services and lengthy stays in hospital will decrease, resulting in less interaction between patients and healthcare professionals, effectively decreasing society's dependence on these professionals.

The aims of patient self-care or self-management will undoubtedly affect the interactions between many stakeholders, including the patient, their families and community, healthcare professionals and healthcare organisations. Echoing the literature studying the successful diffusion of self-service technologies, and the way that people have become accustomed to helping themselves in contexts previously reserved for trained experts, Bodenheimer et al. (2002) allude to the sophisticated baby boomer consumers' willingness and ability to exert individual preferences in terms of their healthcare options. Although plausible it does not adequately consider the potential agency of the socioeconomically disadvantaged to exert much choice over their social structures and physical environments. For this reason, the implications especially for certain types of patients (i.e. those not suited to self-management) as a result of a change in the relationships between patients and healthcare professionals are considered in this study.

Self-management is still relatively new and it is an approach to managing healthcare that is being investigated in many contexts internationally (Blendon et al., 2003; WHO, 2003). Organisations that comprise the NHS have been piloting and commissioning self-management programmes for several years and multiple stakeholders in this research have expressed their interest in and support for my research into the factors that support patient self-management. In light of the considerable resource that has been invested in the development, introduction, implementation, diffusion and on-going research into the impact of self-management, this is a distinct gap in the literature, yet deriving further insights could have practical impact by providing timely guidance to practitioners about the benefits of becoming an Educator.

2.7 Structured education (SE)

SE is theory-driven, evidence-based and quality assured patient self-management education programmes. Before the advent of SE criteria, knowledge and skills for self-management were introduced to patients through patient education activities. Patient education takes place formally and informally, through contact with healthcare professionals, charities and social services, the media, social networks and support groups, as well as SE programmes. Healthcare professionals conduct patient education during the course of 1:1 consultations; patient education group sessions themed by topic; or through commissioned services providing structured group education programmes, which can be led by qualified healthcare professionals or trained lay tutors.[7] Nationally agreed criteria to define SE programme eligibility for health service commissioning were agreed by the 2005 Joint Department of Health and Diabetes UK Patient Education Working Group. The criteria were needed to underpin *NICE Clinical Guideline CG66 on type 2 diabetes* requiring provision of SE for all newly diagnosed diabetes patients or their

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[7] For more information see UK Expert Patients Programme based on the Stanford model designed by Lorig and associates.

carers, with annual reinforcement and review as an integral part of diabetes care (NICE, 2012). SE programmes should incorporate these elements:

1) Evidence-based and suits the needs of the individual to develop attitudes, beliefs, knowledge and skills to self-manage diabetes
2) Structured curriculum that is theory-driven, evidence-based and resource effective, has supporting materials and is written down
3) Delivered by trained educators
4) Quality assured and reviewed by independent assessors for consistency
5) Programme outcomes audited regularly (NICE, 2012).

Chapter 3: Literature Review

3.1 Introduction

The literature review is divided into two parts: the first discusses what is known about self-management and SE and identifies a gap in the literature to investigate the implementation of self-management and SE by focusing on the mental framing that healthcare professionals use when considering self-management. Mental framing is the act of 'locating, perceiving, identifying and labeling occurences within the lifespace' of the individuals that are engaged in framing (Goffman, 1974, p. 21 in Benford & Snow, 2000, p. 614). Considered collectively, mental framing as an active and processual phenomenon is studied as an element in social movements, contributing to the 'generation, diffusion and mobilisation … of ideas and meanings' (Benford & Snow, 2000, p. 614). Mental framing by healthcare professionals can affect the spread of self-management and SE, because they may employ heuristics that influence the commitment of subordinates and colleagues to novel concepts, with implications for changing work patterns and communication styles. They may also influence negotiations for legitimacy of the ideas for their own aims (Singer et al., 1991).

The second part discusses the literature that helped to develop a theory-driven narrative description of the study's findings by offering an interpretation of the potential consequences of Educators' mental frame on self-management and SE diffusion. I discuss various theoretical approaches applied in the literature exploring how professionals affect organisational change in healthcare, including institutional theory, innovation theory and network theory. To develop an interpretation of the Educators' mental framing I discuss the acquisition of knowledge and skills leading to behaviour change as influenced by learning processes. Bandura’s (1986) hierarchies of knowledge shows the role of sociocognitive knowledge (epistemes) derived from experiential professional knowledge, as a counterpoint to common beliefs and opinions (doxa). I link this to the conceptualisation of knowledge transmitted through professional research cultures discussed by Ferlie et al. (2005) in their paper on the nonspread of innovation by professionals. The intellectual negotiation for dominance between the two forms of knowledge into prevailing behaviours, routines, beliefs and attitudes (i.e. institutional logics) will be discussed in terms of how it affects the process of legitimisation and support for change (i.e. mental frame).

As the NHS is characterised by the model of professional medical roles, literature on the role of changing contexts, role flexibility and micro-institutional affordances allowing for change agents to wield cross-cutting influence and create ways to circumvent established practices will be discussed in terms of their influence on innovation diffusion. The discussion will highlight the gap in the literature that fails to detail relevant processes that provide a clear understanding of the role of context and agency for healthcare professionals engaging in self-management and SE.

3.2 Part I: Self-management and SE

The literature on self-management and SE is dominated by clinical trials of effectiveness on chronic disease biomarkers, and small-scale quasi-experimental studies on clinical and learning outcomes, such as increases in knowledge and skills, and self-efficacy (Lorig et al., 2001; Lorig & Holman, 1993; Newman et al., 2004; Norris et al., 2002; Packer, 2012; Randall & Ford, 2011). The latter type of studies tends to be undertaken by self-management programme designers and there is evidence of publication bias excluding studies with no or negative results (Warsi et al., 2004). For the most part these studies looked at patient responses to self-management interventions but there is insufficient detail to confirm that they conform to SE criteria. There is insufficient coverage of effects of disease duration, severity, medication response, or attention to subgroups by patient attribute (e.g. level of education, socioeconomic disadvantage, level of anxiety, fear, comorbidities) (Warsi et al., 2004). Small-scale studies cannot adequately control for therapist effect through large samples. The studies of SE do not adequately address bias from self-selection as those who attend SE are more likely to be those patients who are more motivated and have fewer access or transport barriers. Apart from the Wilson and Childs (2002) systematic review on impact on quality of care from short consultation length that evidences failure to deliver PCC, what is missing is a study of the support infrastructure to encourage patient self-management efforts, such as the services provided by healthcare professionals themselves.

Extant literature addressing the support infrastructure for self-management and SE looks at the strategic need for transforming healthcare organisations to PCC (Bodenheimer, et al., 2002; Chreim et al., 2012; Coulter, 2012; Walsh, 2012). Other relevant literature concerns the role of professionals in changing healthcare, usually studying the spread of PCC or evidence-based medicine (EBM) (Battilana & Casciaro, 2012; Ferlie et al., 2005; Dopson et al., 2008; Mascia & Cicchetti, 2011). These studies do not address self-management or SE specifically. Self-management studies have not addressed economic effectiveness (Bodenheimer et al., 2002).

3.2.1 Self-management as innovation

Self-management is rooted in a number of theoretical developments in healthcare. Both Parsons' (1951) sick role and the Health Belief Model (Becker, 1974) promote the role and responsibility of the individual in recovering from illness and pursuing wellbeing. More recently the concept of 'patient activation' advocates that patients should actively manage their health and healthcare through acquiring the knowledge, skills and confidence to do so (Greene & Hibbard, 2012). The labelling of LTC, such as obesity, diabetes, chronic obstructive pulmonary disease (COPD), coronary hard disease (CHD) and HIV-AIDS, as 'lifestyle' diseases emphasises the influential role of individual choice and risky behaviours in the development of illness. The theoretical shift from a biomedical model of illness to a more holistic biopsychosocial model (Engel, 1977) highlights tensions between the influence of structure and agency when examining disease as a product of psychosocial and biological factors interacting. 'Many chronic health problems are partly the cumulative products of unhealthy behaviours and harmful environmental conditions [...] medical care cannot substitute for healthful habits and environmental conditions [...] self-management habits that promote health is good medicine' (Bandura, 1997, p. 259). Self-management approaches recognise that ownership of relevant expertise is shared between patients and healthcare professionals. Holman and Lorig (2000) suggest that healthcare professionals are less able to accurately detect illness patterns and trends than the patients themselves. A self-management approach involves partnership between patients and their healthcare professionals, whereby the patients provide information about their status and their preferences in order to complement the clinical knowledge that healthcare professionals can impart. Both sides are vital for effective management.

Wagner et al.'s (1998) CCM utilises the agency of patients and healthcare professionals, as well as the administrative structure of health systems. The model describes a system of three parts that leads to better use of resources and improved health outcomes. It focuses on improving the quality of interaction between engaged patients actively participating in their health care; better prepared and proactive HCP; and more flexible and responsive health system administration (Randall & Ford, 2011). The inclusion of the administration is key because it acknowledges the role that incentives and performance metrics have on the level of 'activation' achievable in healthcare professionals and subsequently their patients. The administration serves to embed and preserve an institutional logic (Friedland & Alford, 1991) about the way the system is designed to operate. Institutional logics are prevailing attitudes, beliefs, routines and behaviours that are the foundation of social structures. Combined with historical precedent (i.e. the way the institutions work), this superstructure makes it more difficult for competing institutional logics, and diffusion of self-management to gain traction.

Self-management interventions in several chronic disease categories have been implemented and studied in the past 30 years (Barlow et al., 2010). The concepts of patient activation (Hibbard et al., 2007), and the co-creation of health (Randall & Ford, 2011, p. 144) as a collaboration between patients and healthcare systems, are supported by evidence that patients *de facto* self-care, because they spend the majority of their lives managing chronic conditions by themselves, even if the health outcomes are suboptimal (Lorig et al., 1993). 'Self-care' was featured as a key building block for transforming the NHS into a patient-centred service (DH, 2000). Self-care is taking responsibility for one's own health and wellbeing, in conjunction with primary care, for the prevention of illness and accidents (NICE, 2005). The onus of responsibility for one's own health and wellbeing encompasses 'support from the people involved in their care', combined with the 'ability to evaluate [one's] own health and to adjust behaviour accordingly' (Randall & Ford, 2011, p. 141). Self-management is usually referred to as a subset of self-care that often describes a higher level of expectations including the ability to manage symptoms, treatment, physical and psychosocial consequences, as well as lifestyle changes consistent with living with a long-term disorder (NICE, 2005). Lifestyle changes means behaviour changes and behaviour maintenance, which are difficult to achieve even by people who are not suffering from illness.

Treating chronic disease presents different challenges because diagnosis affects a patient's life irreversibly and because neither the disease nor the consequences remain static, there are 'illness patterns requiring continuous and complex management' (Holman & Lorig, 2000, p. 526). Rather than advancing a cure, the goal of self-management is to maintain a pleasurable life and independent living for patients. Self-management definitions include symptom management, using assistive devices, medication adherence, attending regular appointments with healthcare professionals, fluctuating psychosocial effects, and the added lifestyle consequences of having a chronic disease. 'Efficacious self-management encompasses ability to monitor one's condition and to effect the cognitive, behavioural and emotional responses necessary to maintain a satisfactory quality of life. Thus, a dynamic and continuous process of self-regulation is established' (Barlow et al., 2002, p.178).

A recent review of generic and diabetes specific self-management programmes by Packer et al. (2012) shows there are numerous definitions to describe self-management as a concept because it lacks its own unique theoretical framework. They find significant improvements in self-management knowledge and skills, as well as reductions in depression result from both types of self-management programmes. They find furthermore that GP referral rates onto self-management programmes are low and that accessing patients from low socioeconomic groups is important in order to avoid increasing health inequalities (Packer et al., 2012, p. 2). Descriptions of self-management frequently draw on social, cognitive, behavioural and self-efficacy theories (Barlow et al., 2002). A common emphasis of self-management is the shouldering of substantial responsibility by patients (Newman et al., 2004, p. 1523) to manage simultaneous and complex activities, that include a great deal of learning and skills acquisition, and which may relate to the manifold and interactive consequences of chronic disease.

Although at a granular level, a definition for self-management in the literature is lacking, formal definitions continue to evolve through the growth of practical self-management quality frameworks that help health service commissioners to decide between various types of self-management programmes (e.g. Self-Help Groups, Patient Support Groups, Structured Patient Education Programmes, and trained layperson-led Expert Patients Programmes). Typically self-management programmes should focus on patients' own agendas, employ a theoretical framework for changing behaviours, and involve personal goalsetting to achieve stepwise change.

Self-management, patient empowerment (Anderson & Funnell, 2000), patient engagement (Coulter, 2012) and patient activation (Hibbard et al., 2007) all focus on various aspects of changing patients from passive recipients of healthcare into active co-producers of healthcare value (McColl-Kennedy et al., 2012). Each of these also implies a need for transformation from provider-led healthcare approaches to patient-centred care. Provider-led healthcare organisations were designed in response to acute healthcare needs, and the rise of chronic disease in the past 50 years has highlighted the inappropriateness of its design and configuration to efficiently meet the needs of chronic disease (Holman & Lorig, 2000). In a recent American College of Cardiology Foundation health policy statement, Walsh et al. (2012) detailed key elements of self-management that relay changes needed in the practice and mental framing of healthcare professionals to successfully support self-management:

> [Clinicians should recognise the complexity of therapeutic regimens for patients and that they must be congruent with their] patients' values, goals and culture, [otherwise] it is unlikely that patients will follow the recommendations and perform the necessary self-care behaviours. Interventions that incorporate *mutual or collaborative goal setting* have *demonstrated efficacy in increasing self-care behaviours and reducing distress* … For chronic illnesses … *the patient is the principal caregiver* responsible for interpreting and reporting symptoms correctly, as well as using medications appropriately in the context of social and economic circumstances. *Patients can self-identify problems and healthcare team members provide self-management education, not orders*, that assist patients in taking measures that will improve health. *Patient self-management skills are applied to physical health, psychological functioning, and social aspects of chronic illness.* Patients desire tools and services that help them and their caregivers better manage their conditions and achieve their mutually agreed upon goals. For example, clinicians can empower patients by supporting them through referrals to culturally appropriate condition-specific support groups, as well as community-based services… (Walsh et al., 2012, p. 8) [my emphasis].

The intention of patient-centredness is to be responsive to the needs of patients but self-management strategies bring risks such as increasing health inequalities.

Disadvantaged groups have less access to resources. Poor levels of health literacy[8] mean they are less equipped to translate medical and health information into understanding how to apply it to their own lives. These groups may require a stronger guiding hand directing resources to them, which is typical of a paternalistic approach that assumes the right to make decisions for another (Marquis & Huston, 2009, p. 74).

This right is being challenged by the practice of patient-centrism, although it is an established privilege granted to the professionals' claim to possess 'extraordinary knowledge in matters of great social importance' (Hughes in Schon, 1991, p. 4). The claim of knowledge brings status and power. 'Medical information, when taken in isolation and without formal medical training, can often lead to out-of-context diagnoses and treatment recommendations' (Walsh et al., 2012, p. 9). The authorised use of lay experts to teach patients about living with their conditions can lead to confusion about what works, i.e. what are the reliable sources of authority and knowledge, and also may impede the building of a trusting relationship with healthcare professionals, with negative consequences on treatment compliance. Schon (1991) discusses the crises of confidence in the professions and the public record of failures, which has contributed to calls for reform and limitations on professionals' exercising any rights without obtaining informed prior consent.

However, patient-centrism also means accepting as currency the subjective assessment of what is an acceptable patient outcome, which can be an assessment formed without extraordinary subject knowledge. The behaviour change process tends to focus on stepwise achievement of proximal subgoals in a process of

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[8] Health literacy, defined as the degree to which individuals have the capacity to obtain, process and understand basic health information and services needed to make appropriate health decision (Ratzan & Parker, 2000), is essential to successful self-care management. Recent literature reviews suggest that those with limited health literacy have less knowledge of their disease, poor self-care behaviors and worst health outcomes (Schillinger et al., 2003; Baker et al., 2002). Additionally, limited health literacy has been shown to be greatest among vulnerable groups such as the elderly, those with less education and minority groups (Nielsen-Bohlman, Panzer & Kindig, 2004). Major obstacles in planning and implementing interventions to improve health literacy in these vulnerable populations are: 1) a lack of systematic research on the development of culturally relevant disease specific health literacy assessment tools and 2) a lack of research on the development and efficacy of health literacy based interventions.

building self-efficacy (Bandura, 1997). Prioritised personal goals may differ widely from those clinical outcomes desired by their HCP, and which are used by administration to measure performance. Promoting self-management may have an impact on how healthcare professionals evaluate changes to their accountability, roles and responsibilities. Lack of clarity about these issues may manifest as resistance to supporting patients to self-manage.

Warsi et al.'s (2004) systematic review of self-management education programmes for effectiveness and to critique the methodology of 71 studies of different self-management programmes for different disease types, found evidence of publication bias and suboptimal research design, including studies undertaken by the intervention designers. They conclude that small to moderate benefits have been evidenced, particularly for diabetes programmes resulting in reduced HbA1c (glycosylated hemoglobin levels) in diabetes patients as well as patients with hypertension. Their review suggests that the nature of diabetes management, with its focus on optimising fasting blood glucose levels, and compliance with medication and diet regimens, may increase the suitability of a self-management approach for diabetes patients over those of other disease categories. They were unable to assess for patient attributes such as disease duration, disease severity, level of education, social supports, confidence and competence to self-manage (level of self-efficacy) and medication effects because studies tended not to include them. They suggest that a closer examination of subgroups would indicate whether certain groups benefit more from self-management than others. They make no reference to patient experience, patient empowerment, the experience of self-management educators or the quality of self-management support provided by healthcare professionals.

Self-management support can be understood in terms of a partnership approach with regular appointments, supported by key improvements to the flow of information (Epping-Jordan et al., 2004). In the WHO (2003) report on chronic disease trends, their recommendations focus on information flows at the macro level between sectors (such as harmonising messages about LTC care and prevention through public health, agricultural and occupational health and safety legislation), at the meso level within health care organisations and across disease specialisms, and at the micro level between healthcare professionals and their patients. Throughout the literature on self-management, information sharing features strongly, and although a necessary condition, critics have worked to dispel the notion that provision of information through traditional health education is sufficient to trigger self-management behaviours (Lorig et al., 2001). The literature does not, however, study healthcare professionals' attitudes to information sharing with patients.

Coulter's (2012) study of leadership and increasing levels of patient engagement in healthcare provision shows there is evidence that patient engagement, particularly the involvement of patients in making decisions to do with their health, leads to improved outcomes. The results of the recent UK Department of Health pilot, Diabetes Year of Care, to increase levels of patient self-care through different programmes, show clinicians who took part were convinced of the value of patient engagement, derived new knowledge and skills, as well as experiencing job satisfaction (Coulter, 2012, p. 11). She describes the influence of clinical leaders who help successful change in organisations in US studies as partly to do with a willingness 'to take risks, including challenging their colleagues to change traditional work patterns and communication styles' (Coulter, 2012, p.13).

Attitudes to risk affect engagement among healthcare professionals and they also feature within patients and the healthcare services. For patients, unpredictable treatment outcomes may result from the contribution of personality and lifestyle to the progression of the disease. Attitudes to risk differ between individuals. Lifestyle decisions can increase risk factors by failure to comply with treatment advice. Heller (2011) details the gap between risk-taking personalities and risk-averse organisations and how this needs to be addressed in self-management practice.

One way of influencing patterns of risky behaviours is through patient education. Traditionally related to health literacy[9], patient education refers to programme content dictated by healthcare professionals around symptom monitoring and skills acquisition, such as how to monitor blood glucose (Lorig et al., 2001). These programmes do not typically include explorations of how having the disease would affect the patient's life functionally or emotionally. Recent developments have shifted the focus of structured patient education programmes to prioritise the information needs of patients as well as increasing knowledge about the disease or

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[9] Health literacy is "the ability to access, understand, evaluate and communicate info as a way to promote, maintain and improve health in a variety of settings across the life-course" (Rootman I, Gordon-El-Bihbety D, Canadian Public Health Association. A vision for a health literate Canada: report of the expert panel on health literacy 2008. Accessed May 31, 2011. http://www.cpha.ca/ uploads/portals/h-l/report_e.pdf.)

condition. This is because a patient will fail to eat well, monitor blood glucose, and maintain an insulin treatment regimen if they are crippled by fear and anxiety about their condition, or unsure about whether they can continue to function normally. Getting patients to articulate their concerns, and building a relationship with healthcare professionals where they feel comfortable to voice them, may be difficult to achieve within current appointment lengths, which are designed to increase efficient throughput of patient loads and derive greatest value from expensive resources (i.e. highly skilled clinical staff).

Criticism of short appointments is the focus of the slow medicine movement (Sweet, 2012), where healthcare professionals are encouraged to take much more time to accurately diagnose illness and thereby reduce waste from unnecessary tests and inappropriate treatments. Further evidence of the challenge of changing existing work patterns to become more patient centred is provided by Wilson and Childs' (2002) systematic review of studies on the relationship between brief appointments and adequate diagnosis and treatment of psychosocial issues by GPs. Their findings highlight a negative correlation between brief appointments and addressing patients' psychosocial problems that is not compensated for by increasing appointment frequency. In the event that healthcare professionals dedicate more time to patient appointments, they still may not have the expertise or confidence to advise patients about how best to deal with a non-clinical problem. Healthcare professionals must also beware of appearing to be dismissive, or shirking responsibility through using a referral mechanism. Simply signposting a vulnerable person to 'find their own way' to assistance can be construed as poor quality care.

3.2.2 Empowering patients through structured self-management education programmes

Lorig et al. developed the concept of the expert patient at Stanford University in 1979 with studies of self-management of arthritis through lay-led group education (Lorig, 2010). The SE programme they developed for chronic disease self-management was trialled by the DH in 2003 and subsequently mainstreamed in 2006 with the introduction of an Expert Patients Programme (EPP) using lead tutor training under licence from Stanford University. NICE (2012) clinical and commissioning guidelines for diabetes make clear reference to design elements that should be present in high quality SE programmes. This practical guidance underpins the requirement for health service Commissioners to make SE programmes available in their areas.

Since 2006 there has been growth in the competitive market of different self-management training programmes (e.g. X-PERT, DESMOND, DAFNE, Warwick Diabetes Manual, Talking Health); quality assurance organisations like the Quality Institute for Self-Management Education and Training (QISMET) creating quality standards; and The National Register of Self-Management to offer a resource to verify the accreditation status of lay-tutors and assessors, which is run by EPP. Reviews of self-management approaches (Barlow et al., 2002; Newman et al., 2004; Packer et al., 2012) show the importance of repeat opportunities to reinforce self-management skills to follow up SE programmes. The challenge is to get healthcare professionals to change their work patterns and communication styles in order to provide this self-management reinforcement during regular review appointments.

Both patients and practitioners require activation in order to take advantage of opportunities to reinforce the acquired self-management skills. Talking Health, one of the SE providers, addresses the fact that practitioners require training to do their part. They market their lay-led self-management and empowerment training to 'patients *and health and social care professionals to help them develop their professional practice and ability to support people with long-term conditions to be involved in decisions about the care they receive*' (Talking Health Network, 2012) [my emphasis].

3.2.3 Resistance to change: the role of institutional logics

Coulter (2012) lists further institutional barriers to patient engagement in the NHS as including: a 'widespread perception that improving patients' experience is not as high a priority on the national policy agenda as patient safety or sound financial management'; coping with multiple competing pressures; feeling hidebound by policies, procedures and regulatory requirements; lack of dedicated team to focus on qality improvement; and negative or defensive reactions from colleagues (Coulter, 2012, p. 15). She concludes that these barriers are present in international studies as well as the NHS and that they 'represent real hurdles that can only be overcome with concerted effort' by a number of people at various levels in the organisation (Coulter, 2012, pp. 15-16).

In the NHS there are overarching competing institutional logics that are in dispute over the progression of patient self-management. One proposes a healthcare service best serves the public through specialisation and centralisation of knowledge within an institution and the other best serves the public by diffusion of specialist knowledge into the community. The first approach welcomes patients into a centre of expertise, the second approach wants to keep them out except in case of emergency or acute illness. An example of this tension is the language used currently to measure positive health outcomes as reducing hospital admissions; a goal of providing cures has been superseded by goals to control adverse symptoms and keep patients out of hospital by preventing exacerbations whilst in the community.

Without a recognised 'gold standard' for a self-management definition (Barlow et al. 2002), it is difficult to judge the adequacy of current practice. Self-management interventions to increase the population of expert patients have existed in various guises, addressing particular conditions with multicomponent interventions that include a didactic element. Recognising the difficulty of lifestyle and behaviour change, they aim to do more than impart information, and include developing skills in problem-solving, decision-making and goal-setting (Packer et al., 2012, p. 7). Hibbard et al.'s (2007; 2009) studies applying the Patient Activation Measure (PAM) to the tailoring of self-management training show positive outcomes for disease management. The implication for clinical practice is that practitioners will have to become adept at understanding their patients' PAM scores. Achieving high quality health outcomes from this new model of interaction involves a greater degree of change in the role of practitioners so that they support self-management. However, the motivations for practitioners to embrace these changes are not straightforward. McDonald et al.'s (2008) study into nurse identity construction through their relationship with patients concludes that changing the traditional hierarchy and privileging patient expertise over professional is fraught with conflicts of interest. Reconfiguring the relationship, by elevating patients as experts, 'would threaten the ordering process, particularly when traditional methods [of categorisation and identity creation] enable nurses to cope with ambiguity' (McDonald et al. 2008, p. 307). Institutional resistance to self-management concepts can be read as practitioners preferring the present efficiency of categorisation and clear accountability for health care, and in doing so will raise the spectre of patient unsuitability for self-management, and increased risk to patient safety from a de-skilled and inefficient health system.

Although clinicians may continue to harbour doubts about the wider benefits of self-management by expert patients, and weigh this against potentially negative impacts on job satisfaction, i.e. demotion from clinical expert to a role as a partner in patient care and a trainer of self-management skills, the expectation that a clinician will support self-management is unambiguous.[10]

3.2.4 The role of information to change mental frames

This section discusses the strategy of supporting self-management through providing information to increase awareness and knowledge as a first step to behaviour change. There is ample self-management literature proving that information provision is not enough to change behaviour (Lorig & Holman, 1993). Bandura's sociocognitive theory (1997) emphasises the importance of self-efficacy, or the confidence to apply the required skills in the circumstances to good effect, in transforming knowledge into practical action. He also describes hierarchies of information or evidence that are absorbed differently. Building self-efficacy can be done through a quick process of learning through one's own empirical experience; or through a slower processing of given information.

Normally the literature makes reference to behaviour change in patients, as the subjects with unhealthy behaviours. However, as the subject of this research concerns the views of X-PERT Educators, the role of information in changing mental frames will be discussed in terms of its usefulness to the activation of clinicians. As an example of the quicker acting, experiential learning, it can be expected that healthcare profesionals who engage in supporting self-management will be more convinced through empirical experience of the benefits of self-management programmes, and begin to account realistically for the potential of their patients to identify perceived barriers and eventually to overcome them. This reflective practice (Schon, 1991) will help healthcare professionals to understand what their self-management knowledge gaps are and how they might address them by becoming Educators.

By extension, it will be harder to change the mental frames and attitudes of those healthcare professionals who have not had much experience supporting self-management, but are resistant to the concept as presented to them by third-party policy makers who are aiming to strip back costs and destabilise the present system. Healthcare professionals are being asked to make leaps between third party

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[10] The National Service Framework for Diabetes 2001 articulates the changing relationship in *Standard 3: Empowering people with diabetes*: All people with diabetes 'will receive a service which encourages partnership in decision-making, supports them in managing their diabetes and helps them adopt and maintain a healthy lifestyle. This will be reflected in an agreed and shared care plan in an appropriate format and language. Where appropriate, parents and carers should be fully engaged in this process' (DH, 2001, p. 5).

research about the health outcomes of self-management and implement change in established practice. According to Thaler and Sunstein (2008) decision-making processes are affected by perceived switching costs and it is common to put off making difficult decisions indefinitely and go with the minimum effort default choice. It is plausible that healthcare professionals perceive high barriers to adopting self-management because the scale of endeavour is off-putting. It involves transferring a wealth of knowledge from the NHS to patients and developing capabilities, and investing in training and development within the practice environment, in order to do so efficiently. The following examples of perceived barriers are reinforced by the dominant institutional logic and existing information systems.

> a) Resource scarcity affects the NHS and it takes time to activate and engage patients. Managing LTC is person-centred and there is a mismatch between subjective definitions of optimal self-management and those of a publicly funded, risk averse health service. The amount that patients and healthcare professionals can agree on concordance with a treatment plan depends on whether disease management occupies the forefront or is hindmost in the patient's priorities. If the priority of a patient's self-management plan is enjoying a familiar quality of life, how do they communicate this to their healthcare professionals and get them to agree to this? How does the system administration recognise this agreement and clarify issues of accountability? Will the administration reward the patient-centred efforts, and view them favourably if the consequences turn out to be increased costs and negative health outcomes (e.g. increased exacerbations, hospital admissions, non-compliance)?

> b) Self-management to encourage health promoting behaviour change faces too much competition in the marketplace to be successful and the need to address information asymmetry about health and wellbeing is an uphill struggle. Even with increased investment in patient education and training, the real effects of poverty and pricing signals in the environment have stronger influence over consumption behaviours and wellbeing. What people value is not easy to change. The choices they make are not entirely irrational. For example, people are faced with the choice between buying 6 apples or 24 bags of crisps for the same money; the choice of exercise in unsafe areas or an attractive choice of sedentary activities that are socially

> acceptable. They must deal with time poverty, food deserts, inflationary costs and a lack of health and wellbeing skills.

In order to overcome these perceived barriers, healthcare professionals will need to identify them, either through a series of consultations or reflection during training and development opportunities. They will need to acquire relevant information, improve their communication skills, set goals and practice achieving them. In teaching patients to self-manage, healthcare professionals will learn about local contexts affecting patients, patient priorities, available support and services, results from accessing them, and link this to health outcomes. Healthcare professionals will need to learn how to communicate 'better' i.e. discuss the things that 'interest' patients in order to begin to self-manage and continue to relate changes in their condition effectively so that healthcare professionals can be prepared and proactive. This view supports the theory that healthcare professionals who are involved in self-management programmes are more likely to adapt their skills to reduce information asymmetry with patients and perceive strong likelihood of better outcomes as a result.

3.2.5 Overcoming barriers to adoption of self-management

Firstly, self-management strategies can be seen as undermining the authority of the NHS and devaluing its potential contribution to society. NHS Policy advocates a role of supporting self-management as a means of developing a patient-centred service. Patient-centred approaches may mean embracing suboptimal expectations of health outcomes and requiring its most highly trained staff to effectively deskill, spending time to learn soft communication skills that could be provided by others. They require healthcare professionals to become familiar with the contextual issues affecting their patients, and to address them professionally, treating patients holistically. Even if their problems may not be directly medical or may appear unrelated to the context of the examination room, healthcare professionals must learn how they may be contributing to non-compliance or lack of concordance with healthcare professionals' advice. Acquiring this knowledge does not mean the healthcare professional will be empowered to change or influence the non-compliance issues.

Secondly, for all this change, much of the approach to supporting self-management is familiar from their professional training in how to communicate with patients. Yet evidence shows that improvements are still needed:

> 'Similar to methods to enhance communication between clinicians and patients, many options for clinician-delivered patient education exist. In-person communication, online resources, written materials, group seminars, and self-monitoring tools all represent methods for informing and activating patient consumers. Assessment of understanding is an integral component of clinician-facilitated patient education and must be incorporated into the process [of PCC] to ensure success.' (Walsh et al., 2012, p. 6).

Current guidelines recommend Advanced Skills Development training be offered to healthcare professionals working in cancer care, for example, however, this does not address the fact that most relationships with patients are formal and that this formality has a protective function for the patient and the professional, especially when undertaking intimate examinations and discussing highly personal issues. Furthermore, offering advice in areas where there may be no real expertise puts credibility in the healthcare professional's authority at risk. As some patients may respond better to an authoritative service than a diffuse structure of supportive services, this may affect patient outcomes.

Thirdly, a patient-centred strategy may reduce costs by analysing root causes of patient non-compliance, and increase efficiency by tailoring services to meet these needs, but it is also a more expensive approach. Personalisation entails more complex variables and offers less easily identifiable opportunities for economies of scale (EOS) to make savings. Personalised care is more time intensive and less systemisable:

> It has been estimated that it can take up to 4 visits with a clinician before the acquired knowledge can be sufficiently synthesized to affect diagnostic testing strategies and impart changes in anticipatory care. It takes time to evaluate and consolidate the unique needs of an individual patient and to develop a management plan that considers an individual's multiple medical and social variables. Each meeting with the same clinician allows for accumulation and synthesis of information that is impossible to capture on any 1 episodic encounter (Walsh et al., 2012, pp. 10-11).

Some economies of scale have been recognised in the literature as there are common hallmark issues related to living with long-term conditions of any kind (Lorig et al. 2007). These include the need for lifestyle coaching, goalsetting, ways to reduce isolation, opportunities to interact with others in a similar situation, and find a new role as a lay-tutor to help others. There are also similar information needs, i.e. where to seek support and information about new treatments and services; discussing impact on lifestyle; coping skills; dealing with loss of function, health, identity; not feeling depressed, isolated or rage. However, there are limited benefits to sharing resources across disease types or across various points along a disease's trajectory, i.e. from initial diagnosis to long-term management because of fluctuations in severity and changes in patient and disease lifecycle. Sharing self-management support resources may lead to potential confusion and patient dissatisfaction from being part of a group education programme with little practical overlap, that constantly refers to other conditions or where discussion focuses on stages of treatment that appear to be irrelevant to the patient's own experience.

Fourthly, it is possible that self-management will increase health inequality because it will further disadvantage the most vulnerable and those with least access to resources (e.g. due to transport costs, inaccessible technology, low level confidence and communication skills, etc). There is a higher risk of chronic disease among disadvantaged groups. The risk is increased if healthcare organisations systematically reduce their access to the most highly trained experts. Those least able to help themselves will be expected to set personal goals to recover wellbeing and to repeatedly rehabilitate themselves. Leaving aside socioeconomic disadvantage, the ill are often cognitively disadvantaged, experiencing problems concentrating or absorbing information due to pain, stress, depression, or medication effects. In a study among 77 older patients with heart failure most had inadequate cognitive and emotional responses for effective symptom management (Walsh et al., 2012, p. 10). The very task of managing chronic disease can be complex, changing and unpredictable, and understanding how to interpret symptoms accurately requires high levels of knowledge and skills. Self-management is not for everyone, and health outcomes may suffer if the healthcare service is transformed to expect it for the majority of patients.

However, there are two arguments against this criticism. First, is that 'health benefits are accelerated by community-wide efforts to reduce habits that impair health' (Puska et al., 1983 in Bandura, 1997, p. 260). In keeping with the WHO recommendations addressing macro level integration of chronic disease prevention across social sectors and policy initiatives, improving self-management skills in the community will create force fields favouring preventative social norms. Consistent with the view of environmental and psychosocial influences on disease, altering community norms will 'create self-sustaining structures within the community for promoting practices conducive to health. Community ownership is best achieved through community enablement for conducting effective health promotion programmes' (Bandura, 1997, p. 308).

Secondly, the self-management approach is relatively new. As discussed above, self-management is a contested area, with differences between policy adoption and practice, which studies as yet have failed to capture.

3.3 Part II: Institutional theory

Institutional theory analyses organisations to understand the ontology of social structure: how rules, norms and routines come to be established and disestablished as accepted guidelines for social behaviour over time. The dimension of time is important in order to understand that institutional theory attempts to contend with and comprehend the continuous accretion of activities and relations into detectable social patterns. This constant state of productive flux, conceived of by Giddens (1984) as structuration, is a concept that emphasises the nature of a process of production and reproduction rather than a static structure under analysis. The institutional environment can be seen to be composed of three pillars: regulative, normative and cultural-cognitive structures (Scott, 1995). These provide meaning, coherence and stability to an institutional field.

> Regulative elements stress rule-setting, monitoring and sanctioning activities. Normative elements 'introduce a prescriptive, evaluative and obligatory dimension into social life' (Scott, 2008, p.54). And cultural-cognitive elements emphasise the 'shared conceptions that constitute the nature of social reality and the frames through which meaning is made' (Scott, 2008, p.57) (in Scott, 2008a, p. 428).

More recently, van Dijk et al. (2011) elaborated the interstices between the three pillars, when developing a concept of 'micro-institutional affordances', referring to conditions of the institutional logics and structures within organizations that actors may exploit in strategic action.

> The notion of affordances does not refer to specific regulative, normative, or cultural-cognitive institutional elements, but to configurational properties among those elements (such as contradictions) that allow action possibilities (see Gibson, 1979). The term 'affordances' is used because it connotes that these properties are not determinants of behaviour, but must be enacted. Furthermore, 'affordance' is a relational concept, indicating that

> these properties offer opportunities only to specific actors and strategic behaviours (van Dijk et al., 2011, p. 1489).

Early institutional theory focused on the phenomena that went into the construction of enduring rules, norms and routines of behaviour in order to understand the mechanisms of stability and order (Scott, 2004). Institutionalism occurs when a belief, norm, or routine behaviour has become an accepted and authoritative social structure. Institutional logics, or sets of 'material practices and symbolic constructions which constitute a field's organising principles and which are available to organisations and individuals to elaborate' (Friedland & Alford, 1991 in Scott et al., 2000, p. 20), are utilised by participants in the field 'as cognitive maps that inform belief systems … to guide and give meaning to their activities' (p.20). Institutional actors, which can be individuals or organisations, act as carriers and creators of institutional logics. Governance systems are exerted to regulate and control the actions of actors by other actors (p.21). Institutionalism is detectable by observing the degree of 'isomorphism, or similarity, to explain the stability of organisational arrangements in a given population or field of organisations' (Greenwood & Hinings, 1996, p.1023). The challenge of accurately depicting shifting patterns is complicated by the fact that typically within organisations, there are informal rivals, or non-congruent actors, that contest the institutional logics, and parallel systems that operate concurrently with institutional logics (Reay & Hinings, 2009). When detected, these have been studied for their sustaining or deleterious effect on the organisation's activities and strategies. By extension this has allowed an understanding of their effects on institutional logics, as well as to the diffusion of radical innovation and its implementation (for an example, see van Dijk et al., 2011).

For analysing fast-moving organisational fields, neo-institutionalism gave students of organisational change some perspectival advantages. It tended to differ from the study of 'old' institutionalism, which depicted the dynamics of power, influence, coalitions, competing values, and informal structures, by looking more closely at the way that counter-movements from non-congruent institutional actors participated in the legitimisation of new institutional structures. Called neo-institutionalism by DiMaggio and Powell (1983) it served to broaden the focus of institutional theory to include the study of change in institutionalism by looking at 'legitimacy, the embeddedness of organizational fields, and the centrality of classification routines, scripts and schema' (Greenwood & Hinings, 1996, p.1023). The hallmarks of neo-institutionalism are the 'extent to which the behaviour of organisations in the field creates a coherent structure or pattern of interaction as revealed by increasing interaction rates, amount of shared information, mutual awareness, and shared governance arrangements. Most empirical studies of field structuration have emphasised the process by which an orderly social structure is constructed over time by the interactions of a shifting set of collective and individual actors' (Scott et al., 2000, pp.26-7).

3.3.1 Institutional theory, the role of context and professional agency on the spread of innovation

Institutional theory is employed in social science to examine concepts and systems that span from micro to macro levels: from interpersonal interactions to global frameworks (Scott, 2004). Its theoretical flexibility rests in its acknowledgement of external forces from the wider market environment and trying to understand how organisational forms and processes are affected by them, and either serve to reinforce, undercut or dismantle them over time. We can map the institutional actors within enabling and precipitating dynamics of change, as well as mapping those forces blocking change, but we cannot really predict what will happen as every situation and actor introduces variability (Greenwood & Hinings, 1996).

The emphasis on institutional actors and institutional environments, or context has been studied at varying levels: Scott et al.'s (2000) study of institutional change in healthcare organisations takes an organisational field level view; whereas Scott (2008b) looks at the organisational level when considering the influence of professional associations across organisational boundaries and national borders. Dopson et al. (2008) conducted a meta-analysis of 49 different UK healthcare case studies at different within and inter-organisational levels of analysis and conclude that an understanding of the role of context is underdeveloped in the literature. In recent examples of the application of institutional theory at a micro-organisational level, scholars have looked at levels of individual interaction and linked them to their environments using social capital theory, network theory and structural holes (see Battilana & Casciaro, 2012; Mascia & Cicchetti, 2011).

Dopson et al. (2008) provide an excellent summary of institutional theory's application to understanding organisational change in healthcare when considering EBM diffusion in NHS settings. They specifically focused on the theoretical conceptualisations of context and how they translated into factors influencing the actions of agents in organisational change processes. They survey interpretations of context from: positivist contingency theory; a phenomenological viewpoint making it not easily quantifiable; and Pettigrew et al.'s (1992) contextual and processual approach; and they argue that all definitions fall short of describing the complexity of contexts. They assert that this may be attributable to the consequences of methodological approaches that select a level of analysis, forcing scholars to treat context as if it were a static or unitary item. They state, furthermore, that it is important not to 'underplay' the 'ways in which actors interact with and mobilize aspects of context' (Dopson et al., 2008, p.215). Any unidirectional view of context will be flawed because they portray passive organisations, groups and individuals that are subject to contexts that shape their behaviours,

> but with no leeway in choosing which aspects of context to bring into the organisation and with no influence with which they could reshape the context … aspects of these contexts are somehow separated out rather than treated as an 'integrated configuration' (Dopson et al., 2008, p.216).

Dopson et al. discuss theoretical approaches to understand the way that institutionalisation impedes change processes. Citing Dimaggio and Powell's (1993) work on decisions to adopt change depending on legitimacy within the organisational field. Dopson et al. find that legitimacy is influenced by organisational dynamics, or historical 'institutional pressures associated with certain fads and fashions' that will influence individual actors in a complex way that results in the mobilisation of policy or ignoring it (Dopson et al., 2008, p.216). In calling for further research into the mechanisms that engage agency for change across social and cognitive boundaries, Dopson et al. indicate that current knowledge has yet to identify the factors that 'generate engagement and high attendance levels (as opposed to the operation of paper machinery which is unable to engage in healthcare workers) … Sometimes bridging or facilitation roles could be helpful in reducing the time- scale for shared learning and changing the negative perceptions that sometimes built up between different professional groups (Dopson et al., 2008, p. 229).

In relation to the spread of self-management and structured education, Dopson et al. (2008) highlight the importance of professional agency as well as the emergence of new roles or new types of actors. Ferlie et al. (2005) compared two qualitative studies in UK healthcare tracing diffusion of eight innovations. Their study showed that uniprofessional groups spread innovation with more facility than mixed multiprofessional groups because of social and cognitive barriers that can potentially retard spread. The cohesion of professional groups is ascribed to the sharing of a greater degree of knowledge and beliefs in common, resulting in communities of practice[11] which more efficiently legitimises by adopting a group position on the spread of innovation. They explain that because communities of practice are highly institutionalised and often unidisciplinary, this facilitates agreement on redefinition of roles and jurisdictional boundaries that come with changing practice.

They go on to assert that change within a community of practice is distinct from the barriers to learning and change that occur *between* professional communities of practice. They contend that agreeing legitimacy of innovation involving moves across social or identity barriers pose greater challenges. In this they take issue with Wenger (1998) who argues that communities of practice

> have permeable peripheries and can be readily constructed 'from scratch' in new settings. A community of practice emerges through negotiation in a work context over a short period of time... So communities of practice may be built up where individuals share common roles or an epistemic culture (Ferlie et al., 2005, p. 129).

Ferlie et al. discuss such epistemic culture manifesting as cognitive boundaries using the example of GPs' critical reception of RCT evidence because it stems from experimental conditions that discount many of the most salient factors affecting practice outside of the acute setting.[12]

I suggest that legitimisation of 'evidence' depends on the source or type of knowledge (episteme or doxa) according to Bandura's hierarchies of knowledge concept, and therefore it can be said that processes changing knowledge into behaviours highlights the existence of tailored process mechanisms for rejecting 'well-founded' evidence. I understand these to be intellectual enactments, or affordances to ruminate on the legitimacy claims of evidence transmitted from professionalised research cultures and consider them against evidence gathered

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[11] Communities of practice are 'work-related communities created through sustained collective pursuits of shared enterprises' (Ferlie et al., 2005, p. 128).

[12] For example, GPs are encouraged to change practice according to EBM research, which they resist because the evidence is from studies conducted in conditions far removed from the primary care setting. They tend to have longer-term relationships with their patients across multiple pathologies. This holistic patient view is not represented in the recruitment of control groups for RCT, and moreover RCT evidence tends to result in denying patients potentially useful treatments. Ultimately it is the validity of evidence as generalisable to a different context that is at stake (see Ferlie et al., 2005, p.130).

during sociocognitive learning through work. These intellectual processes have direct consequences for the successful creation of epistemic change (i.e. the diffusion and legitimisation of new institutional logics). Because Wenger's concept of communities of practice emphasises the impromptu coalitions of multiprofessional individuals working together on a topic, it surmounts social boundaries, and generates its own seam of epistemic artefacts or context-specific working knowledge. This implies that rather than being hampered by social boundaries or creating cognitive boundaries, such communities of practice can establish competing institutional logics by exploiting micro-institutional affordances.

3.3.2 Networks as context

Actor-Network Theory looks at collectives or groups and studies the relationships between actors or nodes. These network relationships are characterised according to their strength and their ability to create or produce factors influencing behaviour (Latour, 2005). Innovative approaches like self-management are still experimental in terms of application to different contexts and therefore working towards establishing their legitimacy claims. Competing or rivalrous logics before legitimacy is established can be managed by developing *collaborative relationships* (Reay & Hinings, 2009). Such actor-network relationships between healthcare professionals can exert formal and informal regulative, normative and cultural-cognitive pressures that affect the legitimacy of rivalrous logics. This is appropriate as further factors cited by Dopson et al. (2008) as influencing legitimacy for change are basically social:

- fit with the core needs or belief structures of the profession,
- social barriers,
- varying degrees of interdependency within networks of professionals,
- varying degrees of personal involvement and detachment,
- and geographical distance.

Inherent to innovation diffusion is the role of partisanship (or politics) as much as participation by influential agents. Scott (2008b) described the agency of professional associations and their 'soft power' role in changing prevailing behavioural archetypes and attitudes at a global level (i.e. at a level beyond the scope of state governance), which would typically resort to regulatory power to coerce subjects to conform and eventually institutionalise innovations from the top-down. Contrast this with the lessons from Mascia and Cicchetti (2011) who studied the dynamics of professional networks, looking at the influence of contacts and interstices (structural holes where ties are weak or non-existent) that influence the adoption of EBM into clinical practice, concluding that those physicians who are ‘highly constrained in their interpersonal networks are less likely to report adopting EBM, suggesting that cohesion induced by social interaction may hamper, rather than foster, the diffusion of scientific information within professional groups’ (p.798). The influence of professional networks is further investigated by Battilana and Casciaro’s (2012) study of the role of NHS professionals to implement divergent organizational changes from the point of view of contingency theory. They focused on both the use of informal networks, such as their regular groups of professional contacts (as opposed to formal networks, such as professional associations) and their subjects’ positions in such networks such as acting as a broker between network contacts and their information (i.e. where there are structural holes). Structural closure in a network is ‘the extent to which an actor’s network contacts are connected with one another … low degrees of structural closure creates a network with ‘structural holes’ and brokerage potential (p. 382). Structural holes allow change agents to move with fewer constraints, thereby increasing access to different sources of information that may trigger nonconformist thinking. Structural closure reinforces institutionalised thinking.

> [Occupying] a network position rich in structural holes exposes an actor to nonredundant information (Burt, 1992). To the extent that it reflects originality and newness, creativity is more likely to be engendered by exposure to nonredundant than to repetitious information. *As for normative pressure, network cohesion not only limits the amount of novel information that reaches actors, but also pressures them to conform to the modus operandi and norms of the social groups in which they are embedded, which reduces the extent to which available information can be deployed* (my emphasis, Battilana & Casciaro, 2012, p.383).

They differentiate between change initiation and change adoption as possible outcomes of change agents’ influence and find that structural holes aid both change initiation and change adoption, and furthermore can hinder the adoption of change that is less divergent from the status quo.

I argue that the network of Educators in my study is not as cohesively aligned with tight-knit well-established structures (such as medical professional roles or healthcare settings cognitively bound by knowledge from research cultures), and therefore is likely to be richer in structural holes that allow for brokerage opportunities with those outside of the network. These holes also allow for the flows of new information characterised by new types of knowledge (topics and skills) into the network. This new knowledge is being received through exploiting affordances presented to Educators to privilege locally contextualised and personally derived epistemes through experiential learning. This route to learning is atypical of learning in institutionalised networks such as training based on a medical professional role or within a healthcare setting (Mascia & Cicchetti, 2011). Furthermore these outlying networks operate in a space that is peripheral to the processes that tend to legitimise first and foremost the knowledge transmitted by and within predominant research cultures (Ferlie, et al., 2005). This allows them as a multiprofessional community of practice to establish, legitimise and reinforce with more facility new cultural-cognitive elements from experiences as an Educator.

3.4 Professional agency and institutionalisation: a space for cultural-cognitive, regulative and normative change

Schon (1991) describes the power and privilege of professionals who gain their status on the basis of knowledge accrual and become thereby institutional agents in a cultural-cognitive process of institutionalisation: a combination of structural beliefs, routines and practices that perpetuate the knowledge claims and related structural artefacts of institutional logics (Scott et al., 2000). Schon describes professionals as earning respect and trust which allows them to operate in relative freedom as a result. With professionalisation arise associated networks that create regulatory mechanisms of control, which effectively allow professionals to monitor and govern themselves and each other. This implies insularity of control mechanisms along professional classes: doctors govern doctors; nurses do not govern doctors. Therefore professional autonomy is only ever partial; another downside of knowledge-in-practice as a regulative and normative mechanism is that it is also restrictive: Schon therefore outlines the rationale for the reflective practitioner utilising reflection-in-action, or becoming a researcher in the practice context:

> [The reflective practitioner] is not dependent on the categories of established theory and techniques but constructs a new theory of the unique case. His inquiry is not limited to a deliberation about means which depends on a prior agreement about ends. He does not keep means and

> ends separate, but defines them interactively as he frames a problematic situation (Schon, 1991, p.68).

The reflective practitioner can as needed loosen the confines and constraints of knowledge-in-practice by finding ways of practice that deviate from the strictures of knowledge-in-practice guidelines. He calls this process repertoire-building research (RBR):

> when practice situations do not fit available theories of action, models of phenomena, or techniques of control, they may nonetheless be seen as familiar situations, cases or precedents. RBR serves the function of accumulating and describing such exemplars in ways useful to a researcher-in-action (p.315).

Growth of this personal empirical evidence-base in a local context means constantly increasing the legitimacy of deviation by the practitioner from knowledge-in-practice. This is an example of deinstitutionalising and implies moreover, the presence at any given time of many different approaches to variable situations in practice. Greenwood and Hinings (1996) do not describe the action of a confluence at the interpersonal level of institutional logics at any given time, but they describe precipitating and enabling dynamics, or institutional and market conditions that are conducive for competing or rivalrous forces to come into existence, such as personal or departmental interest, dissatisfaction, value commitments, power dependencies and capacity for action. In particular they assert that several factors need to be in alignment in the market context as well as in the organisational context, and that understanding the process of radical change also requires scrutiny of institutional logics.

In my study, evidence that Educators' mental framing is supportive of self-management would be a signal of precipitating or enabling dynamics for innovation spread. An increased flow of new information is evidence of structural holes, which also indicates lack of structural cohesion and weakness of social and cognitive barriers that impede innovation spread. For clear scrutiny of institutional logics that influence spread of self-management I consider the following:

- the clear market signals broadcast to healthcare professionals that healthcare organisations need to adapt because of demand exceeding shrinking supply

- that leadership for change in the direction of PCC has been central to health service policy since 1997
- administrative organs of healthcare institutions have been introducing, implementing and managing initiatives in support of PCC, including self-management programmes
- medical professionalism
- professional associations
- status hierarchies based on expertise
- division of labour into primary and secondary care
- cultures of research
- tendency to privilege medical or holistic approaches to care.

Moving from contextual conditions that are ripe for enactment of agency in innovation spread, I now discuss the personal aspects linked to agency that motivate enactment. Scott's (1995) pillars framework discusses institutionalising elements that could account for the personal motivation for professionals to act and behave as they do, such as compliance with regulation, normative forces obliging them to act a certain way, and cultural-cognitive forces, which dictate expectations about behaviours, approaches, rules and beliefs. It is characteristic of institutional logics that they are prevailing practices and that conformity is the norm (Scott, 2008a). However, in the healthcare context it may be that this is more complex (Dopson et al., 2008). Schon describes professional behaviour as dictated by a process of:

- frame analysis: 'the task of reshaping the norms and expectations which the other party brings to the interaction' (p.309)
- frame awareness: 'the possibility of alternative ways of framing the reality of [the professional's] practice' (p. 310)
- and the discussion of alternative frames, values and approaches to practice that are polemical and primarily ideological.

He sets professionals in opposition to those who unthinkingly conform to institutional logics out of self-interest: 'The protagonists of the various points of view do not reflect on their frames but act from them, seeking to defend their own positions and attack the positions of their opponents' (p. 312). Further interpretations of the role of self-interest in decisions to accept or legitimise change include: the implications of habitus on identity creation, role reinforcement, job sustainability, and the wish to maintain control and autonomy over specialist subject areas in the face of managerialist interference.

Dopson et al. focus on the need to understand the drivers at the individual level that influence a professional's attitude to competing forms of evidence and the decision-making process behind spreading or hindering innovation in a given situation or context. This has implications for both winning support for change or rivalrous innovation, as well as sustainability of change, as it relates to factors contributing to job satisfaction such as variation, autonomy and creativity rooted in Maslow's (1943) theory of motivation. According to Coulter's (2012, p. 11) study of leadership and patient engagement, positive views among clinical leaders were linked to the acquisition of new knowledge and skills, and job satisfaction as factors behind their championing of patient engagement programmes like self-management and structured education. Among the institutional barriers to patient-centred care in the NHS and internationally, she lists multiple competing pressures including a widespread perception that improving patients' experience is not as high a priority on the national policy agenda as patient safety or sound financial management' as well as 'feeling hidebound by policies, procedures and regulatory requirements' which place ever more constraints on professional autonomy (Coulter, 2012, p. 15). Coulter describes 'clinical leaders committed to learning from patients' experiences and using this knowledge to make healthcare delivery patient centred … willing to take risks, including challenging their colleagues to change traditional work patterns and communication styles (Coulter, 2012, p. 13). Diffusion of change by spreading self-management and structured education may be preferable although it means leaving behind more comfortable, familiar, tried-and-tested, and long-unchallenged forms of practice that may be seen as unsustainable. Professionals who engage as institutional actors also get the privilege of actively legitimising through sociocognitive learning, using and refining empirical evidence through the freeing tactics of early innovation adoption. When innovation becomes institutionalised there is a risk that it becomes less stimulating and relevant as it become standardised. Echoing Bandura's (1997) hierarchy of knowledge, Ferlie et al. (2005) discuss the prejudices surrounding types of information transmitted through research cultures preventing less readily absorbed due to scepticism about the originating source or authority. Dopson et al. discuss this in terms of healthcare professionals' non-engagement with policy documents.

Dopson et al.'s description of exercising agency by choosing the forms of evidence that guide professional practice can be seen through Sen's (1997 in Saito, 2003) conceptualisation of freedom as linked to wellbeing: ‘Positive freedom is a good in its own right: being free to choose how to live one’s own life is one of the good things of life. Thus freedom is one of the dimensions of wellbeing’ (Sen, 1997 in Saito, 2003, p. 21). He cites two processes of economic and social development: firstly, accumulation of human capital which ‘concentrates on the agency of human beings – through skill and knowledge as well as effort – in augmenting production possibilities [and secondly,] the expansion of human capability, which ‘focuses on the ability of human beings to lead lives they have reason to value and to enhance the substantive choices they have’ (Sen, 1997 in Saito, 2003, p. 24).

Choosing to support the legitimacy of an innovation and changing practice, and how this relates to a sense of freedom, can be understood as an example of wellbeing and advantage as described by Sen (1982) in his Capability Approach. Wellbeing is the achievement of functionings and capabilities for quality of life. Functionings ‘represent the various things a person manages to do in leading a life ... capabilities of a person reflect the alternative combinations of functionings that a person can achieve [and] quality of life is assessed in terms of capability to achieve valuable functionings (Nussbaum & Sen, 1993, p.31). Sen asserts that the attainment of wellbeing depends on two distinct but related concepts: first is achievement and the second is freedom. They relate to four interdependent but non-identical concepts:

1) Wellbeing achievement
2) Agency achievement
3) Well-being freedom
4) Agency freedom (p.35)

In this study I am translating the concepts of wellbeing and agency into terms of job satisfaction. If healthcare professionals are alert to the concepts of achievement and freedom, and how they pertain to improving levels of job satisfaction within highly structured systems – where constraints mean reduced professional autonomy and less respect of professional expertise (i.e. contractual obligation, QOF payment frameworks, quality auditing, clinical guidelines and care pathways) then it follows that deviation from institutionalised practice may be seen as a welcome opportunity to practise personal forms of empirical enquiry because they privilege one’s own knowledge from professional experience. This epistemic approach is structurally appropriate for the variation proposed in PCC and self-management support, both of which involve responding proactively to the individual circumstances of patients and their priorities.

3.5 Forces against self-management institutionalisation

A counterargument says there will be few signs of institutionalisation because self-management dis-establishes the prime position of healthcare professionals: it undercuts the framework privileging the interests of healthcare professionals. Conceptually self-management poses a threat to healthcare professionals as it reduces patient dependency, circumscribing their role in and influence over the lives of patients. It also can be said to be more difficult: patients need time to become motivated to collaborate with healthcare professionals to change their behaviour and their lives. Isn't it easier to prescribe a pill? Wholesale adoption of PCC and self-management is mediated by the acts of identity creation and role reinforcement of healthcare professionals (McDonald, 2009) in relation to their patients. It is also mediated by the pursuit of self-interest in the spread or non-spread of innovative practice (Kramer & Cole, 2003). According to this view, self-management threatens the sustainability of the interests of healthcare professionals. From a market perspective, they become less critical than lower-skilled self-management educators in responding to the overwhelming majority of demand for chronic disease healthcare over time and the utility of healthcare professionals' to society decreases. Ultimately reducing the demand for complex care reduces supply of complex care specialists.

Studies within institutional theory have also shown that to a certain extent external market forces are responsible for the socially privileged position of healthcare professionals coming under threat of destructuration (Scott et al., 2000). An example of this in the US healthcare context is the rise of powerful health insurance managerialist interests over medical decisions that previously were the domain of healthcare professionals. Ironically with the diffusion of self-management, healthcare professionals are being called upon as institutional change agents to actively dismantle their own institutional architecture: the fundamental values and practices that privilege their medical expertise, thereby sustaining their roles and identities, are shifting beneath their feet. Like the threat to doxa of a scientific paradigm shift, the legitimacy of self-management is in crisis from the start according to the institutionalised interests of healthcare professionals. Furthermore addressing the legitimacy crisis of self-management will be through provision of an evidence base that will satisfy institutionalised research cultures;

these are biased toward acute care settings and privilege certain types of evidence over others that may be more relevant to measuring self-management effectiveness.

Supporting self-management involves power redistribution: it implies that healthcare professionals must turn the controls for non-acute disease management over to the patient, no matter how ignorant and unskilled the patient may be. Despite holding the key to the prescription pad, the dominance of medical expertise within the relationship between patients and healthcare professionals currently is meant to be neither didactic nor prescriptive. The acceptable face of expert knowledge is guidance rather than diktat (Walsh et al., 2012). Consider for example the change in accompanying cultural-cognitive signifiers: the shifting terminology from *adherence* to prescribed treatment to patient *concordance* with a treatment plan agreed with healthcare professionals.

There are, of course, limitations to both patient-centredness and self-management. Even their advocates would not want to see the baby follow the bathwater. The Hippocratic Oath and due consideration of patient safety in risk-averse organisations are examples of institutional logics that register the outer limits for the advancement of patient centredness and self-management (Heller, 2011). These enduring institutional logics can be understood as an example of what Ferlie et al. (2005) identify as the power of professionals to block change. They assert that engaging professionals in the change process is fundamental, but here I have set out how getting healthcare professionals to champion self-management is contradictory and raises expectations of nonspread. Therefore, it is appropriate that this study looks at change as it works on the destructuring of the professional's institutionalised point of privilege on the basis of expert knowledge, through the views of Educators who are engaged in the change process for evidence of institutionalism of new logics.

3.6 Conclusion

The literature on self-management and SE focuses predominantly on the impact on patients at the micro-level and healthcare organisations at the macro-level. There is a need for a meso-level study into impact on healthcare professionals who are called on to support self-management approaches and SE programmes. Extant literature on self-management and SE is dominated by clinical trials of effectiveness on disease biomarkers, and small-scale quasi-experimental studies on clinical, psychosocial and learning outcomes, such as increases in knowledge and skills, and self-efficacy. For the most part these studies looked at patient responses to self-management interventions but there is insufficient detail to confirm that the programmes conform to SE criteria. The studies of SE effectiveness do not adequately address bias from self-selection, as those who attend SE will be those patients who are more motivated. What is missing is a study of the supporting infrastructure that encourages self-management and SE efforts in patients and healthcare professionals.

Extant literature on PCC and related concepts like patient engagement reference self-management but do not explore it from the perspective of healthcare professionals' or explore their motivation to support it and spread it. Literature on innovation spread in healthcare holds lessons about how the support infrastructure for self-management and SE might develop but does not specifically address these two areas. There is coverage within the literature studying the transformation of healthcare organisations to PCC or the role of professionals in changing healthcare, usually studying the spread of PCC or evidenced-based medicine but these studies do not address self-management or SE specifically. Extant self-management studies call for research into its sustainability but have not addressed economic effectiveness or factors related to the support from healthcare professionals sufficiently.

The literature review on institutional theory and healthcare does not address self-management and SE but highlights lessons for situating the enabling or blocking dynamics of professional agency in context. Although institutionalisation is an ongoing process, evidence that points to structuration (including increased awareness, information sharing and shared governance systems) and change within cultural-cognitive, regulative and normative elements in Educators' mental framing can be understood as an indication of self-management and SE institutionalisation. Furthermore it may provide insight into the effectiveness of current efforts to spread self-management and SE. Understanding how being an Educator has changed attitudes, beliefs, routines and expected behaviours within clinical practice will help to show how they are engaging with prevailing knowledge, such as privileging empirical epistemes over those transmitted by institutionalised research cultures, and whether their engagement is as an opposing and thereby destructuring force. The literature shows that mounting opposition or destructurating enactment will probably be aimed at the micro-organisational level of administrative artefacts (e.g. rules, established patterns, attitudes and behaviours) and/or changing the nature of micro-level relationships in networks (e.g. interactions with patients, colleagues, non-Educators, and blockers of innovation). Both micro-organisational artefacts and personal networks can be considered context, which influences (through precipitating, enabling or constraining) the enactments of institutional actors (the Educators). The decision of Educators to enact institutional change by spreading self-management and SE is likely to be based on micro-institutional affordances that create opportunities for personal motivations to prevail over suboptimal or irrelevant institutional logics (or knowledge-in-practice): this will engage cultural-cognitive, normative and regulative change in order to increase overall job satisfaction, because work in a local context can be understood to be more rewarding due to increased autonomy and the achievement of freedom to act in order to improve patient outcomes.

Chapter 4: Methodology

4.1 Introduction

The findings from the literature review suggest that research into the role of healthcare professionals to support and spread self-management and SE in practice is needed. The purpose of this study as indicated by the research questions is to explore the mental framing used by Educators on self-management and SE in order to identify factors and processes that influence the institutionalisation of self-management.

This chapter outlines the methodological approach taken for this study. I consider the epistemological stances of positivism and interpretivism before discussing the research traditions prominent in exploratory research. The research method used for this project is discussed and the research setting and design explained. I then consider sampling issues and justify the approach taken, as well as describing sample recruitment and details of the sample attained for the study. I outline my approach to data collection and analysis as well as limitations of the research.

4.2 Research setting

The study is set in a county in the British West Midlands with the UK's second largest and cosmopolitan city surrounded by a largely rural setting with some small and medium sized towns. The sample population is formally linked to a local administrative tier of the NHS which has procured a licence to deliver across the county a nationally approved, patient-centred, group-based diabetes patient self-management education programme called The X-PERT Programme.

4.3 Epistemological approach

I allowed the research setting, topic and goals to determine my methodology and epistemological approach. Exploratory studies are sometimes considered a prelude to social research (Tellis, 1997). My choice to conduct an exploratory study was supported by Meredith's (1993) paper on theory-building through conceptual models that supports the validity, generalisability and rigor of case and field research findings and insights. Although case studies are 'limited by their generalizability, they can provide an excellent jumping off point for […] topics that are relatively underdeveloped' (Melnyk & Handfield, 1998, pp. 317-18).

A qualitative approach is appropriate for analysis of concepts and themes derived from exploration of views on self-management and SE, about which little is known, and about which in-depth understanding was desired (Bowen, 2005). Qualitative studies adopting a positivist stance tend to do so when seeking evidence of causal relationships evident in the data: establishing propositions that can be tested or identified in other cases (Lin, 1998). The gap in knowledge around the mental framing of healthcare professionals on self-management and SE means that testing for evidence of a previously identified relationship in this research context is inappropriate for the design, although it is constructive to think in terms of plausible causes and alternatives that could be tested for in future research. Interpretivist approaches seek to provide detailed explanations for the causal mechanisms and belief systems evident in the data (Lin, 1998). Interpretivist work can 'help us ask the right questions and even give us additional confidence in our conclusions. [Positivist] methods of scientific inference [allow us] to evaluate the hypothesis and see whether it is correct' and check validity of the explanations across cases (Lin, 1998, p. 167). Lincoln and Guba (1985) call the interpretivist approach post-positivism. Post-positivist approaches assume "all our scientific analyses involve some combination of elements selected from the 'empirical environment' of observations as well as elements we and our colleagues collectively create in the 'metaphysical environment' of assumptions and theoretical models (Alexander, 1983). All of our descriptions, propositions, and generalizations — our scientific 'truths' — are varying admixtures of these empirical and metaphysical elements" (Scott, 2008b, p. 219). As the purpose of this study is exploratory in an under-researched area, an interpretivist approach is appropriate: 'Interpretivist work draws upon notions of credibility and accuracy of description to establish validity, not upon the evaluation of how often the variables are repeated and in what combinations. Interpretivists also have a different understanding of generalization, seeing it as the creation of taxonomies rather than as the discovery of causal relationships that operate across different times and spaces (Lin, 1998, p. 166).

My study fits the naturalistic ontology: maintaining the realities of the study context as much as possible, using qualitative methods, purposive sampling, inductive analysis, grounded theory, case study reporting mode, tentative application of findings, and special criteria of trustworthiness (Lincoln & Guba, 1985). Trustworthiness refers to credibility, transferability, dependability and confirmability and in qualitative studies using interpretive approach replaces conventional positivistic criteria of internal and external validity, reliability and objectivity (Lincoln & Guba, 1985).

4.4 Research design

The most popular qualitative research methods are interviews, observations and archival document studies (Bowen, 2005). To obtain as broad a spectrum of the views of Educators and to infer and understand their mental framing, I chose in-depth telephone interviews. Limited budgets for travel and room allocation, as well as short timeframes and distance from the research setting meant alternative methods such as face-to-face interviews, observation of SE programme sessions or focus groups were not possible. Document analysis was not appropriate because they were not readily available. Telephone usage increases convenience for participants and researchers; healthcare professionals are comfortable using this technology for detailed communication and it suited my wish to establish a conversational intimacy that encourages disclosure. Online surveys, online forums or questionnaires were inappropriate because they tend to limit the length and quality of responses captured, questions tend to be of a more closed nature and they are not suited to spontaneously identifying and following up emerging themes (Fricker & Schonlau, 2002).

Interviews were recorded and transcribed for analysis. I designed a semi-structured interview guide (see Appendix 5) to increase comparability between participant responses and also to allow for unexpected topics to be discussed, enriching the data (Lincoln & Guba, 1985; King et al., 1994). The use of an interview guide is one way to provide more structure while maintaining a high degree of flexibility (Bowen, 2005). My interview questions elicited data on the X-PERT SE programme specifically and the concept and practice of self-management generally. Initially the interviews established familiarity with the participants, the questions were designed to elicit data about the Educators' clinical roles, level of experience, type of interaction they have with patients, their work setting and consultation length and nature of discussions in clinical consultations. This was followed by questions to elicit data on their knowledge of self-management. Specific to their Educator roles, the following questions were designed to elicit their experience with SE, teaching, group teaching and their motivation to become an SE Educator. I was interested in obtaining their views on patient outcomes from SE and whether they saw any impact on their work patterns, attitudes and beliefs as a result of their experience as Educators. I also asked them to compare their practice with non-Educator colleagues, and asked them to identify any barriers to self-management.

One challenge as a researcher is breaching the barrier of tacit knowledge belonging to veteran members of the health service. Terminology and language infused with a particular flavour of conventional wisdom (e.g. what is the prevailing attitude in a 'beleaguered NHS') will be limited by my outsider status trying to accurately decode participants' language and was careful to seek clarification in interviews where needed. I have paid close attention to the process of data collection to ensure that nuances and ulterior meanings are explored and recorded accurately.

Because of time limitations, the research design built time for analysis into the data collection process to allow for a constant comparative method of data analysis called iterative triangulation (Lewis, 1998), giving the opportunity to explore emergent themes both in the literature and in the subsequent interviews. Iterative triangulation is an approach with 'systematic iterations between literature review, case evidence, and intuition' allowing 'the comparison and contrast of newly emerging constructs and theory across case settings. By juxtaposing highly varied case accounts, the […] researcher may achieve creative leaps in theory development, which may in turn require a reframing of preexisting assumptions' (Lewis, 1998, p. 456). This meant I was constantly refreshing and refocusing my consideration of the range of literature that informed my early and subsequent findings.

A Personal Data Capture form was designed to elicit demographic data. Personal data includes name, job title, age, gender, address, telephone number, preferred mode of contact and store voucher preference. In order to aid comparability the research design included a tabular summary of participant attributes (see Appendix 2) to add to the richness of the qualitative data and to provide a springboard for future research. I also describe the characteristics of the network structure in Chapter 1: Introduction in order to aid comparability with other network theory studies.

Each interview was conducted at a time and using a landline or mobile phone number chosen by the participants as most convenient to their private schedules. Interviews took place during evenings and weekends, during days off and lunch breaks. All participants were comfortable with the interview being recorded and were familiar with the concept of anonymity described in the Participant Information Sheets.

4.5 Data collection

Data collection was through in-depth semi-structured telephone interviews using an interview guide designed to draw out detailed information and comments. No other data collection methods were used.

4.5.1 Sampling issues

In order to increase the external validity of case studies with strong internal validity, Eisenhardt (1989) recommends theory-driven sampling to enhance the generalisability of findings and also to assist comparisons with other studies as well as theory-building. In terms of theory-driven sampling, I have used a purposeful convenience sample identified by NHS research partners who acted as gatekeepers in terms of research governance approval, promotion of the study and recruitment of participants.

Purposive sampling instead of random sampling allows me to emphasise quality rather than quantity (Padgett, 1998 in Bowen, 2005). The NHS research partners described the cohort as putative forerunners in self-management practice. The convenience sample is representative of an international population of X-PERT Educators, as well as the population of healthcare professionals who are also self-management educators on other SE programmes.

Inclusion criteria are designed to attract as many participants as possible within a limited timescale to get R&D approval and conduct the study: adult (19-65 years) English speaker with experience delivering the X-PERT Programme to diabetic patients in the English county of Worcestershire. The sample is drawn from the county's population of practising healthcare professionals who are also qualified X-PERT Educators (N=21). Educators are approved to deliver a minimum of three 6-week programmes per year under the terms of the licence. Each weekly course lasts for 2.5 hours; a full programme is 15 hours. The PCT's contract with the participants' employer or linked organisation pays £1,000 per 6-week programme as long as there are at least 12 patients attending, and a minimum of 10 patients complete the programme. Patients are encouraged to bring partners or carers to the sessions and often do.

4.5.2 Sample recruitment

Recruitment across two NHS sites was by an email campaign and with further assistance from the X-PERT Programme Managing Director, NHS contacts that supported the study's R&D application for R&D governance approval, the lead of the Diabetes Specialist Nurse Team, and the manager of SE programmes. Participation was also encouraged by word of mouth among colleagues, which may have primed participants in some way. Before the study, I attended a one-day X-PERT Educators' Update Conference as an observer in March 2012. The delegates present were most, if not all, of the study's local population. I introduced myself and outlined my study into diabetes self-management during the morning's icebreaker session and participated in group activities as an observer.

An electronic poster advertised the study (see Appendix 1) using MailChimp, an e-marketing web service for two months (01 June – 01 August 2012). I designed an autorespond function to make it possible to volunteer for the study with one click. MailChimp allowed me to monitor who was opening the email and when, as well was who was not responding, although this may be misleading as recipients could preview the email without opening the email. An inconvenience allowance of £30 in store vouchers was offered to encourage participation because the one-hour telephone interviews had to take place outside of NHS hours. All interviews were conducted using an interview guide, digitally recorded while taking handwritten notes and subsequently transcribed verbatim. The last interview took place on 18 August 2012.

The response rate was 52.4 per cent (n = 11). The sample was comprised of 1 Dietitian, 2 Practice Nurses, 1 General Practitioner and 7 Diabetes Specialist Nurses. Each participant worked in and had experience of at least one of the three healthcare settings: primary care, secondary care, and community care. Participants were aged 37-61 and there was one male and 10 females. The total dataset is roughly 220 pages of transcripts plus personal data capture forms. All participants were assigned a study ID in order to ensure anonymity.

4.6 Data analysis

I used transcript analysis and an inductive approach to identify patterns using coding into themes. Inductive analysis is appropriate to identify 'patterns, themes and categories of analysis coming from the data; they emerge out of the data rather than being imposed on them prior to data collection and data analysis' (Patton, 1980, p. 306 in Bowen, 2005, p. 211). I used a grounded theory approach because it is 'inductively derived from the study of the phenomenon it represents … it is discovered, developed and provisionally verified through systematic data collection and analysis of data pertaining to that phenomenon' (Strauss & Corbin, 1990, p. 23). Transferability of the study would be assisted by obtaining 'thick' descriptions of phenomena recognisable to readers as applicable to other studies (Feagin et al., 1991).

Analysis was done systematically in a way that increased my intimacy with the data. I took handwritten notes directly onto the interview guide. This allowed me to record and follow up emergent themes, and annotate their appearance in a way that reflects my own response to the data as a researcher. The recordings were transcribed shortly after the interviews were conducted verbatim with emotional outbursts and pauses also transcribed. This allowed me to take note of my own areas for improvement to pose questions clearly, and modulate my tone in following interviews. This process allowed me to repeatedly consider the impact of my own neutrality or expressions in sympathy with the emotions of the interviewee, either to make them more comfortable and likely to disclose views honestly, or whether it might be construed as encouraging participants to respond in a way that they thought would please me. Each transcript was printed, analysed, grouped and annotated by hand to draw out key themes. This was possible because of the small sample size. Participant attributes elicited during the interview or provided on the Personal Data Capture form were organised into a spreadsheet for comparison and categorisation.

My interview guide evolved as emergent themes were presented as the interviews progressed. Specific examples include questions about Educators' attitude to and relationships with other healthcare professionals in referral networks, current efforts to quality assure healthcare professionals' practice, and historical differences between geographical areas providing SE and their attitude to it. This allowed me to take opportunities to increase credibility through corroboration and triangulation between participants where possible. I did not worry about outliers or lack of corroboration because of the small-scale exploratory nature of the study whose sample was characterised by a high degree of variability in participant attributes (e.g. different clinical job roles, levels of experience and work setting), which I anticipated before conducting the research. Where outlier views emerged, I considered their reliability and trustworthiness against other data. I systematically analysed and annotated the transcripts several times, highlighting themes and coding emergent themes. Because this research topic was not addressed sufficiently in the literature, highlighting gaps in understanding, I began to concentrate on the emergent themes and potential application of theory from other fields. '[Theory] helps direct research by identifying those parts of current thinking (as embodied by current theories) that are either unclear, incomplete or the subject of a paradox' (Melnyk & Handfield, 1998, p. 313). Evidence was grouped by hand according to fit with headings conforming to Scott's (1995) pillars framework and DiMaggio and Powell's (1993) structuration framework and Greenhalgh et al.'s (2004) innovativeness test. This test was to confirm that the participants considered self-management and SE to be innovative and therefore not yet institutionalised. Themes were tabulated and relevant quotes extracted by hand and organised in terms of whether they communicated drivers or barriers to self-management and SE.

During two months' data collection, a more directed review of relevant literature also served to refine my interview guide resulting in a mixture of pure induction with early structure (Langley, 1999). For example, in order to deal with the variation in attitudes to self-management and SE that I began to see as attributable to differing job roles, employers, geographic location or work setting, and possibly the influence of official agendas within my dataset, instead of trying to control for variation I treated the situation as an opportunity to get a richer contextual perspective. Iterative triangulation was instrumental in giving me a methodological basis for treating the various perspectives from each of the job roles in my small sample as an opportunity to enrich my own data by treating participants as mini case studies, rather than seeing variance in participant attributes and degree of corroboration between participants as potentially posing a risk to the study's validity. Case studies are multi-perspectival analyses, including the voice and perspective of actors and relevant groups of actors, as well as looking at the interactions between them (Tellis, 1997). This meant my early stages of analysis developed a purposeful consideration in subsequent interviews of the relationships between Educators and their non-Educator networks, particularly the influence of professionals on the practice of other professionals. Early classification of personal motivation to become an Educator revealed differences between attitudes and job roles, and highlighted frictions between types of professionals and their interactions with other types of professionals, which I started to interrogate more openly and which triggered my use of a network perspective in my research. This meant that rather than a grounded theory strategy I was using a loose design informed by theory that allowed me to gather salient participant attributes (such as personal motivation for becoming an Educator, and teaching experience) for within group comparisons, as well as focusing on process analysis-type evidence of change (pre- and post-becoming an Educator) such as seeking evidence of integration of X-PERT Programme's core principles and curriculum into regular clinical practice.

An objective of judging whether self-management was being institutionalised in the mental framing of Educators required some analysis of the process of change that I had explored in the interviews. I reflected on the reliability of very loosely time-bound recall evidence and had to consider how I could conduct a process analysis in order to study behaviour within organisations with a view to context, activity and actions that unfold over time (Pettigrew, 1997) without a longitudinal study or a more clearly delineated event history. This is because approaches to studying implementation usually involve a longitudinal study of process analysis, whereby responses to an event or stimulus are considered in order to identify relationships between variables. However, the timeframe for this study made a longitudinal approach impracticable. The issue was how to analyse whether a conceptual process was taking place. Drawing on my previous experience in industry, I employed the early stages of a conceptual business process model used to develop new projects and assess interim progress (Figure 7). Both stages help to identify drivers and barriers to introduction and implementation: a) identifying responsibilities and b) identifying interfaces between the system being introduced and the environment.

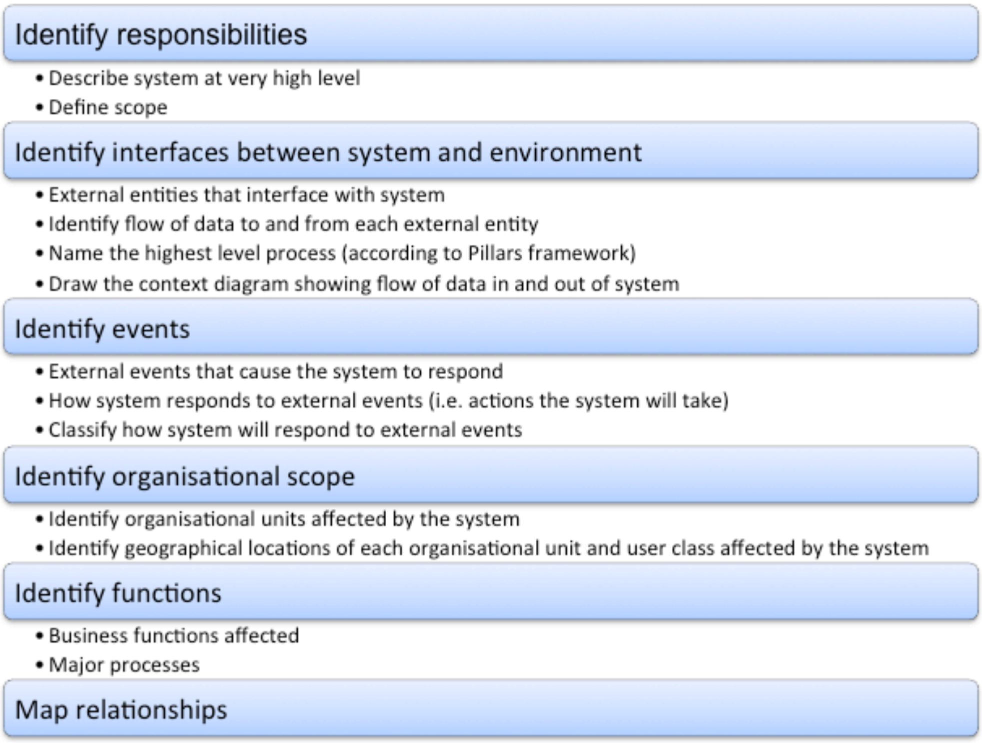

Figure 7: Conceptual Process Modelling (adapted from Borysowich, 2008)

To satisfy the first stage, my research aimed to describe self-management and SE as the system and identify the environment into which it is being introduced and the scope of its impact on that environment. This analysis together with the literature review highlighted a need to explore the perspective of healthcare professionals responsible for self-management and SE and their engagement with their new and pre-existing responsibilities. The second stage of the process emphasises the importance of mapping relationships that are relevant to the new project or system being introduced. Therefore my interview questions helped to focus attention on mapping barriers presented by relationships with patients, colleagues, organisations and their own associated professional roles in the institutional environment, and how they enable or block self-management.

Although it is usual to employ a longitudinal approach to estimate convergence of prevailing attitudes toward a phenomenon, I used a qualitative approach with interpretive methods adapted to the description, interpretation and explanation of a phenomenon (Lee, 1999). Guided by Ferlie et al.'s (2005) approach to narrative strategy of qualitative process research, my aim was to construct a story from the data that produces chronological ordering and provides the building bricks for concepts, understanding, and theory that is closely linked to data (Golden-Biddell & Locke, 1997).

4.7 Limitations

Time constraints meant I was not able to conduct a complete process-based analysis to assess pre- and post-Educator experience effects on mental framing, which places some limitations to the rigor of my conclusions pertaining to the influence of this experience on changing ideas and meanings around self-management and SE for healthcare professionals.

Although I was interviewing a set of interested stakeholders, i.e. those who are being paid to deliver SE, I did not anticipate that this would create a bias that prevented me from obtaining a spectrum of views about diabetes self-management because of the assurance of anonymity.

Trustworthiness is an underlying issue especially as the financial sustainability of SE is at risk due to changing commissioning regimes, and in a climate of NHS reform and economic shrinkage, underlying political motivations for the responses should be given due consideration although the time limits again made this impracticable.

There was evidence that participants were discussing the study between themselves, which presents a risk of bias through priming before the interviews took place. This may have influenced recruitment or participants' views. Bias from self-selection is a concern for the validity of this study and positive views of self-management and SE amongst Educators perhaps would not be a surprising finding, however I deal with this in the research design by delving more deeply into the reasons behind such views.

Normally including systematic negative case analysis would have been a way to enhance rigor, however, reexamining every case after initial analysis to see which characteristics of properties of emergent themes were applicable to all cases is not always possible in a small-scale study. Furthermore an exploratory study allows for identification of emergent themes that may not come up in other interviews.

Not being able to control the conditions of the interview was a minor limitation. It was apparent that two of the interviews took place at the workplace, and brief interruptions resulted. I think this also made one of the respondents slightly more circumspect in her responses compared to other participants, although this may also be due to her supervisory role in local SE delivery.

There was no time to allow for member checking of transcripts in the research design although I am quite sure that there would not have been interest in this because it is time consuming. The scope of the project also did not allow for the audit trail to be tested by another investigator to judge dependability.

Chapter 5: Findings and Discussion

5.1 Introduction

This section reports the views of Educators about diabetes self-management and the X-PERT Programme and shows how Educators conceptualise self-management and SE. These views point to the mental framing that they employ when making decisions about supporting or blocking the spread of self-management and SE. As mental framing is an element of the act of generation and mobilisation of ideas and meanings in social movements, like changing beliefs, attitudes, and routines (Benford & Snow, 2000), the chapter begins by discussing the framing of self-management at a practical and conceptual level by Educators. I present their views on the X-PERT Programme; explore their working definitions for self-management and what they imply; and explore how Educators conceive of what self-management and SE means to healthcare professionals and patient welfare.

This is followed by a presentation of the evidence for self-management's institutionalisation: first I discuss the results of a test for innovativeness (Greenhalgh et al., 2004). Then I present my findings from analysing the data in terms of the two early stages from the conceptual process model framework (Borysowich, 2008): identifying responsibilities and identifying interfaces between the system and the environment. The findings are presented here as a discussion of drivers of and barriers to self-management institutionalisation according to Educators' responses.

A summary of the key findings are that:

1) Educators have positive views of self-management as a concept and healthcare approach and X-PERT as a programme. They value the new perspectives afforded by becoming an Educator to their professional practice, and see these as improvements to the quality of care delivered to diabetes patients. They understand the reasons for resistance to self-management and SE in non-Educators. This is because they are familiar with the institutionalised research cultures that remain sceptical about the legitimacy of innovative interventions that have not yet been proven to have long-term effect. They have addressed their own similar forms of scepticism by learning from their recent experiences as an Educator and previous

empirical learning from careers as healthcare professionals with a lead or special interest in diabetes care.

2) There are definite signs of self-management institutionalisation through SE provision. Evidence includes the engagement of new types of actors. There is evidence of activity related to positive reinforcement of pre-existing normative values, as Educators are engaging as institutional actors promoting best practice in order actively to improve their professional practice and patient outcomes. Finally there is evidence that new shared governance systems with regulative and corrective functions on non-Educators' practice is taking place.

5.2 Views on the X-PERT Programme

Apart from Coulter's (2012) brief discussion of professionals' views of Personalised Care Plans to encourage patient engagement in self-management as worthwhile, there is no literature studying the views of healthcare professionals about self-management, or specifically SE Educators, with which to compare the following findings, and therefore they represent a new contribution.

There was strong agreement amongst all participants that X-PERT Programme is a worthwhile programme that is well designed; acknowledged to be an improvement on previous patient education efforts; and perceived as delivering benefits to patients as well as healthcare professionals. The range of opinion was from supportive to enthusiastic to passionate.

X-PERT satisfies requirements for SE provision and normative expectations for regulative quality assurance that Educators are happy to uphold because it contributes to their perception of delivering best practice:

> *I'm interested in helping patients learn more about their diabetes and because it's structured, it's standardised, it's monitored … measured, I felt that it's absolutely essential … to have something like that … it was a requirement anyway … we wanted to have a proper structured course for patients. (P11)*

Negative or mixed views of X-PERT were in the minority and mainly to do with the amount of work involved compared to the resources made available, and feeling anxious about knowing enough to answer patients' questions. The amount of work includes: the steep learning curve to become an Educator; running the course; a lot of preparation in terms of refreshing knowledge and getting refreshments; setting up and taking down boards; and getting patients' health profiles data from uncooperative surgeries.

> *[We're given just enough resources] to tick the government boxes … but we're not doing the data collecting … Nurses are having to do it instead of clerical assistants or whatever … Practice Nurses won't continue to deliver X-PERT without admin support [for invitations, letters, health profile building]. (P3)*
>
> *But it is so time consuming to actually chase all these people up and keep records and all the rest of it, but that's actually our biggest problem with it. We haven't got the staff. (P3)*
>
> *We're trying to deliver [X-PERT] with existing staff numbers [without] a reduction in patient numbers. (P2)*
>
> *I was kind of shocked … the information that we were given to give to patients was new to us, to be honest … a lot of the in depth diet advice was a shock because we didn't know it [laughs]. And you kind of think, well I've been doing diabetes for some time now … you'd think you know quite a fair bit about it but a lot of information about carbohydrates and balance of good health, estimating amount of carbohydrate was all completely new, so we went away thinking: 'Oh my goodness, we're supposed to know this,' [laughs]. So it was a very steep learning curve between completing the course and running our first X-PERT. (P7)*

Although they are convinced of its value based on their own observations, participants accept that X-PERT is being judged for legitimacy according to established research cultures. This contributes to participants feeling unsure about X-PERT's chances of long-term sustainability without more robust longitudinal data to prove lasting benefits to patients. This is especially important due to future commissioning decisions being made by parties that were described as: prioritising economic benefits, and who lack an understanding of what SE is, how it adds value, and overlooking important outcomes in any cost;benefit analyses. P3 described a big struggle to define structured education because people didn't understand that it wasn't the same as the old patient education, and therefore didn't understand the costs. This is problematic for SE sustainability because

> *GP consortia [are] only interested in money. (P3)*

When asked whether they thought X-PERT represented good value for money, most believed a case should be made that takes into account intangibles such as standardisation across the health service *'in terms of making sure that everybody is delivering the same message' (P4)* as well as quality of teaching materials and programme design, although several participants acknowledged that programmes delivered in GP Practices were not yet breaking even on costs or were calculated as cost-neutral.

5.2.1 The concept of self-management: working definitions

Participants showed variation in terms of understanding what self-management is and this affected their expectations for their patients and themselves as clinicians and Educators. Table 1 shows the types of definitions in use. Although definitions tended to display a bias either toward the healthcare professionals' interests or those of the patient, they tended also to reflect the interests of both stakeholders in a collaborative relationship. This conforms to the literature describing self-management as a partnership between patients and healthcare professionals requiring adaptation from both patients and professionals (Lorig et al., 2001; Randall & Ford, 2011; Walsh, 2012).

Table 1 Working definitions for self-management

Self management is:
'to increase patient autonomy' (P6)
'so a patient will know what's good and isn't good; they will know parameters of where they need to call for help and who to go to, and that would be successful self-management' (P3)
getting patients to increase their understanding of the GPs' priorities around managing parameters: a *'good level of knowledge about what diabetes is…and an understanding of what the parameters are that we're looking at, and then having an adult conversation with them as to how we achieve the targets that we're looking for within those parameters' (P5)*
equivalent to patient education
understanding the disease, how it progresses, potential complications and what they can do about it
a working relationship with healthcare professionals (collaboration more than emphasis on patient autonomy)

5.2.2 What self-management means for healthcare professionals

Most participants demonstrated that they had previously conceptualised aspects of self-management for themselves before being trained as an Educator, saying it had been part of formal training and updates, covered in diabetes magazines, conferences and White Papers.

> *People were prescribed diet … an insulin regimen … an exercise regimen … but life's not like that and people didn't follow that anyway, because how can you? No two people are the same. So in all the time that I have been nursing in diabetes, I've always recognised that the person with diabetes has to look after their diabetes, maybe having some help and advice from healthcare professionals. But it's not us that have to live with it. (P2)*

Many participants referred to the common sense approach of self-management, as well as needing to find a better way to educate patients than the ineffective approaches they had been using as experienced healthcare professionals working in diabetes. Patient education before X-PERT was:

> *a brief conversation: that Type 2 diabetes is that your pancreas isn't producing enough insulin and the insulin it is producing, your body isn't using effectively, and that's the sort of level that we left it at. (P5)*

Participants seemed to grasp the wider implications of self-management diffusion quite readily, either locally within their own service, team or department, or as a benefit for the NHS generally to manage growing demand for diabetes care. The level of experience as an Educator (i.e. number of X-PERT programmes delivered by participants) did not seem to affect the confidence they showed when explaining how self-management changed their knowledge, skills and practice within their professional context as clinicians and what it meant in terms of their expectations for patients. The benefits to the Educators and patients of X-PERT are easily identified by participants and respondents indicate that these benefits are readily assimilated into their clinical roles with almost immediate effect after X-PERT training, which was described as:

> *… in many ways a complete eye-opener. A lot of the stuff that we were taught on the course, and a lot of the stuff that I find difficult, I guess because of a lack of knowledge, is not so much the side effects of medication or talking about those sorts of discussions, it's the whole calorie thing and the portion size, and the what not to eat, and the what you can eat, and that was sort of a revelation to me … quite enlightening… (P5)*

The core content of the X-PERT training seems to cut across institutionalised specialisms that have created rigid domains of practice and research cultures for dietitian, nutritionist, GP, Practice Nurse, Diabetes Specialist Nurse and Diabetes Consultant roles. Part of its innovative value is to shift diabetes care far more from a medical domain into a medical and lifestyle domain, which means rigid medical professional institutional structures are being de-emphasised.

5.2.3 What self-management means for patients

Responses regarding the impact of SE on patients can be split into two categories: practical and conceptual. On a practical level, participants expressed a wide range of self-management expectations for patients attending the X-PERT course. No participants believed that attendance on the course would result in optimal control because of the complexity and life-long nature of diabetes. Participants said by the end of the programme patients understand their diabetes.

> *[The] mists had been cleared … they actually now understand what diabetes is all about and what really it was that they were trying to achieve. And I think that's the bit that we fail at in the general day-to-day clinic. It's very difficult to get so much of the information across in a way that's logical. You can't do that within a 20-minute or 40-minute consultation … it absolutely does take that 5 or 6 weeks of the course for them to assimilate that information in more than the bite-size that you're able to give them in clinic. (P5)*
>
> *[Patients will] understand what diabetes is all about … understanding the normal process of your body and then what happens to that process when you get diabetes … the reason they get complications. Because often they're told: 'Oh yes … it affects your eyes, and it affects this and it affects that' but they actually come away knowing this is the reason why diabetes will affect my kidneys… when they come for Annual Review now, they actually know why they're having these blood results and what are the targets … and why they have these targets … which is really good because they're in control. (P9)*

Participants suggested that commonly 2-3 people of every group (ranging from 12-25 people) would definitely benefit from self-management education, often in terms of changing diet and/or activity levels. Some participants expressed confidence that everyone who attends would benefit in some way, although this might prove to be invisible as auditable findings and clinical outcomes.

> *So they'll get the knowledge, they definitely get the empowerment, and that's definitely borne out by the results of the empowerment questionnaire. They definitely get support from other members of the group … Patients who've been on definitely are more knowledgeable because with the recent change in HbA1c reporting, I've been able to explain that to them and they already know what an HbA1c value was. (P7)*

Respondents report anecdotal evidence of behaviour change in patients from small changes (e.g. thinking about portion size for the first time) to quite radical behaviour change (e.g. doing the 600 calorie a day diet).

Importantly, because it indicates conceptual and practical barriers, participants describe the process of transformation from passive patients into engaged patients as *'quite alien'* (P7) to patients as well as healthcare professionals who are unfamiliar with the self-management approach.

> *[Patients] aren't used to that model of care and … health professionals … we've all been very much the medical model … 'Dr says this, therefore I will do it'. So it's very new to all of us, I think. And the emphasis is, right from Week 1: It's your diabetes. It's your course. It's your handbook. It's what you want to do. It's not for me to tell you (P7)*

It may be that healthcare professionals are more concerned with their own experiences and priorities, such as satisfying clinical targets:

> *[Related] to what you say about test parameters, GPs and ultimately consultants have fixed targets to be working towards: GPs so they can attain their QOF points and Consultants because they want to prevent complications, I guess. So they, I'm grossly generalising, but it is very much target led and clinically led, whereas I think the service that we provide as DSNs is more holistic and patient-based, and we're looking more at quality of life and helping people to live with their conditions rather than just achieve a good HbA1c. (P8)*
>
> *I think it's difficult for them to get that really, and I think it difficult for us as well because ultimately they have to go onto Metformin … Obviously they can decline, but most people don't [laughs]. So you've kind of got certain goals that you kind of need to make, but those patients don't know anything about those goals until you explain to them…. So I would say it's*

> *a bit of a struggle sometimes. Having said that the focus of X-PERT is keeping your goals small. (P7)*

Certain job roles and remits are perceived to be more closely aligned with the Educator role, contributing to a greater and easier acceptance of the demands of self-management on healthcare professionals:

> *We do patient education as a major part of our job... we're used to group education in dietetics. (P1)*
>
> *It's what we've always done – or thought we'd always done! (P11)*
>
> *[Education] has long been the remit for the Diabetes Consultant and Diabetes Nurse [Teams]. (P6)*

This may change 1) given longitudinal evidence of impact on clinical control and development of complications and 2) if the gap between roles and their understanding of self-management closes through rationalising all professional targets to incorporate self-management principles.

Meeting professional objectives during a patient encounter is important, but being an Educator has changed their approach to engaging patients by eliciting their priorities and concerns:

> *Over the past few years I've really altered the way that I provide my consultations and the way that I do the majority of my care ... to find out what's important to that individual and if they say the most important thing to me is to improve my control, then great, we can work on quite specific things to improve their control. But it may be that they just want more energy to be able to play with their children. Or they may want to stop the hypos that wake them up every night, or, you don't know until you speak to them.... It is guided to a degree by what they've been referred for. For example, if they've come to start a BLP1 [injectable regimen] then we will discuss the implications of that and why it's appropriate, and find out what they think. But if they don't want to, then I wouldn't go ahead just because the GP's referred them for it. (P8)*

Different priorities held by healthcare professionals mean that conversations with patients that alternated between traditionally prescriptive and self-management approaches could be confusing. Participants describe using the patient-centred approach learned from Educator training in their practice, aiming to 'throw back' patient questions, involving patients more by saying, *'Well, what do you think you should do?' (P7)* Although participants say, during X-PERT they stick to the dialogue and refer patients to the handbook which provides some suggestions and prompts, they acknowledge that this is not always possible in consultations because of the risk of '*confusing or frustrating [patients]' (P7)*. On the whole patients still seek advice and guidance from professionals whose claim to authority is through their expertise. Patients may get confused and disengage if they do not receive the help they seek.

Partial diffusion presents further barriers: institutionalisation of self-management is affected by continuity of care post-X-PERT because the creation of engaged patients is not sustained. DSNs often deliver X-PERT and the typical audience (newly diagnosed Type 2) is not their usual client group. This means patients will learn self-management skills but may be frustrated by the quality of information and attitude they face when returning to their GP surgery. For example, during X-PERT the patients will be told what kind of tests they can expect during their Annual Review with their GP or Practice Nurse and that they can request those results and chart their progress using their Health Profile tool in the handbook in preparation for their appointments. But patients are often told: *'The results are fine and you're doing okay' (P6)* without sharing the test results in advance of the appointment, which can be a problem for continuing self-management efforts. Increasing familiarity with the X-PERT approach will help prevent poor communication alienating patients:

> *... talking about the complications ... every medicine has got two names, which is really confusing for them. We healthcare professionals are pretty bad at using abbreviations and we use long names for things. (P10)*

So continuity of care between Educators and non-Educators relates to poor fit between priorities from a patient contact, communication style and awareness of X-PERT Programme content. One participant recommended that a partial solution for continuity of care is to overhaul the Annual Review to harmonise with the format and content of the X-PERT programme to increase continuity of care *(P2)*. These views have not featured in literature on self-management and SE.

5.3 Testing for innovativeness

Data confirming innovativeness provides counterfactual evidence that respondents do not think that self-management and SE are institutionalised yet. To do so for this study not only makes logical sense for a process study of institutionalisation, but there is also a lack of studies on the progress of self-management policy implementation in the literature.

Participants were emphatic about the novelty of knowledge and skills that X-PERT introduced to them, including: the dietetics-based content, the logical organisation of the medical information, simplifying language and concepts, visual and interactive style, and the opportunities for patients to practise and develop self-efficacy. Respondents think SE also represents a big change to routine practice because it eliminates unnecessary repetition through group education and provides unprecedented access to patients and more thorough coverage:

> *[We provided] a half-day carbohydrate counting group before, and now we've got a 5-day course. It doesn't compare, really. (P1)*
>
> *… because of time constraints, there's no way that I can cover everything that gets covered in the X-PERT Insulin programme, so they get inferior education [in a typical 1:1 90-minute initiating insulin consultation]. (P3)*

To analyse this systematically I used Greenhalgh et al.'s (2004, p. 40) four criteria to assess the innovativeness of 'a set of behaviours, routines and ways of working, along with any associated administrative technologies and systems'. The results are shown in Appendix 3 indicating a mixture of responses rather than absolute agreement over each of the criteria.

When considering data that denied self-management was innovative, it became clear that these responses are correlated to key participant attributes such as current and previous job roles, which affect perception of novelty based on pre-existing teaching experience and dietetic knowledge in particular. When taking these variations into account, there is strong evidence to suggest that the sample perceives the self-management approach in X-PERT to be innovative.

5.4 Self-management institutionalisation: drivers and barriers

To understand the role of context and agency on self-management institutionalisation, participants' views of key drivers and barriers for self-management were tabulated and organised thematically (see Appendix 4). Further analysis of these themes led to my organising them into *effects on actors* and *the role of context* summarised below. The literature does not address drivers and barriers of self-management at the level of healthcare professionals.

5.4.1 Drivers of self-management agency

A) Cultural-cognitive elements

Knowledge and knowledge claims are key drivers for Educators. Participants were able to cite many examples of how becoming an Educator satisfied their personal and professional interests in exciting ways.

> *I thought I knew what healthy eating was [laughs] … of course we refer patients to the dietitian but we're not there in the consultation, so we've learnt such a lot about diet. It's been fantastic. (P11)*

All respondents emphasised the importance of acquiring wholly new and relevant knowledge and skills that surprised and refreshed their perception of the quality of care they were now able to offer to patients compared to before they became trained Educators. This appreciation seemed to hinge on the appropriate fit between the work of an Educator and integration with the existing aims, duties and experience of their main clinical job roles.

> *Isn't that what we should be doing with general practice anyway, or with consultations anyway? All consultations should be, or the majority of consultations should be patient-centred anyway, so we should be respecting the [issues] of the patient anyway rather than it being our wishes. (P5)*

Even the more distal areas of learning, such as motivational coaching and practical goal-setting, or the prolonged programme design (which posed the most challenges to Educators, first due to unfamiliarity with these techniques, and second because of the slower pace of communication to accommodate different adult learning styles) were found to be acceptable personal challenges.

> **JGJ: So I'm hearing from you that you don't think that the 5 or 6 weeks is too much. You think that it's sort of in the 'goldilocks zone'…**
>
> *P5: Ah [laughs] no, I, when we first did it, the first course we did 5 weeks and I thought that was enough, we just didn't do the game at the end. We just didn't do it because I thought that was a lot of nonsense and rubbish. But we got told off about that, so the last two courses actually we've done it with the game at the end and the patients actually have been happy to do the 6 weeks.*
>
> **JGJ: You sound surprised.**

> *P5: Yeah, there is a slight element of overkill, a slight element that you're getting a little bit repetitive. But it is interesting, you know, the last course that we've just done, there was – the lights switched on with the patients on the last week, you know, they finally got it then, as opposed to Week 1 or Week 2, of what they were trying to achieve. It certainly doesn't need to be any longer than 6 weeks.*
>
> **JGJ: No. But it's interesting that in your own observation you saw that it seemed to all bed-in in the sixth week for some of them.**
>
> *P5: Yeah, and I guess it was my naivety, really, you know, I was thinking actually patients were going to get this quickly and they're going to understand it, you know, I guess, the course is designed for a level of intelligence, and you know with all teaching, I guess, you end up teaching to the middle, don't you? If you teach at too low a level, then those that are so far ahead will get bored and disengage and won't come back to the clinic, or won't come back to the course. So you've got to pitch it at the middle, which means that those people who are at the bottom, it's going to take them several repeats before they sort of finally click.*

Their acceptance is also rooted in:

- the nationally approved SE criteria which ensures it is *'structured… standardised … monitored…measured…a proper structured course for patients' (P11)*;
- the rest of the X-PERT programme's core principles making intuitive sense to the participants: *'I saw sense in it and saw a real need for it' (P3)*

and because they had observed that these programme techniques were beneficial to patients.

Hierarchies of knowledge: Research cultures At all times it was apparent that participants took comfort in the knowledge claims of self-management, and gained confidence from them when advising patients to try techniques because they are proven to work:

> *[I derive confidence from] being able to say 'it's evidence based'. (P9)*
>
> *[I can confidently say] 'We know this works' to patients'. (P6)*

Many participants cited evidence of effectiveness from published RCTs and regular audit results provided by X-PERT management. Participants have a keen understanding that obtaining follow up data for audit cycles, although sometimes arduous tasks, were a key part of delivery and sustainability of the programme.

> *I mean anecdotally I've had patients in who've said: 'Oh, the course is great. It's making a huge difference. I'm doing this, that and the other.' … So there's that sort of evidence but we haven't got any concrete stuff yet to say actually it has made a difference. (P5)*

Scientific evidence is being privileged as knowledge over anecdotal evidence from patient feedback even though it is also reinforced by the Educators' own observations in clinics. Some respondents express anxiety about the dominance of the institutionalised attitude to legitimacy granted only through established research cultures, which do not understand SE or how to measure its benefits and non-clinical efficacy claims.

> *… the GPs … will turn out and say…, 'Oh yes, well that's national data, what are the results here in Worcestershire?'… they absolutely tore her to pieces at an Update that she was doing last week for GPs because although…'a thousand people did it' we had only [data for] 80 [patients], or even less … results for 6 months, and even less for a year. And they were kind of saying, 'Well, this is rubbish, you can't possibly say that this is effective and that this works.' … [She] did say, 'This is just the data on the people that came back' and they said, 'Well, that's self-selecting, that doesn't count'… which of course is quite right. (P3)*

Educators understand that the programme is under scrutiny, especially in light of changing GP-led Clinical Commissioning Group (CCG) regimes and different economic priorities in GP Surgeries focusing on positive income streams from delivery of X-PERT. They describe a clear divide between those who know and understand self-management education and those who clearly do not, leading to inappropriate resourcing decisions (e.g. price-led room bookings and not permitting homemade healthy alternative refreshments) that contradict some of the core principles of X-PERT (e.g. working in a comfortable appropriate environment and trying new things). One respondent said in light of the current evidence base, delivering X-PERT in the Surgery could be seen as a *'heart over head altruistic' (P5)* decision although there may come a time when this is seen to be insufficient grounds to sustain provision.

Privileging empirical epistemes over doxa from research cultures. Although participants understand vulnerability to X-PERT's legitimacy on both effectiveness and value-for-money fronts without longitudinal evidence to back it up, they also showed that their personal support and belief in self-management education was being reinforced by empirical evidence from their own observations: seeing how health information finally transmits into patient knowledge and understanding. Educators working as GPs or Practice Nurses were able to describe the value of continuity in following up changes in patients that they witnessed when delivering the programme, as well as during subsequent patient contacts (e.g. Annual Reviews, patient appointments and X-PERT Annual Updates), describing the benefit of having more *'adult conversations' (P5)* (i.e. discussing treatment options a higher level). Although one participant did express dismay when she realised that a patient who had been on the programme evidently '*did not retain any of the information' (P7)* at follow up, participants felt that generally speaking, conversations between patients and clinicians could be more sophisticated and less paternalistic as a result of patients attending the course. For all participants X-PERT was seen as a significant improvement on previous efforts of patient education although participants were not confident to assert there would be lasting benefits without longitudinal studies to back this up.

Appearance of new types of actors. Scott et al. (2000) identified the appearance of new types of actors as a sign of structural change. The self-management literature acknowledges that patients and healthcare professionals must become engaged and activated, but it does not present a detailed view of this process through new types of actors.

Change in actors relates to the appearance of new holders of knowledge. This has implications for how new actors are using their knowledge to change institutions. Participants are accessing new occasions to learn from patients about their issues with disease management, and from working collaboratively with colleagues through X-PERT. This is due to group interaction between patients and Educators, and jointly delivering X-PERT between professionals with different experience and clinical backgrounds when working in isolation is the norm.

When asked if they observed differences between their approach and that taken by non-Educators, participants often said that they were unable to comment on the approach taken by non-Educators during diabetes consultations because healthcare professionals tend to '*work in isolation' (P11).* This meant that poor quality diabetes information and advice used by patients was assumed by participants to be mediated by ill-trained non-Educator healthcare professionals but this could not be confirmed. The conditions of working in isolation were also a factor in participants appreciating the opportunity to work in partnership with colleagues, providing many opportunities to learn new knowledge and skills, as well as finding a new appreciation for their colleagues' particular strengths and differentiated roles in patient welfare *(P3, P5)*. This meant that participants were able to play to strengths and support each other, especially when they felt their knowledge and authority were *'being challenged [by engaged patients] in front of the group' (P7)*. Working together seems to reduce the perceived intellectual and emotional burden of dealing with engaged patients *(P7)*. The emotional burden may reduce over time because healthcare professionals need lead time to upskill appropriately and gain confidence. However, the rate of innovation (e.g. novel sweeteners, new studies, media stories) means that the onus on Educators to keep up to date and to feel confident about their knowledge is great *(P7, P10)*.

Making practice more patient-centred increases access to self-management education. Respondents describe practical reinforcement of earlier theoretical teaching in medical school or nurse training on how to be patient-centred *(P5)*. Through X-PERT patients remind Educators how their own priorities are driven by personal circumstances that would affect their diabetes management.

> *[Often] when they get the diagnosis, and this is only anecdotal from what the patients have told me, their biggest question is 'What can I eat?' and they want that information today ... They can't, in my experience, take everything on in one go ... just to answer their immediate concerns ... You have to go with their agenda, really because everyone's different, aren't they? There are some people concerned about.... medication or 'when am I going to start feeling better?' if they're caught late. So I let them set the agenda for that first consultation. (P7)*

They also highlighted lessons from X-PERT about the different ways patients learn and understand medical and other health information, needing to ensure patients *'repeat back' (P7)* what was said to them in consultations to improve communications.

Respondents describe the ways their Educator experience was changing their regular clinical consultations (P4, P5, P7, P8) and the way they train colleagues.

Examples include using the Eat Well Plate and visual aids to explain diet change techniques and what diabetes is and its effect on the body (P6). Respondents describe sharing X-PERT teaching elements with patients who are unable or not inclined to attend SE, sometimes as a taster '*to whet their appetite*' (P10) to attend SE. Participants acknowledge this represents improvement to their regular practice because it incorporates the simplified language, concepts and tools that are much more accessible to patients (P5), although they also acknowledge such change is inferior to X-PERT itself because it is much less thorough (P11). Although consultation lengths vary at the discretion of the healthcare professional, one participant had concerns about giving patients too much time as it reduces equity of access available to others (P7). Others mentioned that there is too much to cover during short clinical appointments (P3, P11).

Importing X-PERT elements into 1:1 consultations may decrease health inequality by increasing access to elements of self-management teaching for those who are not suitable for a group course, or are unable to attend due to lack of motivation, scheduling conflicts, mobility issues or travel restrictions.

> *I probably wouldn't have used the Healthy Eating plate before. And I certainly wouldn't have asked to go away and, like a food diary, complete the Healthy Plate and let's have a look at it again the next time you come back.... So an awful lot of what we do in X-PERT you can actually utilise on a 1:1 ... You just can't really help carrying on some of the things you've learned in X-PERT to 1:1... (P11)*

Even with the most hard-to-reach patients, X-PERT delivers patient benefit. One participant described a pilot delivering X-PERT in a high-security long-term prison with positive patient outcomes according to the Prison Nurse feedback; this showed that barriers such as low literacy and limited influence over what food is available could be overcome due to the visual learning and tailoring the food labels and supermarket exercise to the foods that were offered in the prison canteen (P1).

Educators spoke of the value of seeing the difficulty that patients have in coming to terms with their diagnosis as *'humbling'* (P9), reminding them to be patient-centred. They described the value of inculcating patients early in their diabetes journey with some knowledge and management skills, and especially being able to answer their specific questions and alleviate their anxiety and give them a sense of empowerment to cope with their diabetes diagnosis.

Participants see delivering X-PERT as a valuable way of getting to know their patients better in order to build a better collaborative relationship because it is 15 hours of contact. One participant described changing perception of *'difficult'* or *'nuisance'* (P7) patients as a result of better collaboration and getting to a level of more informed decision-making.

Because word of mouth generated self-referrals and the ability to bring partners and carers to sessions (who are increasingly diabetic themselves), participants were able to suggest that there were wider benefits to the community that were not being captured in audits (P8).

Participants also described sharing tactics for patients to manage their healthcare providers by encouraging them to prepare questions before attending appointments (P6), and providing them with reference materials and explaining how they will be useful in the future when the patient seeks clarification (P10). One participant described it as a tool to translate complicated terms that might be used by non-Educator doctors or nurses, because healthcare professionals can choose between complex and simplified language and unthinkingly communicate with the former (P10).

B) Enacting micro-institutional affordances to change normative and regulative elements

Normative change. Respondents report change in their own levels of professional anxiety and job satisfaction from using a self-management approach with patients. Supporting patients to self-manage clarifies the normative responsibilities of healthcare professionals and patients. Previously professional anxiety resulted from patients not complying with treatment or not understanding the risks of their decisions. Being an Educator gave participants a way of working to a level of reassurance that patients were becoming better informed about their care and that their decisions to refuse treatment and other types of shared decision-making could be rationalised as part of respecting patient rights and patient choice rather than signalling failure and demotivating healthcare professionals.

> *Because they don't always make the choices that we'd like them to make. [laughs] … difficult patients, who won't comply with what you know is beneficial for their health and actually I used to fret over them, and they used to cause me anxiety … self-management releases me from that to a degree because I don't feel responsible for them in a way anymore. They are taking responsibility for themselves and provided I can hand-on-heart*

> *say they are making an informed choice, then that releases my anxiety as a clinician. (P7)*

Professional anxiety also stems from feelings of impotence: participants described seeing patients when it was too late to change their condition because risky habits over a lifetime had taken their irreversible toll. DSNs particularly relished the ability to inform and educate patients at the beginning of their diabetes journey and to share their expert knowledge. Participants describe this earlier contact broadly in terms of remedial work, making up for poor standards of patient education elsewhere in the health service, and that as a consequence they might reduce their professional frustration and improve their own professional outcomes when helping those patients in future.

> *[I] could see the consequences on patients' health 5-10 years down the line [of poor quality education patients were receiving] and realising that [DSNs couldn't compensate for this single-handedly, and Practice Nurses couldn't get sufficient education to patients]. (P3)*

Being an Educator highlights the inadequacies of current regulative processes to quality assure diabetes care, and as a result supporting self-management and SE can be construed as a normative activity for ensuring patient welfare. A respondent described a surgery's good performance for diabetes care according to QOF point achievement, and the realisation that this was happening almost in spite of patient welfare because this success for the practice happened before X-PERT. The respondent acknowledged how much better diabetes care is since delivering X-PERT. The normative aspect was underlined when the respondent described delivery of X-PERT by the surgery as a 'heart-over-head altruistic' decision. Although this was tempered by a strategy to ensure some kind of return on the investment to the practice was to see how the practice's services could be reconfigured to take advantage of the lessons learned from delivering X-PERT. This resulted in changing the content and order of delivery of patient education during 1:1 appointments. This signals innovation adaptation in a divergent form rather than the convergence of X-PERT as the ultimate shape of self-management institutionalisation.

5.4.2 Barriers to self-management agency

A) Not all patients are suited to self-management and SE

The activation of Educators' agency, expressed as enthusiasm and support for self-management through SE, is tempered by their view that it is not suitable for all types of patients, which will have an impact on the institutionalisation of self-management. When asked to consider barriers to self-management many participants reported patient attributes that made them unsuitable for group education, such as mental health problems, language and learning difficulties, and hearing impairment. Experiments with translators and signers joining the group were described as disruptive, although one participant described the supportive group dynamic that embraced a 40-year old diabetes patient who had Downs Syndrome but good cognitive and social skills as presenting no problems at all. Referrals with medical histories flagging potential issues with group education due to mental health issues were filtered by Educators by initial telephone calls explaining the X-PERT Programme so that the patient could make an informed decision about attending or not (P10).

When asked about people who would not be able to self-manage, examples included those whose physical bodies were so unpredictable that the best control would be through an insulin pump. Patients who are angry or in denial, or have low-to-no motivation to change were also mentioned as either not completing the programme or not attending in the first place (P7). This has implications for the effectiveness claims as audit data is biased due to self-selection (P3).

Another concern with the audit data is the distinction between newly diagnosed diabetes patients who were ‘caught early’ or ‘caught late’. Diabetes patients who are asymptomatic and were detected early may not have the big change in HbA1c one year after the X-PERT Programme compared to those who are caught late, and are suffering from diabetes symptoms and more motivated to do something that makes them feel better (P7).

B) Social and cognitive barriers to diffusion

Ferlie et al. (2005) describe social and cognitive barriers between actors in multiprofessional groups obstructing innovation spread. The findings confirm that structural barriers within the wider multiprofessional diabetes care team do exist, particularly in the quality of referrals to attend structured education, but they are less pronounced in the closer knit multiprofessional self-management community of practice inhabited by Educators. This is discussed more fully in Subsection 5.5.

For localities where routes to specialist patient education were established three years before the introduction of X-PERT, social and cognitive barriers to SE were already removed as evidenced by referral rates from GPs reported by respondents to be 100% of all newly diagnosed T2 patients. Although some participants reported this as positive, others questioned whether this was good practice as uptake by referred patients is only around 40%. Respondents described instances of GPs' negative attitudes toward SE providing the first hindrance to patients' attendance by wondering *'how anybody ever finds 6 half-days to go'* to attend the course (P1) or their general perception that the programme length makes it impractical for patients in work. Others reported a suspicion that GPs are not treating referral onto SE with the same attitude as they would any other type of diabetes treatment, saying it should be treated as *'the first pill'* (P11), and imagine referring GPs are probably not discussing the value of the programme with patients appropriately so that they are primed to look forward to the letter of invitation. One participant was emphatic that doctors in particular lacked empathy about different learning styles, representing a social and cognitive barrier to SE:

> *[On] the whole, the doctors … seem to really struggle to understand that not everybody is as intelligent as them and that they don't all learn like they do … I still think that a lot of them don't see that you actually need to do the education in another way. They still think that all you need to do is tell the patient and give them a leaflet and that's it. (P3)*

Participants raised the fact that some of the important decisions about who and how to refer are in the hands of those who do not appreciate what it is or how it works despite multiple awareness raising initiatives.

> *[The] GPs and Practice Nurses who aren't familiar [with X-PERT], they may not realise how good it is, and you sort of feel like you're doing your best to try and portray how good it is and how most of the patients benefit … they don't always look convinced because they see it as a 6-week programme, a very long programme, time consuming and very costly to run. … you listen to how enthusiastic [the GP Educators] are about X-PERT … they're delivering it, and they can see the benefits. And of course it's a lot of those other people [laughs] other GPs [laughs] and sometimes Nurses, who can't actually see that because they haven't actually experienced it. (P11)*

Inadequately resourcing for both clinical time and X-PERT is raised as a problem, with some Educators reporting work on some of their days off to deliver or complete X-PERT clerical and organisational tasks. One participant mentioned a need for 100% Educator roles (P6), although this may contradict another respondent's prerequisite for good quality X-PERT delivery being a healthcare professional with very good diabetes medical and lifestyle knowledge and authoritative problem-solving that will be able to respond to patients' questions during the course of the programme (P7).

As a new type of actor, patients are also part of the multiprofessional community of self-management practice and the major social and cognitive barrier identified by participants is the confusion caused by the changing relationship they have with healthcare professionals. Patients were described as struggling to understand the alien concept of self-management, being more comfortable with the passive patient role, expecting *'Nurse to fix it'* (P6).

Finally, two participants suggest that referrals and the quality of referrals would not pick up until they were intelligently incorporated into the QOF points system (P2, P11). Doing so would address the social and cognitive barriers among Practice Staff who fail to understand the value of SE by translating it into regulative and financial terms.

5.4.3 Interpreting the views of Educators in terms of wider institutionalisation of self-management and SE

The issue of inadequate resources for X-PERT delivery is likely to result in self-management being institutionalised but in different formats that are perceived to be less costly. Issues such as insufficient clerical staff resource to chase the patient data pre- and post-programme and insufficient time to deliver the programme as well as to manage patient caseloads were mentioned. Because X-PERT is standardised, the licence agreement stipulates that Educators stick closely to scripted dialogue and course content. This means condensing the programme is not permitted, although participants exhibit a wish to find shortcuts or efficiencies in order to reduce the overall length of the programme. Specific reasons for this are unclear. The financial incentive offered to deliver X-PERT is also described as a hurdle because it is perceived to be too low with respondents describing it as cost-neutral or not yet breaking even, which will also drive behaviours to find efficiencies, affecting delivery.

The barriers to getting surgeries to deliver X-PERT are complicated by several factors: participants cite unmotivated Practice Nurses for reasons of low remuneration and overwork, and general feelings that there isn't time to do everything (P7). Size of surgery and population of diabetes patients are also key factors (P6). The attitude to cost is also a major factor: both in terms of releasing staff to deliver X-PERT and loss of clinical time for patient appointments leading to waiting lists (P5), as well as undertaking a programme with high overheads (e.g. licencing, materials, on-going training) (P1, P8) and questions about long-term benefits compared to alternatives (P3).

The emergence of alternative provision is also a factor in diffusion of X-PERT to surgeries (P1). With the introduction of external quality assurance bodies for structured education commissioners (e.g. QISMET and Diabetes Education Network), as well as rising competition among SE programmes to be commissioned in other areas, there are signs that developing in-house programmes (e.g. adapted from the Bournemouth BERTIE programme, Gloucestershire's BANANA Programme, Shropshire's STILE Programme) may be seen as a more economical alternative although there is no evidence of this (P1). This means that it is likely that as long as there are resources available to fund diffusion through organised efforts, self-management and SE institutionalisation will probably happen in divergent forms rather than through convergence of programmes such as X-PERT as the new institutional logic.

5.5 Network effects: the role of context on self-management diffusion

According to Scott et al. (2000) profound social change involves new types of actors therefore the conceptual difficulty of transforming patients into new types of self-managers is a specific challenge in terms of effective institutionalisation of self-management. Figure 8 shows the actors in a multiprofessional diabetes self-management community of practice.

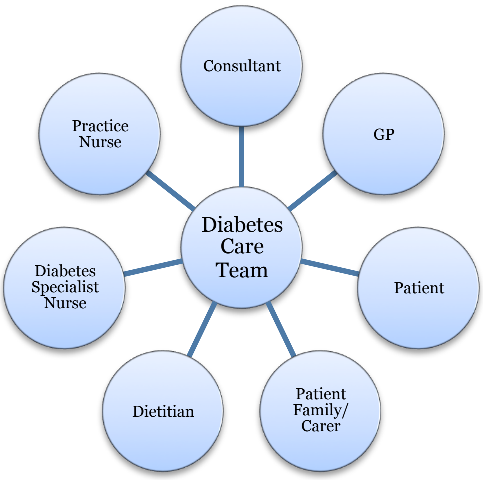

Figure 8: Actors in an integrated diabetes care model of multiprofessional community of practice

The reskilling and redeployment of healthcare professionals into proactive supporters of self-management seems slightly less onerous, however, especially if there is continuity of role and purpose between their clinical role and an Educator role. All participants were asked to explain what their job entails, to describe the context in which they work, and why they wanted to become Educators. Almost all participants described prior involvement in teaching, training or educating other healthcare professionals through activities such as:

- Local Enhanced Services (LES) Insulin Management Training for GPs
- Link Nurse Training
- Updates for DSNs
- Lunchtime Education Sessions or other Sharing of Good Practice Training within GP surgery
- Training Ward Nurses
- Mentoring and Training Student Nurses and Nurses Post-Registration
- Training Medical students and Registrars (GPs in training)
- Being a partner in a Teaching Practice

Motivation for becoming an Educator was described as a natural extension of their personal interests and main job role, which seems to contribute to satisfaction with X-PERT. Therefore spread of self-management by increasing the population of Educators can be understood as mediated by a harmonious fit with personal interest in diabetes, teaching and current job roles and remits.

Furthermore, the participants' existing job roles provide institutionalised opportunities to increase awareness of self-management to non-Educators. Two respondents describe their involvement as Educators or their agreement to deliver the X-PERT Programme, as the result of the enthusiasm and word-of-mouth marketing of current Educators during a LES Update or Link Nurse training session. All contact with non-Educators presents opportunities to legitimise self-management within a situation where the Educator possesses authority through specialist knowledge over non-Educator audiences. However, because these training events usually have packed agendas and they are of short duration (e.g. half a day annually) I suggest that this is not sufficient to teach self-management concepts in any depth as Educator training usually takes 3 days and therefore is not as strong a vector of diffusion and institutionalisation as becoming an Educator.

These opportunities to train colleagues are important, however, because it was generally agreed by participants that diabetes self-management is a collaborative effort, involving patient engagement as well as engagement from referring colleagues in order to work. Therefore responses from participants about their own views as X-PERT Educators often included discussion of the views of other stakeholders in a wider diabetes care network that they wished to reflect on and report. This wider network includes Educators, their non-Educator colleagues (e.g. programme delivery and clerical assistants), referral networks (e.g. GPs, Practice Nurses, Consultants, practice staff, patient self-referrals), patients, their partners and carers (increasingly with diabetes themselves), organisational decision-makers and programme commissioners.

As a nascent multiprofessional self-management community of practice ('B' in Figure 9), this local X-PERT Programme delivery network is comprised of interdependent institutional actors with power to influence the spread or non-spread of patient self-management to the wider network ('A' in Figure 7). Educators located in the B network are forerunners in self-management diffusion.

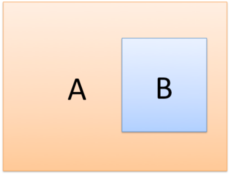

Figure 9: Relationship between different diabetes care networks: Educators (B) also belonging within the wider network of non-Educators (A)

When asked to identify barriers to self-management it became clear that existing management strategies to diffuse self-management through network A are not going to plan. The PCT and Acute Trust run three different programmes to increase levels of diabetes patient management in the primary care setting:

- X-PERT Programme: to increase patient self-management and up skill healthcare professionals in methods to support it
- Local Enhanced Service (LES) for Insulin Management: a mandatory half-day per year training by Diabetes Specialist Nurses for GPs who are practice leads for diabetes care
- Link Nurse Training: for Practice Nurses with a special interest in diabetes trained by Diabetes Specialist Nurses

Figure 10 shows that despite formal opportunities for learning up to date information and skills for diabetes management being made available by the PCT and Acute Trust, the degree of uptake in the county is patchy, resulting in persistently hard-to-reach GPs and Practice Nurses who may be delivering poor information and advice to diabetes patients.

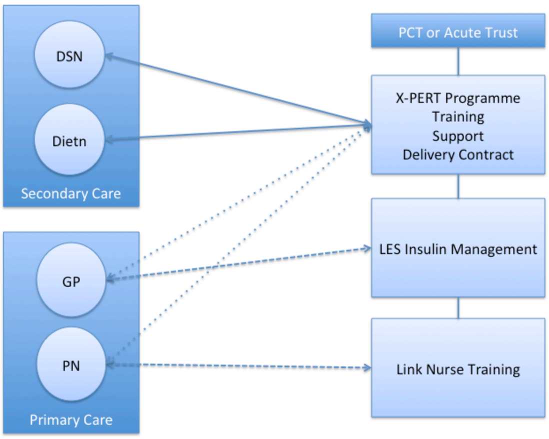

Figure 10: Strategies for improving diabetes management skills in wider network (levels of higher and lower participation indicated by stronger and weaker arrows respectively).

As participants describe it, despite the PCT providing X-PERT training, some administrative support and financial incentives, the expectation that more surgeries would deliver X-PERT has not materialised. Not every surgery has practitioners assigned as leads in diabetes, therefore they do not access the LES or Link Nurse updates. Responses suggest that non-participation in X-PERT by more healthcare professionals in surgeries may be due to:

- the steep learning curve in order to become confident Educators
- laziness and X-PERT being very demanding to deliver
- inadequate financial return
- not enough time
- feeling underappreciated in surgery and not willing to do more
- thinking X-PERT programme is too long/impractical/costly option
- awaiting evidence of long-term effectiveness in local audit data.

Although one participant said it was still early days for the 2-year old LES and it has increased the number of GPs who are able to initiate insulin, it will still take time for Diabetes Lead GPs and Practice Nurses to learn the skills to manage changes to insulin (P2). Generally the failure of surgeries to avail themselves of these three training opportunities has meant the level of patient referrals to DSNs has not decreased as a result. There is increasing pressure on DSN resources currently and in the future: first because they are delivering the majority of X-PERT programmes, and second because availability of programmes will need to increase to meet current levels of demand. Almost all participants confirmed an increase in numbers of patients diagnosed with diabetes and at younger ages, especially among males in the 30-40 age group rather than the usual 60+ age group. Because LES and Link Nurse training are short and infrequent, there is insufficient time to cover self-management skills in depth. Therefore the best opportunity to learn these skills is by becoming an Educator or at least observing an X-PERT course in its entirety to become familiar with the core principles and to experience patient interaction in this setting.

5.5.1 Driven to destructuration: reducing hold ups and jumping the queue

The following sections describe two instances of destructuration through the exploitation of context-bound micro-institutional affordances that exist between institutionalised processes a) in order to benefit patients b) to control for negative effects of colleagues' poor practice and c) to serve the healthcare professionals' own interests. They describe changes to the way patients come into contact with diabetes specialists that deviate from institutionalised practice. These instances illustrate how novel institutions form as a result of Educators enacting institutional change.

5.5.1.1 Hold ups and DSN Episodes of Care: Deviating from institutionalised processes for patient flow through referral networks

Background information: DSNs and Episodes of Care

Both Consultants and DSNs are medical specialists, with expert knowledge of medical treatment and diagnosis of complex problems to do with diabetes. Although traditionally situated in Secondary Care, most DSNs described the context of their services as having been moved into the Community.

DSNs tend to deal with complex patients (i.e. those who are experiencing problems controlling their diabetes, often due to comorbidities) with Type 1 diabetes, although they may see some Type 2 patients who are on insulin if they are experiencing problems outside of the scope of their GP's or PN's expertise. They will see patients who are referred to them by Consultants, GPs or PNs in order to initiate a treatment or to 'trouble-shoot' and resolve a complex change of treatment. This means that activities like an Annual Review are seldom conducted by DSNs and long-term relationships with patients are less common. Although one DSN looks after patients who are on insulin pumps, most DSNs will have patients in their caseloads for a limited period of time, called an Episode of Care.

The episode of care is concluded when the DSN judges that the patient is 'competent and confident' to manage their diabetes regarding the initial reason for the referral. At the conclusion of an episode of care, the patient is referred back to the care of their GP practice. If the patient has been in hospital, then it is usual for the DSN to follow up their diabetes care into the community before being returned to the care of their GP practice. Although an episode of care has been completed, it does not prevent a patient from contacting the DSN or Consultant clinic directly in a self-referral for additional support. Initial consultations are 60-minutes with a lot of investigation into lifestyle and concerns that the patient has. Follow up appointments tend to be 30-45 minutes depending on the types of issues identified during the initial consultation. Telephone consultations of up to 15-minutes are often used to follow up on a biweekly basis to see how changes in medication are being tolerated.

Healthcare professionals tend to be situated by role within a system of health and social care that is dictated by the alignment of specialist skill with complexity of medical attention required by the patient. Every patient movement is disruptive in terms of continuity of care and approaches to care, as well as costly in terms of the time and effort required to translate medical records into knowledge accessible by the attending healthcare professional. The division of labour by specialism mapped in a diabetes care pathway routes a patient through a network of healthcare services.

System overrides occur if there are concerns about patient safety. The Hippocratic oath to 'do no harm' supersedes the management logic of optimal throughput to help integrated services to collaborate effectively as a system. Variability in the flow of patients occurs either because patients 'drop out', or detours or delays are introduced based on variability of expertise within healthcare professionals.

Participants were asked to describe when they would become part of a diabetes patient's journey and the nature of their contact. Examples from the data show key factors for variation along the care pathway include need for referrals and timing of referrals (i.e. if and when patients are moved from one healthcare professional's care to another).

The data describes a second reason for a system override dictated by healthcare professionals: when they identify a need to exert informal regulative controls on colleagues outside of their normal range of correction (i.e. working in different professional capacity or working in a different healthcare setting). As destructurating agents, Educators introduce changes to the referral pathway through the positive introduction of delays or by removing need for movement from one professional to another. This occurs if:

- healthcare professionals have transferable knowledge and skills from previous experience to deal with the problem themselves
- healthcare professionals have broader experience through working several roles simultaneously (e.g. as a clinician and X-PERT Educator, or as a DSN and a Practice Nurse)
- there is specialist diabetes lead status in a surgery
- there is a personal interest in diabetes or teaching
- there are resource issues (e.g. waiting lists).

Being an Educator may provide additional skills to deal more effectively with patients without moving them on. Not being an Educator or Diabetes Lead may flag to referring colleagues that the surgery's diabetes skills are of questionable quality. One participant described prolonging her contact with a patient during an episode of care if she knows that the level of support needed by the patient could not be met adequately by referring the patient back to the GP surgery at that point:

> *[When] the Episode of Care is completed, we refer back…to the level that we know that the GP or the Practice Nurse…have that knowledge and expertise to be able to follow up care…I think it's very much based on our knowledge of the surgery that the patient belongs to because … I know which practices are part of the LES and at what level they're working to the LES … I have that pre-knowledge (P11).*

All participants (apart from the dietitian who described improvements in her diabetes knowledge) described improvements to their diabetes care because they are able to discuss dietetics knowledgeably and with much more confidence as a result of their training as Educators. This means that potential demand for referral to the county's sole community dietitian is reduced. Furthermore all participants agreed that the quality of patient education they are delivering, whether it is within the X-PERT Programme or during their regular 1:1 patient consultations, has improved in terms of quality of advice given to patients regarding how to improve diabetes management through dietetic knowledge and skills when compared to their previous practice. So although the plan to reduce demand for DSN appointments has not been through uptake of LES and Link Nurse training, the effects of X-PERT training over time may help to reduce demand.

5.5.1.2 Jumping the queue: professional self-interest and destructuration of institutionalised care pathways

Background information: Diabetes Care Pathways before introduction of SE

Before the SE referral route was required by NICE for newly diagnosed Type 2 patients, they were primarily looked after by GPs and Practice Nurses, with occasional referrals to Dietitians for 1:1 or group education appointments, and to DSNs in order to resolve complications to do with poor diabetes control[13] typically for a specific problem and for a fixed duration or episode of care.

Type 1 patients, and some Type 2 patients, would also be assigned to a Consultant specialist in diabetes, who works in conjunction with DSNs, although a concerted effort has been made to move the majority of patients off Consultant lists and back into the care of their GPs. Patient preference sometimes dictated whether diabetes management was through contact with Consultants, DSNs, or GPs and Practice Nurses, especially if there was already a relationship through the Consultants' office to the DSN service. In order to speed the transition of patients back into GP care, a LES for Insulin Management was set up in the area two years ago in order to train GPs how to initiate insulin. Annual insulin management training lasts half a day. Practice Nurses also get diabetes care updates via regular Link Nurse training.

Figure 10 shows typical points of contact from referrals between healthcare professionals for T1 and T2 diabetes patients. Dashed arrows indicate lower frequency of contact. The rationale for contact is patient need: a diabetes patient may stay for prolonged periods within the care of their GP and Practice Nurse, without needing to seek attention from the Dietitian, DSN or Consultant because their diabetes is under control.

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[13] This description of diabetes services is derived from the interview transcripts. I acknowledge there are likely to be variations within the research setting that prove to be exceptions to the data I have collected.

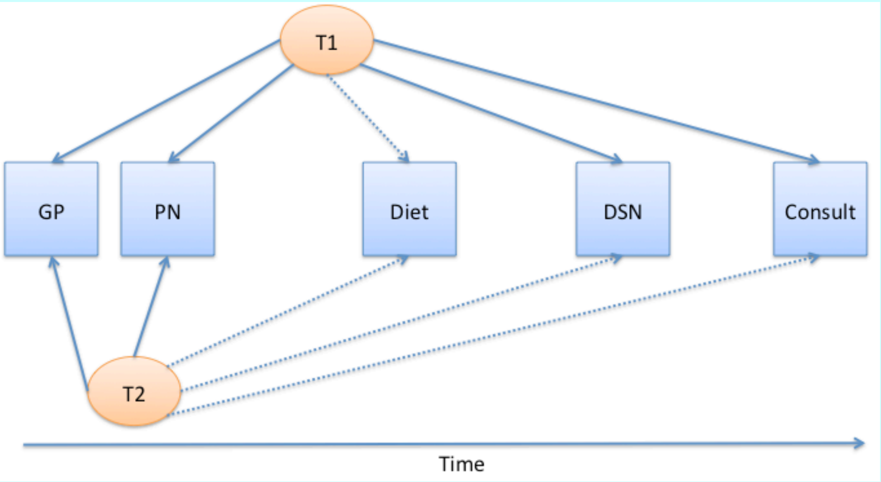

Figure 10: Typical journey of contact with healthcare professionals with diabetes patients

However, the vagaries of a progressive chronic condition include development of complications due to movement through stages of the disease and the patient lifecycle: where physical deterioration from ageing increases risk of illness, and health decreases as a result of disease progression and/or prolonged exposure from risky health behaviours. Therefore, what I have tried to depict is the importance of time related to access to diabetes specialists.

It was common for DSNs who were interviewed to lament that their typical point of contact with patients was almost when it was too late to do anything really constructive about managing the diabetes. They described speaking with patients who had come to them because they were experiencing complications, often the result of comorbidities; these were patients with decades of experience living with their diabetes but without a clear idea of what the disease was or how to manage it. Often Educators described evidence shown to them by patients of poor quality, misguided, and out-of-date information that had been given to patients by their GP or Practice Nurse. They also described patients who had ingrained a lifetime's worth of poor knowledge into bad diabetes management habits that were difficult to reverse because the patient had managed so far by doing what they'd been doing. The DSNs in particular talked about the value to their own work of gaining access to Type 2 patients through X-PERT because they normally would not be dealing with them unless they experienced complications.

> *We didn't have anything to do with T2 newly diagnosed patients previous, at all, they were always under the care of the GP or Practice. We only saw patients when their progression in their diabetes was many years ahead… a lot of people would come to you even ten years after their diagnosis and*

> *still have no understanding of what it was. So it was great to be involved at the very beginning, so that you felt you were going to make a difference to them in the future…giving them knowledge and ideas of how to manage this condition really. (P11)*

Being an Educator allowed DSNs particularly to jump the queue (see Figure 11), thereby destructurating the institutionalised care pathway guidelines, and directly address issues that they had previously identified as part of their own informal root cause analysis when reflecting on poor patient outcomes and their low sense of professional empowerment.

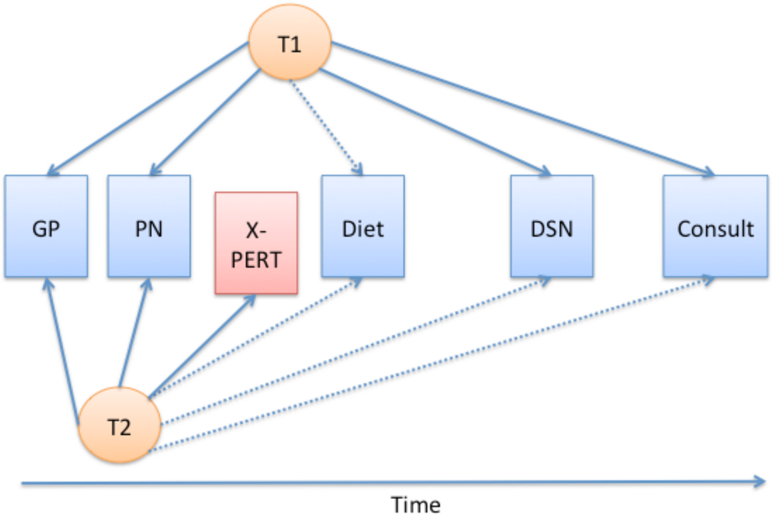

Figure 11: X-PERT provides diabetes specialists earlier access to Type 2 patients who may never progress to being cared for by Dietitians, DSNs and Consultants

The causes for their own professional dissatisfaction were understood by DSNs to be mediated by the poor quality of patient education and out-of-date information and guidance meted out by professional non-Educator colleagues in the diabetes care network. Information flows that should occur through the three training opportunities are not taking place in a way to improve the situation.

However, information flow and shared governance mechanisms are occurring as a result of enactment by Educators despite the existence of institutional barriers. Multiprofessional groups with different status and pay grades have social barriers that mean there is insufficient scope within the group to issue sanctions or to use coercive tactics on each other, although certain members may have identified the root cause for poor patient outcomes in terms of poor diabetes information and advice coming from other professionals. Educators however are able to exert corrective pressures on the practice of others non-confrontationally. First this is because engaged patients learn to question the care and authority of their GP and

Practice Nurses, especially when armed with X-PERT learning and reference materials. Second is also through patients contradicting and challenging their GP or Practice Nurse's authority – to such an extent that they are provoked to remark on the changes in those patients, triggering occasions for them to comment to DSNs about the changes or to seek clarification about related information or concepts. This provides an important feedback loop to Educators about more swingeing changes that result from X-PERT on self-management institutionalisation. Educators get a glimpse of the way X-PERT is raising awareness in GPs and Practice Nurses of their own diabetes knowledge gaps. It is hoped that they may be inclined to act on an identified need to update their diabetes skills. As these regulative enactments by Educators go against the grain of institutionalised barriers they are evidence of structuration of competing or rivalrous logics.

A counterfactual or barrier to this precipitating dynamic for self-management adaptation is that the healthcare context is built on specialism and referrals. Therefore GPs or Practice Nurses who are not inclined to make changes will be able to refer patients to SE without having to change their practice, although as described above this has implications on continuity of care and sustainable patient engagement. This presents challenges to the idea of self-management diffusion as a paradigm shift subsequently manifesting as convergent practice. A likely result may be parallel institutional logics co-existing as different specialist approaches with institutional agents acting as brokers between the two. Again this type of self-management institutionalisation would manifest in divergent forms.

5.5.2 Institutional actors and their contexts

What emerged strongly through the data is the way that institutional actors are exerting their agency to influence the context of their own work (i.e. their bread and butter self-interest) as well as upholding normative ideals, such as optimising patient care. For a healthcare practitioner in diabetes, whose role is to find solutions (in terms of medical treatment or lifestyle management) leading to good diabetes control, they must work closely with patients and health service colleagues in a multiprofessional community of diabetes practice. As previously discussed, Ferlie et al. (2005) show that disagreement within multiprofessional communities of practice[14] are difficult to resolve due to social identity barriers as well as cognitive

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[14] My own use of the communities of practice concept echoes Ferlie et al.'s example of a diabetes care team, where the focus is the disease type rather than agreement over accepted practice of how to treat it. The latter type of community of practice tends to be made up of a

barriers: ‘individual professionals within so-called multidisciplinary teams often found it difficult to agree to the role redefinitions indicated by [innovation]; their findings confirmed that ‘established professional roles and ‘jurisdictions’ got in the way’ (p. 128).

This social network manifestation of context brings with it institutionalised identities, relationships, attitudes, routines, pathways, knowledge and beliefs. Further structural components including physical and other resource elements such as time, energy, reward, job descriptions, governance and research cultures also affect the perception of an actor’s freedom to exert agency. These structural components can be seen as the role of context. Participants are showing that they are escaping the constraints that result from the structural cohesion of context in order to improve their own performance at work by addressing root causes for underperformance. This involves engaging and identifying new types of actors (engaging patients to self-manage) and by travelling back in a time-oriented structural configuration dictating when professionals interact with patients (engaging with patients before the onset of complications). By deviating from institutionalised quality processes that privilege medical professionalism into a rigid status hierarchy (doctors over nurses), and that dictate division of labour according to medical professionalism (primary, secondary and community care) and static biomedical descriptions of a patient’s stage in the diabetes journey, Educators are enacting and instigating additional quality assurance and informal regulative governance processes.

Participants said they derived a key value from being an Educator and that is through delivery of a well-designed and evidence-based patient education that is appropriate to patient needs. Delivering acknowledged good practice brings a normative reward (doing what a professional should be doing). However, this also brings a corrective measure, as it makes up for poor practice elsewhere in the multiprofessional community of practice. Moreover, participants did not describe the problem of poor patient education as an abstracted concept, rather they often tended to link the problem of poor information and advice to the linked source: out-of-date practice staff.

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closer-knit and practically aligned set of individuals, i.e. all vascular surgeons and use of low molecular weight heparin.

> *If [Practice Nurses] spent as much time learning about [asthma, heart disease, COPD, children's immunisations, travel vaccines, sexual health clinics] [puffs], as they would need to learn about diabetes, they would be forever in the classroom. So I can understand that there's limitations to their knowledge and skills... But there's some old-fashioned ideas still out there in places and pockets. (P2)*

The implication of non-Educator colleagues' poor practice is interesting because this distinction is mediated by changes described by participants in their own practice as a result of becoming an Educator:

> [Before facing the steep learning curve to become an Educator] *We thought we knew about diabetes! [laughs]* (P7)

Therefore their suspicions about bad practice elsewhere in the network comes from their own acknowledgment that they too used to be delivering comparatively ineffective patient education in the past. One participant described the endless repetition of the same information to patients with no effect on patient knowledge or behaviour, wondering if what they were doing was any good and sometimes feeling:

> *I'm not doing anything right here (P11)*

But now she can see that patients are benefiting from X-PERT. Their recent experiences as Educators have made them more passionate about eradicating poor patient education generally for the benefit of their patients but also for their own effectiveness as professionals (seeing them too late to do anything about it).

In terms of personal agency, the satisfaction expressed by participants with being an X-PERT Educator can be understood as a functioning, a highly contextualised skill that contributes to an individual's wellbeing in that context. Because of the highly institutionalised structure of the NHS, being an X-PERT Educator is also a capability, the possession of that functioning in time and opportunity, in other words it is an example of micro-institutional affordances first to correct their own performance in a virtually autonomous way (rather than being critically managed from above) through ensuring contact with patients at the beginning of their diabetes journey, as well as correcting the performance of colleagues whose position in the highly institutionalised NHS would normally make them beyond the reach of correction by DSNs or Practice Nurses, because they are more senior or remote from their secondary care or community setting.

More generally being an Educator is a way of instigating micro-movements of reform to address bad practice in GP surgeries. This reform is characterised by bottom-up, sideways, or going-around movements:

- **Bottom-Up:** from engaged patients asking GP and PN provocative questions during and following X-PERT;
- **Sideways**: diabetes leads who are non-Educators are getting brief updates during LES Update Training and Link Nurse Training from Educators; changes in patients from X-PERT is being mentioned during Practice Meetings and Lunchtime Education sessions; medical students and trainee nurses are increasingly attending X-PERT as observers
- **Going around**: delivering X-PERT to newly diagnosed before onset of complications, referring patients out of the influence of out-of-date GPs and Practice Nurses, giving Type 2s the benefit of early access to highly specialised diabetes medical treatment and lifestyle management expertise.

There are several ways in which prevailing institutional logics are contributing to poor practice and increasing dissatisfaction with current approaches to diabetes care. These create precipitating or enabling contexts for structuration of competing or rivalrous logics:

- Present governance mechanism for GP performance (such as QOF or self-governing professional associations) is inadequate to ensure good patient education because it does not require or pay for referral to SE, nor does it require SE delivery in practices
- Professionals tend to work autonomously and in isolation. There is little opportunity for observation or quality auditing of information provision or approach taken to agreeing treatment options with patients
- Medical professional divisions are responsible for many areas of tension between GP, PN, DSN due to pay and status differentials, different targets and priorities, different attitudes to patients' rights to information and choice; different attitude to learning styles; different attitudes to who ultimately has responsibility for patient health

- A mechanism for improving relations between GP and PN is needed to increase appreciation of valuable differentiation of roles and skills; and provide an opportunity for Educators to prove the value over time of self-management approach as anecdotal evidence is backed up by LT effects and improved patient outcomes.

Chapter 6: Conclusion

6.1 Introduction

Being an Educator empowers healthcare professionals to improve the quality of diabetes care provided by themselves and also healthcare professionals who do not have a special interest in diabetes. Being an Educator is an effective way of highlighting latent awareness of self-management principles and bringing them to the forefront of healthcare professionals' mental framing, triggering change in their approach to practically supporting self-management. Being an Educator shows healthcare professionals how to involve patients more in their healthcare.

Educators exercise their agency by exerting change to reflect their normative values in terms of good professional practice and patient outcomes. They evidence cultural-cognitive change because they are enacting organisational change based on knowledge informed by empirical epistemes (the employment of intuitive logic at a local level), as well as evidence from research cultures. Reliance upon empirical epistemes and intuitive sense is destructurating institutional logics that inadequately redress poor quality diabetes care at the cost of patient outcomes. While X-PERT is in its innovative stage, Educators enjoy new information flows from new types of institutional actors (i.e. patients) and are able to exercise greater levels of professional autonomy by deviating from pathways and guidelines that sustain the institution rather than improve patient welfare. They are discovering relative freedom from institutional constraints like rigid medical professionalism, which allows them to utilise new forms of governance to correct the poor practice of colleagues who would normally be beyond the scope of their ability to sanction or govern.

Through mapping these interpersonal dynamics to explore new information flows and new governance systems at the micro-organisational level it highlights the existence of precipitating and enabling contextual dynamics that contribute to the role of Educators' willingness to enact organisational change. It also points to the existence of micro-institutional affordances that show organisational change through self-management has potential to spread across multiprofessional groups and across various healthcare sectors. There is evidence of institutional change but given the environmental circumstances self-management institutionalisation is likely to take a divergent form with lots of variation in types of SE being offered to support self-management, rather than X-PERT being the prevailing institutionalised form.

6.2 Drivers for and objectives of the research

Chronic disease is a major and growing global problem. One approach to managing healthcare demand is by increasing patients' ability to self-manage their condition in the community by providing structured patient education programmes. This research explores the mental framing applied by healthcare professionals who are delivering SE as trained X-PERT Educators. It sheds light on their role in the spread of self-management and SE at the micro-organisational level and provides an explanation for how this institutionalisation is happening.

Educators have positive views about patient self-management seeing it as the only realistic option to address growing need for good diabetes control. They see it as intrinsically linked to their ability to help patients as specialists in diabetes. They have seen from their own experience treating diabetes patients that they cannot successfully do so unilaterally without the cooperation of patients and their families. They see involving patients more in diabetes management as a realistic way of improving their own professional outcomes as well as patient outcomes in the long term.

Educators see SE as a big improvement on previous forms of patient education that they have experienced or delivered. They value the early and prolonged access to patients who are starting their diabetes journey in order to provide up to date and evidence-based knowledge and skills during an anxious time of diagnosis.

There is evidence to show that self-management in diabetes care is changing attitudes, beliefs, routines and behaviours. This occurs in Educators from various backgrounds, job role, teaching experience or work setting. There is evidence of self-management institutionalisation through changes to cultural-cognitive, regulative and normative elements within the network of Educators. Although they are spreading self-management principles among non-Educators in their networks, there are many in the wider network that have not grasped the core principles of self-management and are using institutionalised forms of knowledge to judge the legitimacy of the self-management approach because the current evidence base is insufficient to change their own practice. The enduring effects of specialisation may also mean that rather than changing practice to embrace self-management, non-Educators may simply refer out to self-management specialists. This presents real issues for the diffusion of self-management. However, as indicated there are at least three different ways that self-management is increasing awareness in non-Educators through bottom-up, sideways and going around movements.

Educators are taking advantage of micro-institutional affordances to improve levels of professional job satisfaction through 1) privileging epistemes based on professional experience 2) establishing new shared governance mechanisms for correcting poor practice from non-Educators in the diabetes care network 3) taking part in the engagement of new types of institutional actors by educating patients early in their diabetes journey so that they can collaborate with healthcare professionals more effectively and minimise risk of developing complications in the long-run.

6.3 Summary of the findings of the literature

Self-management and SE literature focuses on studies of effectiveness in patients with chronic disease (Warsi et al., 2004) and conceptualises self-management as part of institutional change to PCC in healthcare organisations at the macro level (Bodenheimer et al., 2002; Coulter, 2012; Epping-Jordan et al., 2004; Walsh, 2012; WHO, 2003). What is missing is a meso level understanding of how self-management policy is being implemented by healthcare professionals, who are fundamental to the self-management approach. Lessons from studies into the diffusion of innovation in healthcare indicate that the role of professionals is key (Ferlie et al., 2005), and that self-interest (Schon, 1991; Scott, 2008b) and the complex role of the healthcare context (Dopson et al., 2008; Battilana & Casciaro, 2012; Mascia & Cicchetti, 2011) are implicated in the spread of innovation.

6.4 Key findings

1) Educators have positive views of the self-management approach and the X-PERT Programme.
2) Self-management is understood by Educators to be innovative and that its legitimacy is still being contested (Greenhalgh et al., 2004). Holding this view engages Educators in taking an active role in resolving self-management's current legitimacy crisis (Greenwood & Hinings, 1996).
3) Taking on this role as an institutional actor has resulted in the introduction of new types of actors, which is a sign of institutional change (Scott et al., 2000).

4) There is evidence of changes to cultural-cognitive, normative and regulative elements (Scott, 1995) and that these are manifesting through a partial disregard for established institutional logics (Schon, 1991), which is evidence of destructuration (Scott et al., 2000).
5) There is evidence that progress of self-management's institutionalisation can be understood as being underpinned by the way that Educators steer around ineffective institutionalised systems, finding the micro-institutional interstices (van Dijk et al., 2011) that are failing to improve poor quality diabetes care practices through three types of movement: bottom-up, sideways, and going around, in order to deliver better patient outcomes. These movements involve activating patients, activating colleagues, and circumventing resistant non-Educators in the diabetes care networks. These changes to work patterns result in new forms of governance and information sharing (DiMaggio & Powell, 1983).
6) The perception of 'better outcomes' is a result of Educators engaging in self-management and SE policy implementation by temporarily privileging certain forms of empirical local knowledge over those from established research cultures (Dopson et al., 2008; Ferlie et al., 2005). Knowledge from empirical and anecdotal evidence is being applied in Educators' decision to support self-management and SE a) in the absence of convincing evidence from longitudinal studies and b) so long as criteria for inclusion and measurement from established research cultures continue to ignore factors that are important to the values and experiences that Educators reinforce regularly through clinical and SE practice, and fails to reflect anecdotal patient feedback. The data shows that Educators' mental framing is influenced by a mixture of knowledge from different sources: first, empirical knowledge that is sourced from local contexts, and second, knowledge from a formal evidence base sourced from established research cultures.
7) Educators value opportunities to disregard certain obstructive institutionalised work patterns, establishing new governance mechanisms and information flows (DiMaggio & Powell, 1983) in order to deliver better patient outcomes, leading to higher levels of professional job satisfaction.

6.5 Theoretical implications and key contributions

The study of self-management and SE diffusion by Educators adds another perspective to literature examining PCC and EBM as examples of healthcare innovation. The acquisition by Educators of new knowledge and skills as well as opportunities to use them in new information flows and governance mechanisms develops the work of DiMaggio and Powell (1983) by providing a recent example of destructuration in practice. The study shows how professional motivation to become an institutional actor is partly a consequence of working networks impinging on professional satisfaction and identifies reasons why they engage with self-management policy, which responds to Dopson et al.'s (2008) call for research into motivations and the complex role of context in innovation spread. The findings apply van Dijk et al's (2011) micro-institutional affordances in a new setting, transferring their lessons about champions in legitimacy crises from the context of technology companies to healthcare.

6.6 Practical implications

Self-management is confirmed as an innovation in the mental framing of Educators and this provides a counterfactual to assert that it is not yet institutionalised. For policy makers and those empowered with resource allocation decisions, this study highlights areas where organised efforts to implement self-management and SE have succeeded, and where they have failed to generate planned for changes in demand for services, i.e. DSN consultations and delivery of SE by healthcare professionals in GP Surgeries.

Although none of the participants considered their own training as professionals as a cost-based exercise or considered economic value as a result of their improved self-management support skills, they all described positive changes to their professional practice. Participants discussed factors that improved their practice as a result of being an Educator, such as:

- increasing approachability;
- improving relationships with their patients by learning more about their lives, issues and concerns;
- an ability to listen empathetically and to decipher lifestyle factors contributing to poor diabetes control;
- the ability to simplify diabetes education content and to approach it logically;
- the ability to pitch language at the right level so that patients engage with the subject.

6.7 Limitations and suggestions for further research

Practical limitations prevented me from conducting a longitudinal process analysis to study the impact of being an Educator on the mental framing healthcare professionals use for self-management and SE. This would have added rigor in terms of understanding the causal processes that change mental framing. There was no scope given the limitations for analysis of other types of data, such as the use of document analysis, observations and focus groups to evaluate trustworthiness through corroboration between sources.

This study highlights new ways that healthcare professionals and patients are accessing, holding and using new forms of knowledge. For Educators this includes a hybrid of knowledge types to compensate for research cultures that do not address the themes that most interest them and influence their context of professional practice. This lesson should form the basis of reassessment of evaluation tools that do not adequately measure and monitor for non-clinical outcomes that are important for measuring self-management effectiveness.

A concern among stakeholders in this research is the need for an economic study that reflects the core principles and values of self-management and patient welfare. Future research that is able to incorporate the intangible benefits described in this study into an economic frame would be valuable.

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Appendices

Appendix 1: Recruitment Poster

The University of Nottingham

Worcestershire Acute Hospitals NHS Trust

Worcestershire NHS
Primary Care Trust

We'd like to hear from you if you are:

- Aged 19-65
- An X-PERT Programme Educator
- Experienced delivering X-PERT to diabetes patients in Worcestershire

VOLUNTEERS NEEDED

A research team from the University of Nottingham is undertaking a study of X-PERT Educators' views on diabetes self-management

Participants in the study are eligible to claim a £30 store voucher inconvenience allowance

For details contact: Josephine Go Jefferies
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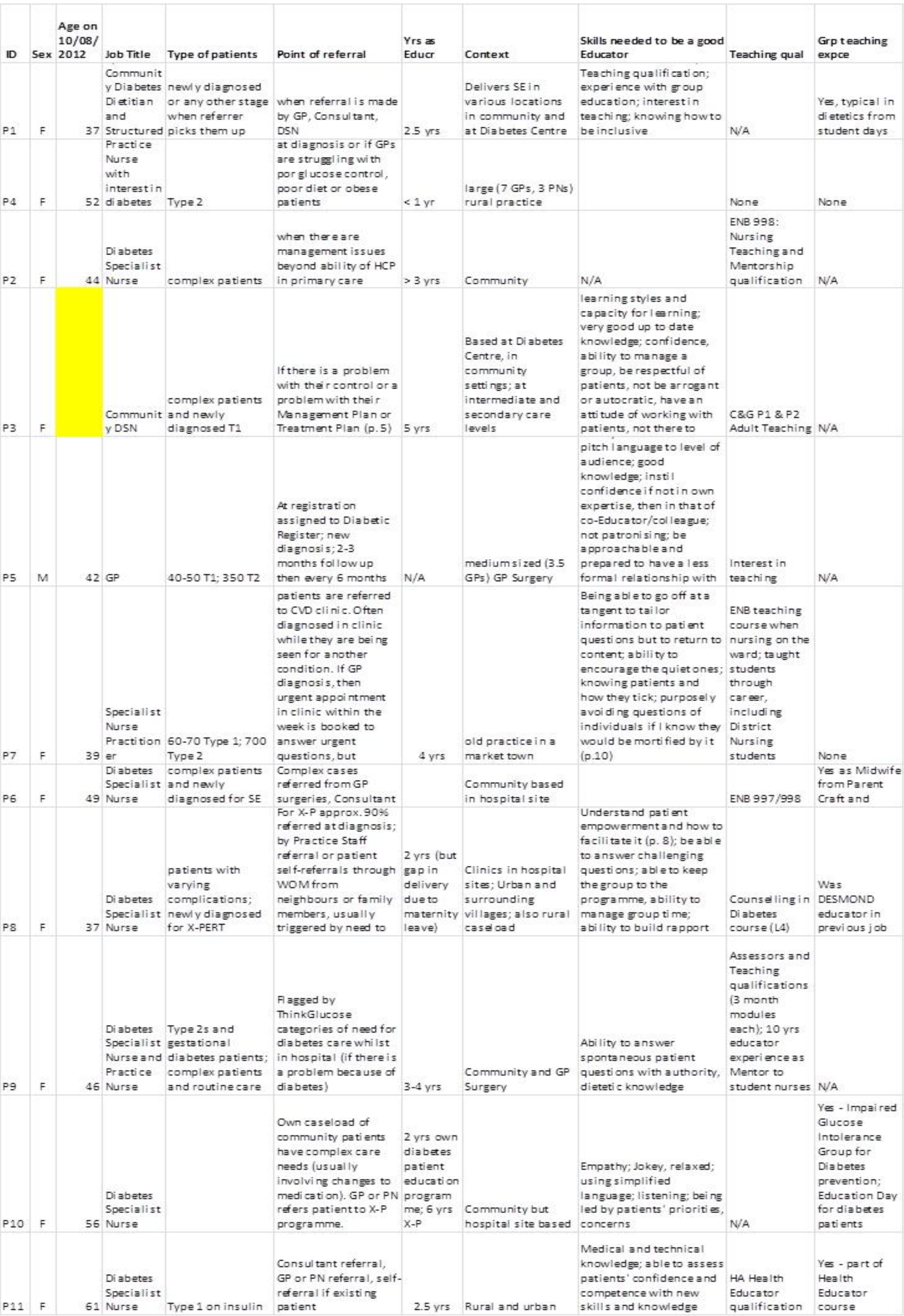
Appendix 2: Participant attributes



ID	Sex	Age on 10/08/2012	Job Title	Type of patients	Point of referral	Yrs as Educr	Context	Skills needed to be a good Educator	Teaching qual	Grp teaching expce
P1	F	37	Community Diabetes Dietitian and Structured	newly diagnosed or any other stage when referrer picks them up	when referral is made by GP, Consultant, DSN	2.5 yrs	Delivers SE in various locations in community and at Diabetes Centre	Teaching qualification; experience with group education; interest in teaching; knowing how to be inclusive	N/A	Yes, typical in dietetics from student days
P4	F	52	Practice Nurse with interest in diabetes	Type 2	at diagnosis or if GPs are struggling with por glucose control, poor diet or obese patients	< 1 yr	large (7 GPs, 3 PNs) rural practice		None	None
P2	F	44	Diabetes Specialist Nurse	complex patients	when there are management issues beyond ability of HCP in primary care	> 3 yrs	Community	N/A	ENB 998: Nursing Teaching and Mentorship qualification	N/A
P3	F		Community DSN	complex patients and newly diagnosed T1	If there is a problem with their control or a problem with their Management Plan or Treatment Plan (p.5)	5 yrs	Based at Diabetes Centre, in community settings; at intermediate and secondary care levels	learning styles and capacity for learning; very good up to date knowledge; confidence, ability to manage a group, be respectful of patients, not be arrogant or autocratic, have an attitude of working with patients, not there to	C&G P1 & P2 Adult Teaching	N/A
P5	M	42	GP	40-50 T1; 350 T2	At registration assigned to Diabetic Register; new diagnosis; 2-3 months follow up then every 6 months	N/A	medium sized (3.5 GPs) GP Surgery	pitch language to level of audience; good knowledge; instil confidence if not in own expertise, then in that of co-Educator/colleague; not patronising; be approachable and prepared to have a less formal relationship with	Interest in teaching	N/A
P7	F	39	Specialist Nurse Practitioner	60-70 Type 1; 700 Type 2	patients are referred to CVD clinic. Often diagnosed in clinic while they are being seen for another condition. If GP diagnosis, then urgent appointment in clinic within the week is booked to answer urgent questions, but	4 yrs	old practice in a market town	Being able to go off at a tangent to tailor information to patient questions but to return to content; ability to encourage the quiet ones; knowing patients and how they tick; purposely avoiding questions of individuals if I know they would be mortified by it (p.10)	ENB teaching course when nursing on the ward; taught students through career, including District Nursing students	None
P6	F	49	Diabetes Specialist Nurse	complex patients and newly diagnosed for SE	Complex cases referred from GP surgeries, Consultant		Community based in hospital site		ENB 997/998	Yes as Midwife from Parent Craft and
P8	F	37	Diabetes Specialist Nurse	patients with varying complications; newly diagnosed for X-PERT	For X-P approx. 90% referred at diagnosis; by Practice Staff referral or patient self-referrals through WOM from neighbours or family members, usually triggered by need to	2 yrs (but gap in delivery due to maternity leave)	Clinics in hospital sites; Urban and surrounding villages; also rural caseload	Understand patient empowerment and how to facilitate it (p. 8); be able to answer challenging questions; able to keep the group to the programme, ability to manage group time; ability to build rapport	Counselling in Diabetes course (L4)	Was DESMOND educator in previous job
P9	F	46	Diabetes Specialist Nurse and Practice Nurse	Type 2s and gestational diabetes patients; complex patients and routine care	Flagged by ThinkGlucose categories of need for diabetes care whilst in hospital (if there is a problem because of diabetes)	3-4 yrs	Community and GP Surgery	Ability to answer spontaneous patient questions with authority, dietetic knowledge	Assessors and Teaching qualifications (3 month modules each); 10 yrs educator experience as Mentor to student nurses	N/A
P10	F	56	Diabetes Specialist Nurse		Own caseload of community patients have complex care needs (usually involving changes to medication). GP or PN refers patient to X-P programme.	2 yrs own diabetes patient education programme; 6 yrs X-P	Community but hospital site based	Empathy; Jokey, relaxed; using simplified language; listening; being led by patients' priorities, concerns	N/A	Yes - Impaired Glucose Intolerance Group for Diabetes prevention; Education Day for diabetes patients
P11	F	61	Diabetes Specialist Nurse	Type 1 on insulin	Consultant referral, GP or PN referral, self-referral if existing patient	2.5 yrs	Rural and urban	Medical and technical knowledge; able to assess patients' confidence and competence with new skills and knowledge	HA Health Educator qualification	Yes - part of Health Educator course

Appendix 3: Assessing innovativeness of self-management (adapted from Greenhalgh et al., 2004)

Criteria	YES	NO
Perceived as new	X-PERT approach totally new: dietetics, simplified language, logically organised approach to material, interactive group learning, patient-led New type of interaction with engaged patients changing relationship and healthcare professionals' authority Out of comfort zone: dealing with challenging questions from engaged patients Learning wholly new knowledge and skills (dietetics, counselling, how to involve patients more; how patients learn) Challenges long-held ideas: (expecting nurse to fix it; healthcare professionals treat and cure; didactic approach; prescriptive approach; giving general assurance to passive patient rather than detailed test results to engaged patients) Patient goal-setting and diabetes ownership is conceptually alien to all stakeholders and still difficult to implement in practice	Holistic approach to patients not new Some awareness of self-management concept from previous training and job experience showing limited influence of healthcare professionals without patient cooperation (e.g. diabetes, midwifery, parent craft classes) Patient education has always been a key part of Consultant, DSN, PN and dietitian role Previous experience with group teaching Checking patient understanding and getting them to 'repeat back' what was said to them before they leave the room is taught in med and nursing school Lack of understanding about how structured education differs from typical patient education means the novelty is not recognised by all stakeholders, especially commissioning decision-makers
Discontinuous with previous practice	Ability to address 'new 'audience of T2 for patient education increasing chance of avoiding complications. 'New' because deviates from normal care pathway where they would not be seen by DSN unless they go onto insulin or experience complications Detailed dietetic approach by non-dietitians is novel Being an X-PERT Educator makes previous approaches to practice	Training, teaching and mentoring consistent with previous practice Cover similar content during 1:1 appointments, but not so thoroughly Even though self-management is about respecting patient choice, and their issues and priorities, the healthcare professional must

	seem obviously out-of-date and ineffective Less worry or anxiety about patient compliance. Because patients and healthcare professionals have different priorities this will affect diabetes control. Self-management allows healthcare professionals to be less anxious about patient non-compliance because it is about informed patient choice.	address patient safety as priority
Directed at improving health outcomes, administrative efficiency, cost effectiveness or the user experience	Specialists gain access to patients at the beginning of their diabetes journey instead of only years later when complications arise and risky health habits are ingrained Able to introduce noise in authority of primary care practice giving incorrect information and advice to patients, in turn leading GPs and PNs to seek clarification and take up opportunities to train and get updates Reduce repetition by teaching in groups Post-X-PERT dialogue with patients is at higher level of understanding in 1:1 consultations Patients understand what the tests are for and how to interpret the results Diabetes makes sense to the patients: no longer ignorant or terrified, and empowered to make changes Patients learn from each other Establishes patient support groups Reduces isolation, patients don't feel picked on by healthcare professionals Better division of labour between care teams and reduced need for referrals (e.g. allocating tasks by what the Nurse is better at, what	Lack of continuity between X-PERT approach and primary care team is typical, leading to frustration and confusion among patients who are trying to engage in self-management Waiting times for X-PERT and X-PERT Insulin do not serve patient needs and DSN time is not optimised because of repetition during 1:1 Longevity of benefits unproven post-14 months Still awaiting follow up data from Annual Updates 6-weeks programme seen as long and costly General wish to identify ways to shorten programme or gain secondary benefits across practice Cost-neutral or Not breaking even but delivering intangible (altruistic) returns Not resourced adequately (professional time, clerical time, appropriate venues and refreshments) Not all patients suited to group education There is not enough time during X-PERT to provide 1:1 support if needed

	the GP is better at, DSN, Dietitian) Positive patient feedback Positive feedback from primary care teams who notice changes in patient attitudes and behaviours Anecdotal evidence of patients changing behaviours Inclusion of partners/carers means better chance of changing behaviour by influencing the person who is in charge of food in the home, etc. Provides good reference materials for future use and development of new analytical skills (e.g. looking at portion sizes and quality of carbohydrates, energy balance) Good opportunity for practice staff to really get to know and establish long-term relationships with patients beneficial for collaborative diabetes care X-PERT core content and principles being used in 1:1 consultations	Anecdotal evidence that some patients do not retain the learning and reinforcement or repetition is needed in 1:1 appointments
Implemented by means of planned and coordinated action by individuals, teams and organisations	Regulative: NICE CG87 SE provision County-wide commissioning of X-PERT SE Programme Financial incentive for delivery PCT paid for X-PERT training and co-delivered first 3 programmes per surgery	GP and Practice Nurse referrals to SE not part of QOF points Not enough data collection support means clinical time is lost, leading to waiting lists Lack of clarity over who should be delivering X-PERT means confusion with job roles (need for full-time Educators raised) Number of surgeries delivering X-PERT did not go as planned so same size DSN Teams have increasing patient load plus X-PERT duties LES Updates for Insulin Management and Link Nurse Training not reaching all practices, so demand for DSN support unchanged

	Not enough GP referrals to X-PERT because GPs skeptical about long-term outcomes, sample bias of evidence base, and unsupportive attitude to length of programme for people in work Referred patients who do not attend may be because those GPs referring 100% of newly diagnosed do so without discussing value of SE with patients as ‘first pill’ in treatment of diabetes

Appendix 4: Drivers and Barriers of Self-management institutionalisation

Participant **reflections about being an X-PERT Educator** were organised thematically into drivers (blue) and barriers (orange) to self-management institutionalisation.

Drivers of self-management institutionalisation

Personal motivators for becoming an Educator

- Belief in patient's right to information; pro-patient empowerment
- Address superficial knowledge of diabetes
- Learn exciting totally new approach, knowledge and skills
- Interest in diabetes
- Division of labour: lead in diabetes for practice
- Wish to upskill and make a positive difference to patient health
- Wanting to deliver a structured, measured, monitored, standardised patient education programme to help people learn more about their diabetes
- Saw sense in it and saw a real need for it: could see the consequences on patients health 5-10 years down the line of poor quality education patients were receiving and realisation that DSNs couldn't compensate for this single-handedly and PNs couldn't get sufficient education to patients (P3)
- Misgivings about QOF points system for taking lead on diabetes in surgeries and adequacy of current efforts to support self-management: *'Although we hit our QOF points and are doing very well, I think we're doing it in spite of the patients in many ways, which is why, as I say [delivering X-PERT I'm interested in] seeing how much more they understand diabetes and how much more empowered they feel to do something about it themselves.' (P5)*
- Altruistic reasons: 'heart over head' decision
- To cover costs and hopefully make a profit
- To address own skills gaps
- Encouragement and enthusiasm of dietitian and DSNs for X-PERT
- Rational choice to spend more time than otherwise would be feasible to educate patients
- Wanting to increase patient self-management skills to reduce burden on NHS

Educator role integrates well with the aims, duties and experience of the clinical job role

- Consistency of undertaking: 'We do patient education as a major part of our job'; *'It's what we've always done – or thought we'd always done' (P11)*; *'[education] has long been the remit for the Diabetes Consultant and Diabetes Nurse [Teams]' (P6)*
- Before structured education, several respondents designed ways to increase access to patient education through own roles
- 8 of the 11 participants had teaching experience (formal and informal), qualifications and/or had an interest in teaching as a member of a teaching surgery. 5 participants had experience of group education before becoming an X-PERT Educator.
- Group patient education had been introduced already to save resources (P1)
- Much better practice because more thorough education (e.g. *'...a half day carbohydrate counting group before, and now we've got a 5-day course. It doesn't compare, really.' (P1) '...because of time constraints there's no way that I can cover*

everything that gets covered in the X-PERT Insulin programme, so they get inferior education, really [in a 1:1 90-minute initiating insulin consultation]' (P3)

X-PERT structured education is perceived as a vast improvement on previous ways of delivering patient education

- All participants felt X-PERT offers better quality education that is more effective at delivering teaching outcomes (e.g. what is diabetes, what is healthy eating) compared to series of discrete 1:1 consultations. Previous patient education was viewed as inadequate: patients were failing to absorb, retain and use information. Understanding of basic diabetes knowledge was missing after decades of consultations.
- It uses a mix of professionally developed visually stimulating interactive teaching aids and sessions are not too long to avoid overwhelming patients with information.
- Supporting a standardised, quality-assured, audited and structured programme is an appreciable improvement on previous patient education programmes (e.g. not just describing healthy eating but focusing on 'how much they're eating' (P11)
- Being able to say to patients: 'We know this works' based on scientific evidence of effectiveness is important
- Not all participants have had the Annual Update experience with their patients. However, some participants report that the one-year post-programme follow up Update Days provides encouraging anecdotal and auditable evidence in addition to the national and locality data provided by X-PERT. They report that it is having beneficial impact on some patients (feeling better about having diabetes, weight loss, coming off medication, treatment for cholesterol, etc).
- Some participants said that there were always 2-3 in a group (of 12 to 20 people) who would make changes in their habits as a result of attending X-PERT
- One participant said the information might not be used immediately but in a patient's long journey with diabetes, it may be come back to them when they are ready to use the self-management techniques introduced during the course.

Professionals are learning from X-PERT: big improvements in new areas in terms of knowledge, skills and managing a patient-centred approach

- Dietetics: 'I thought I knew what healthy eating was [laughs] but all of us say, because we haven't had the luxury of having a dietitian for most of our working life, working beside us, and of course we refer patients to the dietitian but we're not there in the consultation, so we've learnt such a lot about diet. It's been fantastic. And we're very fortuntae that we now have a dietitian on our team…there's only one …for the whole county, but she's worked so closely with us with X-PERT that we have learnt an awful lot, really. An awful lot.' (P11)
- Eat Well Plate, Balance of Good Health
- Carbohydrate awareness (quality and quantity of carbohydrate)
- Portion control (getting patients to assess their intake, create awareness, and reflect on ways to change meals)
- *'…it was in many ways a complete eye-opener, a lot of the stuff that we were taught on the course, and a lot of the stuff that I find difficult, I guess because of a lack of knowledge, is not so much the side effects of medication or talking about those sorts of discussions, it's the whole calorie thing and the portion size, and the what not to eat, and the what you can eat, and that was sort of a revelation to me… quite enlightening really.' (P5)*
- Learning ways to involve patients so that patients get more out of it
- Ways to engage quiet patients about diabetes by personalising to their experience

(e.g. what symptoms have you experienced)

- Improving use of motivational techniques like goal-setting and how to encourage dialogue around setting realistic goals from a series of prompts in core curriculum)
- Group teaching skills
- Improving pedagogy skills, learning styles, relationship building and negotiating a way from patient-centred theory into practice
- Adapting pre-existing teaching and mentoring qualifications to general adult education, rather than HE students (e.g. Registrar, Medical, Nursing and Post-Registration students)
- How to optimise the strengths of the different roles in the practice to support self-management
- How take a much less didactic approach with patients: change from previous highly prescriptive approach to diabetes management 'People were prescribed diet…an insulin regimen…an exercise regimen…bu life's not like that and people didn't follow that anyway, because how can you? No two people are the same. So in all the time that I have been nursing in diabetes, I've always recognised that the person with diabetes has to look after their diabetes, maybe having some help and advice from healthcare professionals but it's not us that have to live with it.' (P2)

Learning from colleagues:

- Professionals tend to practise in isolation (providing no opportunities to oversee, learn from or quality assure work of colleagues) but X-PERT gave opportunity to learn from colleagues' different areas of expertise, especially between:
    - GP and PN: Participants described a clearer understanding in themselves of the strengths in terms of expertise and communication style and relationship with patients. This leads to confidence in managing patients between each other for specific aspects of care.
    - DSN and Dietitians: Provided an opportunity to work with and learn from the county's only dietitian. Normal procedure would be to refer a patient to a dietitian appointment, but again, there would be no opportunity to learn from that contact.
    - X-PERT Educator and non-X-PERT qualified programme assistant or facilitator, student nurse observers, or other observers learn from sitting in on the course, as well as hearing about it, generating interest and referrals. This may narrow the gap in practice between Educators and non-Educators over time.
    - In-surgery Education Lunchtime sessions, plus annual LES for Insulin Management Training Updates and Link Nurse Training are examples of limited exposure to X-PERT to increase awareness of the course and interest in its approach and outcomes

Learning from patients:

- Reinforces previous belief that they must avoid pre-judging who will benefit from X-PERT on the basis of patients' intelligence, ethnicity, socioeconomic class, education, level of skills, knowledge, ability or motivation: *'experience that white, educated, middle class choose not to self-manage despite on paper having the skills and abilities to do so, whereas people with great difficulty reading and writing or even understanding what you're talking about, if presented in a way they can understand and relate to, they will manage it very well.' (P3)*
- Learned new clinical knowledge that would probably have been ironed out before she had first contact with patient (i.e. exposure to side effects of Metformin despite 9

years of experience as DSN: muscle aches, general malaise, intense lethargy) from patient experiences (P8)

- Can be *humbling (P10)* to learn what they face in their daily lives that prevents optimal diabetes control *I think being in with people and realising what a tremendous effort it is for them sometimes, we forget that. And I think this education helps to reinforce that your patient is your focus. They are. Well, they're our bread and butter at the end of the day. But at the end of the day, they are what's important and sometimes what's important to one patient is not important to another. And it helps you to appreciate that as well. (P10)*
- *It really opens your eyes to see the things that people go through at diagnosis, and the interesting thing is how you see people hopefully coming to terms with things a little more and realising how they can start to take control and how the anxiety lifts over the 6 weeks. That's very, very rewarding. (P8)*
- What their level of learning is, what level to pitch language at to engage patients, what their preferred learning style is; how long it takes for patients to learn: *'I guess it was my naivety … I was thinking actually patients were going to get this quickly and they're going to understand it … I guess the course is designed for a level of intelligence, and you know with all teaching, I guess, you end up teaching to the middle, don't you? If you teach at too low a level, then those that are so far ahead will get bored and disengage and won't come back to the … course. So you've got to pitch it at the middle, which means that htose people who are at the bottom, it's going to take them several repeats before they sort of finally click… But even then it was surprising who out of that group sort of got it, and who sort of struggled with some of the concepts.' (P5)*
- That the length of programme is appropriate or too short for some patients, although some participants judged the programme to be too long, *'there is a slight element of overkill … that you're getting a little bit repetitive. But it is interesting … there was the lights switched on with the patients on the last week, ou know, they finally got it then – as opposed to Week 1 or Week 2 – of what they were trying to achieve. It certainly doesn't need to be any longer than 6 weeks.' (P5); 'I think it's enough but I know that a lot of patients at the end of the 6 weeks will say: I wish it was on next week, and they want it to go on for longer.' (P2)*

X-PERT experience is resulting in practical improvements to the format and content of 1:1 patient consultations

- Reinforces core principles of patient-centred care approach: two-way dialogue, increase patient voice in consultations; 'throwing [question] back' at patients; 'you avoid telling patients what to do. You ask them what they think they should do.'
- Two-way dialogue with patients is common approach in nursing but 'allowing [patients] to voice things that you might not have done before' (P6)
- Improves communication: always get patients to clarify before they leave the room: repeat back in their own words (P5)
- Gain insights leading to greater understanding and compassion and empathy regarding practical lifestyle challenges that patients face as reason for non-compliance
- More organised approach to care: what topics to cover in first clinic and follow up appointments, and clarifying to themselves who does what best (whether GP, Practice Nurse, DSN, or Consultant)
- More thorough coverage of topics from X-PERT curriculum that affect diabetes control: discussing what is diabetes, dietetics, goal-setting in follow up consultations from week to week

- Retrospective appreciation that previous 'drip, drip, drip' approach of 'telling patients what to do and not to do' via a leaflet, powerpoint presentation, or a series of short appointments didn't educate patients sufficiently about their diabetes
- Giving patients tasters of X-PERT education to 'whet their appetite' and encourage them to attend during all contact opportunities
- Choosing aspects of X-PERT to deliver what's pertinent to the patient at the time, giving structure to that little bit of education that's needed
- Encouraging patient empowerment and autonomy: *'…those patients who've now gone through the X-PERT course, and say to them, well, 'Your HbA1c is this, your blood pressure is that, your weight is this, which one of those do you think is most important? Which of them is the one that we're going t target? … in the next 6 months, and how are we going to do that? Or How are you going to do that?' (P5)*
- (more convergence) Introduction of patient-held tools that are modeled on the X-PERT Health Profile section of handbook (e.g. printed Cooperation Cards; printouts of Patient Management Plan (software)) that are improvements on a discontinued jargon-filled Worcestershire Care Pathway document
- Importing the simple and clear explanations of diabetes, HbA1c, simplifying aspects of talking about diabetes, goal-setting and lifestyle experiment elements into consultations (P2)

Gain insights regarding their own professional identity and role

- Reinforces knowledge that patients have different/changing priorities that may conflict with their own professional priorities: *'You have to understand that these people are living with a lifelong condition and that often it's not their number one priority. It might be my number one priority because I'm paid to look after it [laughs] and it's true…looking after their diabetes, as long as they're not in pain, is going to be very low down their list of things to worry about, and you have to understand that. I think you have to have a very different attitude if you're going to be involved with looking after people who've got long-term health conditions… a very different attitude than if you were doing acute surgery or something.' (P3)*
- More realistic expectations about their influence over patients' diabetes
- Patient-centred care provides clearer delineation of scope for professional's impact and need for partnership with patients: *'[The] patient has a right to do what they want to – it's their body and their condition…I often have this problem with other healthcare professionals about people that refuse to take their insulin or whatever, and I say to them, you know, you cannot section somebody with diabetes just because they choose not to … take their treatment that's prescribed to them. You can't do that, that'stheir choice. They have the right to do that and you have to accept that.' (P3)*
- The change in relationship from increased patient autonomy can be seen as useful for relationship building as well as to serve the professionals' self-interest in terms of encouraging patient compliance: *'I take quite a pragmatic view, really and I think sometimes you can hit patients hard and say, 'Well, you've got to do this, this and this' and they'll just disengage completely. So sometimes … a shock tactic is absolutely what they need but I think you do have to gauge that patient by patient and I think some of that comes with building that long-term relationship. And you can potter along and then hit them with something, and they will accept that much more perhaps if you've got that relationship with a patient than not.' (P5)*
- Less anxiety about patients' refusal of treatment, e.g. for hypertension, because objective is to get patients to be knowledgeable about their decisions
- Job satisfaction because patients are benefiting, based on audit data (weight loss,

coming off medication, tackling new parameter, e.g. cholesterol) and anecdotal evidence from post-programme Update Days

- **Reframes previous antagonism to 'difficult' or a 'nuisance' patients which can leading to feeling** angry, **disheartened or anxious** about patients**, now focusing on role of working toward acceptable level of understanding to support informed patient choice**
- Reduces professional frustration, feeling that despite all previous efforts, *'I'm not doing anything right here' (P11)* through seeing that patients are benefiting from X-PERT

Building relationships with patients

- For DSNs: opportunity to interact with T2 patients and address their understanding of diabetes years before they would normally meet, i.e. when going onto insulin or other injectable therapies or experiencing complications
- For GPs and PNs: part of building a long-term relationship
- Informal setting and long programme helps put patients at ease and get to know clinical team and services
- More sophisticated discussions: following X-PERT programme, can take topics with patients 'to another level' because they understand the basics and they can discuss implications of treatment and management plans: Patient education before X-PERT was *'…a brief conversation, that Type 2 diabetes is that your pancreas isn't producing enough insulin and the insulin it is producing, your body isn't using effectively, and that's the sort of level that we've left it at.' (P5)*
- The relationship may be changing in terms of the supremacy of professional authority over patients in all things to do with diabetes. Professional authority may be held in abeyance during a consultation in order to respect the patient's wishes, but also to maintain their engagement with the professional in co-managing their diabetes in the long run. **Q: Is there ever the wrong answer that comes as a result of that question: which will we target? What do you think is most important?** P5: *Well, I guess, certainly I think it's then our responsibility to say, 'Well, okay, that's interesting. Why do you think that? What I would foresee as a minor issue is the one that you see as a more significant issue.' And if they can justify why, for instance a minor weight loss might be more important than a significant reduction in their HbA1c, it may well be that in the long run it's better to win that battle than trying to win the war straight away. So I'm happy to sort of chip away at things in that way if that's the way the patient wants to do things. …*

Benefits to patients:

- Earlier access to diabetes specialist nurse team to influence patient knowledge and attitude to disease, self-management skills development;
- May reduce negative impact of out-of-date information provided by GP and PN who do not have a special interest in diabetes, and do not attend annual half-day LES Updates or 3 days per year of Link Nurse mandatory diabetes training
- Newly diagnosed patients who are motivated to do something appreciate the practical knowledge and skills approach
- Patients who have had diabetes for a while regret that they did not know the the information earlier and are grateful for X-PERT as providing new and exciting information
- Get a clearer understanding of local diabetes support
- Building a community support network, people in the group learning from each other
- Sharing experiences binds people and reduce isolation: evidence that self-referrals are

coming from word-of-mouth recommendations between family members, carers and neighbours

- Opportunity to practise what they've learned through supervised practice of new management techniques during the programme
- Increase their autonomy as a decision maker (P6)
- Will have a greater understanding but not expecting that they will take everything onboard (P6)
- Greater understanding will be the basis for more 'adult conversations' during clinics about making responsible choices (P5)
- X-PERT may give patients enough education to know they want to make changes, but may need further help with learning techniques to make those changes (P6)
- They learn about the diabetes health checks that should be part of their Annual Review at the GP surgery
- From adapting programme to look at food they have access to, even long-stay prisoners with low literacy levels who attended X-PERT made changes according to the Prison Nurse, and the prison catering menu changed to include oily fish (P1)
- Greatest benefit may be for patients who are struggling to control their diabetes because X-PERT helps things begin to make sense (P2)
- *X-PERT is 'a very good way of getting newly diagnosed patients, and in fat any of the diabetic patients, much more up to speed with understanding what the disease is and how it progresses and what the potential complications are, and what they can do about it.' (P5)*
- *I think it was more that the mists had been cleared, if you like. They actually just felt that they actually now understand what diabetes is all about and what really it was that they were trying to achieve. And I think that's the bit that we fail at in the general day to day clinic. It's very difficult to get so much of the information across in a way that's logical. You can't do that within a 20-minute or 40-minute consultation … it absolutely does take that 5 or 6 weeks of the course for them to assimilate that information in more than the bite-size that you're able to give them in clinic. (P5)*

Benefits to community

- Patients are welcome to bring partners or carers to attend sessions and participants indicate that many partners/carers also have experience and questions as diabetics themselves. This presents an opportunity to widen participation in audit data to measure programme impact.

Barriers to self-management institutionalisation

Conceptual challenges

- People unfamiliar with X-PERT do not understand the distinction between structured education and the patient education they've been providing all along
- Some people do not understand why you need so much time for the course: *'Some GPs have certainly said to patients: I don't know how anyone ever finds 6 half-days to go.' (P1) 'I think that on the whole, the doctors … they seem to really struggle to understand that not everybody is as intelligent as them and that they don't all learn like they do…and they cannot comprehend, they do not understand that everybody can learn like that…I still think that a lot of them don't see that you actually need to*

do the education in in another way. They still think that all you need to do is tell the patient and give them a leaflet and that's it.' (P3)

- Not enough GPs and PNs are not treating X-PERT like 'the first pill', that attending X-PERT is an integral part of their management as the prescription pad. *'I think there are some practices that will refer anyone and everyone who walks through the door without perhaps discussing it with the patient first…we do get a lot of referrals from people and when we contact the patient they do not want to attend.' (P2)*
- Patients don't really understand goal-setting: 'They're not coming up with specific goals still. You know, it's stuff like I want to improve HbA1c [laughs] and they're not actually breaking it down. So it's still an area that is still quite difficult I think.' (P1)
- The aims and expectations of self-management can be 'quite alien' to professionals who are used to telling patients what the responsible thing to do based on their experience and expertise. It is difficult to avoid providing information and advice and answering patients who ask: 'Well, what would you do?' during a 1:1. This is inconsistent with the X-PERT approach.
- Introduction of X-PERT was not adequately resourced to include collection of audit data
- DSN delivery of X-PERT seems to be a good fit according to their role as educators (e.g. introducing or changing insulin regimens requires teaching of technical information and skills until patients are judged confident and competent enough to be referred back to the care of their primary care team). However, the main demand for DSN expertise is particularly for investigating highly individual and complex cases. Demand for structured education is also growing, judging by increases in patient caseloads, but an increase in delivery by practice staff has not followed according to plan, leading to constant pressure for DSN appointments.
- Takes professionals away from time seeing patients in consultations
- Value for money not proven: remuneration levels currently mean those who are delivering it are either cost-neutral or absorbing a loss – question of financial sustainability
- The time and cost of 6-week programme seen as unsustainable in current climate
- Doubts about effectiveness as Update information is biased due to underpowered and biased trials due to self-selection of most motivated patients who choose to return to Annual Update refresher days; LT progression of illness and no LT benefits identified beyond 14 months; localism may be responsible for scepticism regarding national audit data
- Educator usually lacks continuity through regular follow up with patients post-X-PERT so little chance of reinforcing the core principles
- Having to use unsuitable venues that are procured on the basis of cost only
- No longer allowed to let patients try recipes for recommended food alternatives; refreshments from hospital list only due to risk of food poisoning
- Existence of referral network to specialists means there is less pressure to establish those knowledge and skills themselves;
- Demanding to deliver
- Lack of cooperation from surgeries leading to lower than expected referral rates and inaccessibility of patient health profile data for audit database
- Clinical time reduced due to inadequate clerical support for maintaining audit database

Structural barriers to supporting self-management (meso level context):

- Unclear about definition of structured education and therefore challenge to see GP consortia who are perceived to be *'only interested in money'* commissioning SE in future (P3)
- Insufficient funding and resources to implement SE properly, just enough *'to tick the government boxes ...but we're not doing the data collecting...Nurses are having to do it instead of clerical assistants or whatever...Practice Nurses won't continue to deliver X-PERT without admin support [for invitations, letters, etc]' (P3)* and because there are not enough Educators for the demand (waiting lists for newly diagnosed; what about the patients who have had diabetes and would benefit; demand for X-PERT Insulin programme)
- Trying to deliver X-PERT with the existing staff numbers without a reduction in patient numbers (P2)
- Need to build X-PERT duties into roles more clearly (clear split showing % of time as DSN and % of time as Educator) because two participants described doing tasks related to delivering X-PERT on her day off; or to consider 100% Educator roles
- Lack of clarification about implementing NICE guidance to provide structured education and what time and money will be allocated for it, as well as who delivers X-PERT if surgeries do not take it up
- Variability in surgery size will dictate take-up of X-PERT delivery (number of GPs, PNs, patients and impact from loss of available appointments if delivering X-PERT), availability of appropriate accommodation, whether volume of patients through X-PERT will mean cost-recovery/cost-neutral, cost-negative or sustainable revenue stream
- Perception of diminishing returns: the less motivated will benefit less from X-PERT
- Lack of incentive for surgeries to deliver X-PERT: strucured education not currently part of QOF points
- Accepting referrals from out-of-practice makes delivering X-PERT more demanding for PN (e.g. they do not know the patients and their health profiles)
- Issues sharing patient data with non-surgery Educators before the programme starts and for follow up
- Not all surgeries are configured to have a regular diabetes clinic (they see diabetes patients when they want to be seen), so it's not practical to coordinate Practice staff working together with DSN in the surgery to improve their skills
- Research cultures that almost discount anecdotal evidence from patient feedback and put all value on changes in parameters as outcomes: *I mean anecdotally I'v ehad patients in who've said, 'Oh the course is great. It's making a huge difference. I'm doing this, that and the other.' ...so there's that sort of evidence but we haven't got any concrete stuff yet to say actually it has made a difference.' (P5)*

Patient barriers to accessing support to self-management

Not all patients suited to self-management although attempts have been made to screen referrals by health record and initial phone calls to assess suitability to attend X-PERT by describing the programme and seeing if they'd feel comfortable attending.

- Mental health problems
- Social problems
- Personal problems
- More serious medical problems and can't cope
- Amount and level of information is too much
- Abilities are not met by level of group (too high or too low)

- Dislike group education/accountability to the group
- Vision or hearing impairment
- Cannot read or write
- Dislike of ‘homework’
- Language barriers
- Transport/mobility
- Funding to enable healthy eating and physical exercise
- No control over food in household
- Cannot get time off work
- Family commitments
- Unmotivated/no interest in learning about diabetes/ in denial: *You do see people very regularly…who are either frightened by the idea of learning about diabetes or who are in complete denial and aren’t able to accept that they have diabetes, or who very much have grown up with the medical model where the nurse or doctor tells them what to do and don’t feel able or willing to make those decisions, and from our perspective as DSNs, all we can do is keep providing educaiton at an appropriate level, and it could just be a drip, drip, drip approach, but eventually somebody will take on an aspect of their self-management, and any aspect is going to have a beneficial effect. (P8)*
- Disruption from signers or translators
- Overly vocal group members putting others off
- Who’ve tried and failed and have become disheartened,
- Who just want Nurse to fix it
- Unfamiliarity: self-management is an alien concept – patients uncertain about what is expected of them,
- Lack of consistent approach between X-PERT and practice staff
- Reluctant or unsuccessful at asking practice staff for info, etc when return to surgery care
- Vulnerability or fear of failure and exposure to the group when goal-setting
- Scheduling: no matter when course offered or what configuration (shorter or longer) people always cite problems with attending
- Despite acquisition of knowledge, understanding and skills patients may still not follow the recommendations
- *‘Sometimes they are just people [who have had their diabetes for a long time and they’ve got hyper unawareness, their bodies are unpredictable] that maybe an insulin pump is what they need, and no matter of education, the way their body is, and their diabetes, things are never going to be great …but they always appreciate the group. Meeting other people is a big thing.’ (P1)*
- CONTRA: *‘[People] who aren’t literate, once they’ve been through the … programme, they understand the implications of the different examinations that we do…If they have the ability to attend the course, then they’ve definitely got the ability to …understand basic results and understand whether they’ve improved or deteriorated…they’ve all been able to get something out of [the course] and make some changes.’ (P8)*

Impact on role and identity of professionals and what is and should be expected of them:

- X-PERT Educators Training described as a very steep learning curve because so much of the information is totally new.
- The responsibility of keeping up to date with diabetes is difficult, especially for non-diabetes leads. They will not be enrolled or choose not to take part in half-day annual

LES Updates and 3 days per year of Link Nurse Training. So it's *'a missed opportunity rather than resistance' to learning about how to support self-management (P11)* although P2 and P3 think GPs and PNs are failing to take opportunities available to them to upskill.

- Limitations on what people can fit in: *'There's an acceptance…that you can't do everything" (P11); 'If [Practice Nurses] spent as much time learning about [asthma, heart disease, COPD, children's immunisations, travel vaccines, sexual health clinics] [puffs], as they would need to learn about diabetes, they would be forever in the classroom. So I can understand that there's limitations to their knowledge and skills…some of them are excellent…very good. But there's some old-fashioned ideas still out there in places and pockets.' (P2)*
- Practice Nurses who feel underappreciated or feel antagonism over pay differential between GP and PN (e.g. no Agenda for Change salaries or pensions, etc) and without admin support will not continue to deliver X-PERT despite gaining knowledge and confidence during X-PERT training (P3)
- PN are not inclined to take on more duties, especially considering the large amount of work involved to deliver X-PERT (P7)
- X-PERT can shake professional confidence in competence: *'We thought we knew about diabetes.'*
- Patients being encouraged to write down their questions to ask during appointments: having to field questions from patients can present a challenge to the authority of the professional, threatening their own comfort and confidence in the level of knowledge and skills they possess. A professional can question whether their knowledge is good enough.
- Delivering programme to a group of strangers is a cause of anxiety, especially for PN Educators

Barriers from changed relationship between professionals and patients

- Patients will have been told what to expect in their Annual Review and they may challenge the authority of practice staff: *'[Their] authority is possibly being challenged when patients are asking questions and asking … about their condition in a way they haven't done previously' (P2)* or they do not think they are getting their results enough in advance of their appointments so that they can look at them and ask questions (e.g. patients may be told that their *'results are fine and things are okay' (P6)* but they are being told to ask for their blood pressure and cholesterol levels to monitor using their Handbook). P2 recommends a fundamental change in service design of the Annual Reviews to harmonise with the format and content of X-PERT programme, so that this issue is resolved for patients who attend X-PERT.
- Patients may articulate their knowledge using simplified terminology from X-PERT that their GP or PN do not recognise (e.g. red and yellow pingpong balls visual aid= HbA1c test results) leading to miscommunication or lack of adequate support consistent with X-PERT principles
- Potential discord between professional and patient (e.g. allowing patients to 'choose' which of their health issues is a priority to address may not be the one identified by a professional as most urgent)
- Receiving conflicting advice from GP or PN who follows up care: 'they may be giving advice to patients that is not the same as the advice and information within the X-PERT documentation, the handbooks. It doesn't tally, it doesn't match.' (P2)
- Sometimes professionals have to accept less optimal control of diabetes (due to patient priorities) in the short term and by supporting them, hope to *'choose your battles'* and get the patient to achieve better control over the long-term (P5).

- *'I think some of the aspects of self-management are just about making the choices. Now whether the choices are what the healthcare professional would determine as good choices or bad choices, that doesn't matter. The fact that the person with diabetes feels able to make the choice, that I think is the important part.' (P2)*
- Getting patients to problem-solve and find their own solutions to try is complicated. Although the patient voice is critical for gaining an understanding of the crux of their individual diabetes management problem and what their expectations are, this has to be balanced with the fact that the patient's knowledge is not sufficient to identify contributing factors related to their problems and issues, so it demands proactive approach, but not didactic. That takes time to conduct. *'[Once] you've identified what is acceptable to that individual person, then you can potentially give them 1,2 or 3 options in terms of how you go about doing that…by giving them that element of choice, that actually maybe makes them a little more to try and tackle whatever their particular issue is at that moment in time.' (P6)*
- Group sessions are not conducive to 1:1 support because there is so much to get through in a 2.5-hour session.
- Time-management of the course may mean you cannot address patient wishes adequately, which may lead to patients feeling ignored, overruled, leading them to switch off as what follows may not be appropriate or relevant.

Appendix 5: Interview guide

1. Confirm Job Title – how long in post?
2. Can you describe your role?
3. What size is your patient load?
4. At what point are they referred to you?
5. How often do you see them?
6. What is the average length of your consultations with them?
7. When did you become aware of diabetes self-management as a concept?
8. How did you learn about X-PERT Programme?
9. How long have you been an Educator?
10. What motivated you to become an X-PERT Educator?
11. What were your expectations about becoming an X-PERT Educator?
12. Does being an Educator change the way you practise in your clinical role?
13. How?
14. Have you noticed any consequences/reactions in the way your patients self-manage their diabetes (non-compliance: extreme cases, average across caseload)
15. Do you notice a difference compared to your colleagues who are not Educators?
16. Can you identify any barriers to self-management, in your own role?
17. Can you identify barriers to self-management among your colleagues or within your organisation?
18. Please describe the current level of knowledge about self-management in your area of practice.
19. Describe future prospects for self-management

Appendix 6: Example of the Personal Data Capture form

The University of Nottingham

Worcestershire Acute Hospitals NHS Trust

Personal Data Capture

Final Version 1.0

20.03.2012

Examining X-PERT Educators' views on diabetes self-management

The following information is requested in order

- to generate a Participant ID number for the Study
- to capture information about the type of Participants recruited for the Study
- to record Participant contact details
- to capture preferred mode of contact
- to administer the voucher incentive scheme

Full Name			
Date of Birth			
Gender	Male	Female	
Address	Postcode:		
Email address			
Telephone number			
Preferred mode of contact	Post	Email	Telephone
Preferred store voucher	Marks & Spencer		amazon.co.uk