SPECIFYING THE DIMENSIONS OF CARE THAT MATTER TO PEOPLE WITH LONG-TERM CONDITIONS (LTCs) AND IMPROVING OUR UNDERSTANDING OF PATIENT-CENTRED CARE (PCC)

THESIS SUBMITTED FOR THE DEGREE OF DOCTOR OF PHILOSOPHY

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Abstract

Specifying the dimensions of care that matter to people with Long-Term Conditions (LTCs) and improving our understanding of Patient-Centred Care (PCC)

Thesis submitted for the degree of Doctoral of Philosophy

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Background

The term patient-centred care (PCC) is commonly used in the academic literature and UK health policy. However, this concept is ill defined and little is known about its applicability to the management of people with long-term conditions (LTCs). Several methodologies were used to explore the meaning of PCC, identify key experiences that matter to people with LTCs and consider the implications of these findings for the measurement of patient reported experiences of health care.

Method

Four stages of research were conducted for this thesis. First, a conceptual synthesis of existing PCC and patient experience frameworks to produce an overarching framework of PCC. Second, secondary qualitative analysis of patient interviews to identify key experiences of PCC that matter to people with LTCs. Third, development of a PCC questionnaire for people with LTCs, based on findings from the conceptual synthesis and secondary analysis. Fourth, further

exploration of the questionnaire through cognitive debriefing interviews with people with LTCs and health professionals.

Results

The overarching framework of PCC consisted of 8 domains; access, availability and choice, information, communication and education, relationship with health professionals, involvement in care, respect and dignity, responsiveness to individual needs and preferences, consistency, continuity and co-ordination, and effectiveness of treatment and care. Findings from secondary analysis suggested that many of the domains from the framework were also important in care for people with LTCs, but that some aspects of care held an additional meaning. The themes identified in the secondary analysis were used to generate items for a generic PCC experience questionnaire for people with LTCs. The final questionnaire, '*Your Experiences of Care in Long-Term Conditions*' consisted of 47 questions across three sections. Feedback from the debriefing interviews suggested that the questionnaire had asked important questions about care for people with LTCs and that it was relevant to people with a range of different LTCs.

Conclusion

Development of an overarching framework of PCC demonstrated some conceptual problems in understanding and evaluating the notion of PCC. Findings from this thesis suggest that an overarching questionnaire of experiences of PCC is feasible and acceptable to people with a range of different LTCs. Future research needs examine standard features of the newly developed PCC experience questionnaire for people with LTCs and consider the potential use and contribution of data in enhancing care for people with LTCs.

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1 Introduction

1.1 Overall aim of the thesis

Care for people with long-term conditions (LTCs) is an important topic and growing area of need. Two of the biggest challenges currently facing the NHS are to improve treatment and management for people with LTCs and to effectively measure and evaluate the quality of care delivered (Coulter, Roberts and Dixon, 2013).

In recent years, there has been a great deal of policy drive to improve the quality of care and offer a more holistic and patient-centred approach to health care delivery, particularly for people with LTCs (e.g. Department of Health, 2005a; 2007a; 2009a; Coulter et al., 2013). In the UK setting, quality is recognised as clinical effectiveness, safety and patient experience (Darzi, 2008). The term 'patient-centred care' (PCC) is often used in the literature and policy documents to describe good patient experience, and the practice of PCC is frequently praised as the desired way of delivering health care (e.g. Institute of Medicine, 2001).

However, the concept of PCC is ill-defined and there is a lack of consensus regarding its meaning and content (Mead and Bower, 2000). In addition, the approaches to providing PCC and evaluating this effectively are underexplored in the context of LTCs. Therefore, the leading aim of this thesis is to improve our understanding of the term PCC overall and more specifically how it applies to care for people with LTCs. It intends to identify key experiences of PCC that matter to people with LTCs, evaluate the extent to which they are consistent across

different conditions, and to consider the implications of these findings for the measurement of patient reported experiences of health care.

The aims of this thesis will be explored through opportunities that have been identified at the Nuffield Department of Primary Care Health Sciences at University of Oxford. The specific objectives of this thesis and overall chapter structure are described in more detail below.

1.2 Objectives of the thesis

The specific objectives of the thesis are:

1. To summarise the existing policy literature around patient experience and PCC, particularly in relation to care for people with LTCs.
2. To produce an overarching framework of PCC, through a conceptual synthesis of existing patient experience and PCC frameworks.
3. To understand key aspects of PCC that matter to people with LTCs, through secondary analysis of qualitative patient interviews.
4. To explore ways in which the degree of PCC for people with LTCs can be measured and to develop a PCC experience questionnaire for people with LTCs, based on findings from the conceptual synthesis and secondary qualitative analysis
5. To further test and confirm domains and usefulness of PCC for people with LTCs through cognitive debriefing interviews with people with LTCs and health professionals involved in the care of people with LTCs.

1.3 Overall structure of the Thesis

Chapter 2: Background and context of the thesis.

This chapter provides an overview of the impact of LTCs on the healthcare system and the individual person, explores our current understanding of the term PCC and its application to care for people with LTCs.

Chapter 3: Conceptual synthesis of existing frameworks of patient experience and patient-centred care.

This chapter assesses the existing literature around PCC using the method of conceptual synthesis. It aims to explore the concept of patient experience and PCC frameworks in order to identify existing domains and produce an overarching generic framework of PCC.

Chapter 4: Secondary analysis of qualitative interviews with people with long-term conditions.

This chapter explores patient interviews through secondary qualitative analysis to identify key experiences of health care delivery that matter to people with LTCs and to produce a LTCs specific framework of PCC.

Chapter 5: Item generation for a patient-centred care experience questionnaire for people with LTCs.

This chapter presents the process of item generation for PCC experience questionnaire for people with LTCs based on themes from the LTCs specific framework of PCC identified in the secondary analysis.

Chapter 6: Further testing and validation of themes and items of patient-centred care.

This chapter involves further testing of the themes generated from the secondary analysis and the items of the PCC experience questionnaire for people with LTCs through cognitive debriefing interviews with people with LTCs and health professionals. It also reports on first steps of validation of the PCC experience questionnaire for people with LTCs.

Chapter 7: Conclusions.

The final chapter of this thesis summarises the overall findings and discussed them in the context of the existing literature. The implications of these findings and future research are also discussed.

2 Background and Context

2.1 Objectives of the chapter

The objectives of this chapter are to provide an overview of the impact of long-term conditions (LTCs) and a summary of policy initiatives to improve care for people with LTCs. It also explores our current understanding of the term patient-centred care (PCC), its place within health policy and application to care for people with LTCs.

The chapter begins by exploring the prevalence of LTCs and the impact it may have on the healthcare system (in terms of costs and resource use) and on the individual person (in terms of quality of life). It presents existing policies which debate the need for health care services for people with LTCs to become more generic and patient-centred. The current definition of the term PCC is explored; what it means to overall healthcare delivery and specifically to care for people with LTCs. The chapter concludes by exploring how PCC for people with LTCs can be best measured and evaluated and identifies research gaps that will be addressed in this thesis.

2.2 The prevalence and impact of long-term conditions

More than 15 million people in England have a LTC which requires ongoing management via medication or other therapies (Department of Health, 2012a). LTCs include a wide range of diseases, such as diabetes, arthritis and mental health conditions amongst others. The impact of having a LTC varies dependent on the type of condition, but can include limitations in

participating in daily activities, difficulties in medication management and preventing further ill health, the need for negotiating support and services provision, and increased use of hospital services (Department of health, social services and public safety, 2012b). Equally, many people with LTCs may feel that they are living a perfectly normal life and would like ongoing support in doing so.

The management of LTCs is an increasing concern for the health services (House of Commons Health Committee, 2014). People with LTCs account for a high proportion of health services resource use: 70% of all inpatient bed stays, 64% of all outpatient appointments, 50% of all GP appointments, as well as utilisation of social services (Department of Health, 2012a). The cost associated with treatment and care for people with LTCs is estimated to be £7 of every £10 spent on health and social care (Department of Health, 2012a). The economic impact is further increased by difficulties that some people with LTCs may experience in gaining and maintaining employment.

There are also increasing number of patients with multimorbidity; the co-existence of two or more chronic diseases in an individual (National Quality Forum, 2012; Department of Health, 2012a). Reports of the prevalence of multimorbidity vary greatly, ranging from 23% in Netherlands primary care patients (Schellevis, van der Velden, van de Lisdonk et al., 1993) to as high as 99% in Canadian family practice patients (Fortin, Bravo, Hudon et al., 2005). Some research has indicated that the prevalence of multimorbidies is the norm rather than the exception (Fortin, Soubhi, Hudonet al., 2007; Mercer & Watt, 2007; Barnett, Mercer, Norbury et al., 2012) whilst a recent systematic review of existing studies heavily criticised the

heterogeneity of existing multimorbidity indices, which are frequently based on self-reports and often focused on older people (Diederichs, Berger & Bartels, 2011).

Future estimates for the number of people with three or more LTCs in the UK is predicted to rise from 1.9 million in 2008 to 2.9 million in 2018 (Department of Health, 2012a). The prevalence of multimorbidity increases with age (Salisbury, Johnson, Purdy et al., 2011), which is associated with high mortality rates (Gijsen, Hoeymans, Schellevis et al., 2001) and increased use of health services (Wolff, Starfield & Anderson, 2002; Salisbury et al., 2011), particularly in terms of hospital admissions and longer hospital stays (Vogeli, Shields, Less et al., 2007).

In addition, patients with multimorbidity often have poor quality of life (Fortin, Bravo, Hudon et al., 2006) and are likely to experience depression and psychological distress (Fortin, Lapointe, Hudson et al., 2004; Noel, Frueh, Larme et al., 2005; Van Weel & Schellevis, 2006). Difficulty in providing good care for people with LTCs can result in poor medication adherence, more frequent emergency admission and repeated investigations – all adding to the cost of the healthcare services (Department of Health, 2004a; Smith & O'Dowd, 2007).

2.3 Policy drive towards more generic services for chronic disease enablement

The management of LTCs has been at the heart of health policy since the late 1990s and a number of National Service Frameworks (NSFs) have been published as part of this agenda.

Many of these NSFs cover a single disease (e.g. mental health, cancer, diabetes); however, a specific NSF for LTCs was published in 2005 to establish national standards and identify key interventions for management of LTCs (Department of Health, 2005a). Consequently, the Quality and Outcomes Framework (QOF, 2004) was adopted to help facilitate the implementation of standards of management of LTCs in general practice. However, it is not completely clear what policies are aiming to achieve in terms of more integrated services and how this would enhance quality of healthcare.

The current model of care for people with LTCs is the '*NHS and Social care Long-Term Conditions Model*'[1], which is based on the '*Chronic Care Model*' (Wagner, 1996). The key messages of this model are to deliver personalised services underpinned by self-care support and self-management, which incorporates both health and social care. The model emphasizes a patient-centred approach to long-term health care, where well-informed and self-motivated patients are supported to be proactive members of a multidisciplinary team. Indeed, better LTC management by the individual could lead to reductions in utilisation of healthcare services use and improve the individual's quality of life (Department of Health, 2011).

The model suggests that planning care for people with LTCs should be done in two different stages; firstly at diagnosis of having a LTC and secondly as the disease progresses with time (Department of Health, 2007a). The delivery system of the *NHS and Social Care Long-term*

[1] http://webarchive.nationalarchives.gov.uk/+/www.dh.gov.uk/en/Healthcare/Longtermconditions/DH_4130652

Conditions Model is structured in three levels, in which patients are stratified according to their needs:

- Level 1. Supported self-care; *collaboratively helping individuals and their carers to develop the knowledge, skills and confidence to care for themselves and their condition effectively.*
- Level 2. Disease-specific care management; *this involves providing people who have a complex single need or multiple conditions with responsive, specialist services using multi-disciplinary teams and disease-specific protocols and pathways, such as the National Service Frameworks and Quality and Outcomes Framework (QOF).*
- Level 3. Case management; *requires the identification of the very high intensity users of unplanned secondary care. Care for these patients is to be managed using a community matron or other professional using a case management approach, to anticipate, co-ordinate and join up health and social care.*

To help facilitate this model, the Department of Health initiated the Expert Patients Programme (EPP) (Department of Health, 2009a), which consists of lay-led self-care support for people with LTC, their carers, and their families. The programme aims to support people with LTCs by increasing confidence, improving quality of life, and helping people manage their LTC more effectively. More importantly, it recognises patients as 'experts' in their conditions and encourages patients to take the lead in managing their condition. Evaluations of such a programme for the NHS have shown significant improvement in patient self-efficacy (measured using six items addressing general condition management, distress, non-medication management, discomfort, fatigue, and interference) and anxiety levels, but little reduction in

the utilisation of healthcare resources (Griffiths, Motlib, Azad et al., 2005; Buszewicz, Rait, Griffin et al., 2006; Kennedy, Reeves, Bower et al., 2007).

Although the LTCs model highlights the importance of self-care and care management for single or multiple LTCs, appraisals of care for people with LTCs have highlighted several challenges. For instance, evaluations of best practice have shown that quality of care has remained variable across different LTCs and that there is little consensus on the role that general practice should play in partnership with other care providers to deliver high quality care for people with LTCs (Goodwin, Curry, Naylor et al., 2010).

In addition, evaluations of multimorbidity have shown that self-management continues to be a challenge for patients who often experience the difficulty of managing multiple treatments (Bayliss, Steiner, Fernald et al., 2003). Patients also frequently struggle to access health services (Bayliss et al., 2003) and are likely to receive conflicting advice from different health care providers (Noel, Parchman, Williams et al., 2007). This is not surprising as an increased number of health professionals involved in a patient's health management can increase the risk of poorly co-ordinated care (McCormick & Boling, 2005; Vogeli et al., 2007).

As multiple morbidities become more common and chronic diseases become the core business of health care systems, there is pressure for more generic approaches to chronic disease management (Smith & O'Dowd, 2007; Taylor, Price & Gill et al., 2010; Barnett et al., 2012). The current delivery of care for people with LTCs, including multimorbidities, is often based on those for single diseases (Fortin et al., 2005; Goodwin et al., 2010). Although a disease

specific approach is suitable for certain purposes, using many different health services for the management of individual LTCs can become problematic for patients (Wolff et al., 2002; Starfield, Shi & Macinko, 2005).

Some researchers have argued that a more function-oriented approach is better suited for this purpose; one that focuses on how the patient can best function in a way that suits them (Smith & O'Dowd, 2007). Some have called for the National Institute of Clinical Excellence (NICE) to take multimorbidity into account when developing guidelines (Guthrie, Payne, Alderson et al., 2012). Historically, clinical guidelines have focused on making recommendations about treatments of individual diseases. However, as most people with chronic conditions have multiple conditions, individual guidelines can cause confusion to clinicians and patients.

These issues were further discussed in the '*Transparency in outcomes; a framework for the NHS'* consultation document (Department of Health, 2010a). It highlighted the need for a common approach across LTCs due to a) cross-cutting and common needs of individuals with different conditions and b) the increasing prevalence of people with multimorbidity, for whom condition-specific measures would not work. It also emphasized the importance of treating patients as individuals and focusing on health outcomes which are important to people living with LTCs. It can be argued that this recommendation is contradictory from previous health care policy as it asks for two distinct approaches; a more personalised health care with emphasises on treating the patient as an individual (possibly achieved though the means of delivering PCC) and a more generic health care approach across all LTCs. Indeed, this combination of a more generic yet personalised approach to health care planning is

recommended and echoed in several policy documents, with specific focus on delivering care that is patient-centred.

2.4 Policy focus on patient-centred care

Improving quality of care is a major health policy drive (Department of Health, 2010b) and much emphasis has been put on the importance of positive patient experience and its role in the future development of the NHS (Darzi, 2008; Sizmur & Redding, 2009; Department of Health, 2010b). One of the more internationally widely used definitions of quality suggests six criteria of care: patient-centred, safe, effective, timely, efficient and equitable care (Institute of Medicine, 2001). Nowadays, the vision for most health care services is to become more "patient-centred" (Department of Health, 2005a; Department of Health, 2009b) as this is regarded as the desired way of delivering health care (McCormack, 2004). However, this policy agenda is not entirely new or unique and is in fact rediscovered at intervals and re-launched as a novel vision for a new government (Goodrich & Cornwell, 2008).

PCC has been at the heart of UK policy since the introduction of the Patient's Charter, introduced by the Conservative government in 1991, which included both legal (e.g. respect for privacy, dignity, religious and cultural beliefs) and practical standards (e.g. waiting times and availability of information) (Department of Health, 1997). Whilst basic in design, this helped establish the importance of patient experience and putting the person at the centre of care.

The Patients Charter initiative was continued by the Labour government in 1997; a new document outlining patients' rights and expectations from a health system that was "*determined to place quality at the heart of health care"* (Department of Health, 1997). The principle continued to be embedded in many policy initiatives (e.g. Your guide to the NHS, Department of Health, 2001; NHS improvement plan, Department of Health, 2004b) and further emphasised in Lord Darzi's NHS Next Stage Review (2008), highlighting the need for patient care to be seen as responsive to individual needs and preferences.

An evaluation by the Picker Institute, '*Is the NHS becoming more Patient-centred?'* (Richards & Coulter, 2007), highlighted some key improvements in care (such as waiting time, cleanliness, hospital food), but also stressed the limitations of patient involvement in decision making and lack of information and support with self-care. Overall, the document concluded that although the NHS has improved significantly in several important aspects of care, the service is still far from patient-centred.

Subsequently, policy has been aimed at identifying and strengthening the patients' voice in their health care. Successive government arrangements, such as the Patient Advice and Liaison Service (PALS) and Healthwatch England (formerly Local Involvement Networks (LINKS)), have been established to offer patients better information about services and service quality, with the aim to create a more patient-led NHS (Department of Health, 2005b). This initiative has also been accompanied by several guidance documents such as '*Putting people at the heart of care'* (Department of Health, 2009b), '*Understanding what matters'* (Department of Health, 2009c), and '*Personalisation through person –centred planning'* (Department of Health,

2010c); all developed to aid the process of power shift from health professionals to people who use services.

The PCC paradigm has continued in more recent government policies. For instance, the '*Transparency in Outcomes'* document (Department of Health, 2010a) placed great emphasis on the role of positive patient experience and the necessity to measure patients' perception of care (Point 3; domain 4, pp 30-33). The document argued that high quality personal care means treating people with compassion, dignity and respect, and giving them the level of comfort, information and support they require. Equally, both the '*Equity and Excellence; Liberating the NHS'* document (Department of Health, 2010d), a government white paper for reforming government strategy and transforming the NHS, and work by the Kings Fund (2010), '*How to deliver high-quality, patient-centred, cost effective care'*, emphasized that the public health services need to provide high quality PCC that meet these priorities, through systems such as the Outcomes framework and the NICE quality standards.

Subsequently, NICE was commissioned by the Department of Health to produce a new quality standard on patient experience in adult NHS services (NICE, 2012). Consisting of 14 statements, the quality standard aims to improve the quality of patient experience by focusing on the individual needs of the patient (such as opportunity to discuss health beliefs, concerns and preferences), psychological concerns (such as fear and anxiety) and physical needs (such as nutrition, hydration, personal hygiene and pain relief). By recommending the clinical standards, NICE places emphasis on patient needs, concerns, and preferences to be at the heart of care planning.

In addition, the '*NHS Patient Experience Framework'* (Department of Health, 2011a) was developed to guide the measurement of patient experience across the NHS. The development work was endorsed by the Department of Health, the first of its kind, and approved by the NHS National Quality Board (NQB) for implementation in the NHS. Although focused on outlining critical elements of patient experience, the framework also highlights many important aspects of PCC, such as 'respect for patient-centred values, preferences and expressed needs' and 'emotional support'.

More recently, work has been conducted by the Kings' Fund in the development of a *'Patient and Family-centred toolkit'* (King's Fund, 2014). The toolkit is described as a step-by-step guide for improving processes of care and staff-patient interactions by understanding what a care experience is like, what needs to change and which improvements would make a difference to patents, their families and health care staff. Development of the toolkit was partly informed by the Francis Inquiry, a public inquiry into the role of the commissioning, supervisory and regulatory bodies in the monitoring of Mid Staffordshire Foundation NHS Trust, and the subsequent national agenda of 'putting patients at the centre of decision making'. Work on the toolkit was conducted by the 'Patient and Family-Centred Care programme'; a partnership with the Health Foundation and the King's Fund for improving the experience of hospital care for patients, their families, and staff. The toolkit is described as:

> *"A simple, step-by-step method for understanding what a care experience is like, what needs to change, and which small improvements can make a big difference to patients, families and staff alike".*

It is hoped that the toolkit will be adopted by health care teams across the country to improve services, ranging from paediatric accident and emergency to the care of frail older people. Overall, these policy efforts have aimed to enhance the medical viewpoint with reflection on the patients' subjective experience (Leplege, Gzil, Cammelli et al., 2007).

2.4.1 Policy focused on patient-centred for people with LTCs

Much of the policy around patient-centred services for people with LTCs has stemmed from the specific NSF for LTCs (published in 2005a), which highlighted the need for 'person-centred services' as one of the 11 quality requirements (see appendix 1) in care for people with LTCs (Department of Health, 2005a). The NHS also emphasised the need to put the individual at the heart of care, to integrate services to promote independence and empower patients and health professionals.

Consequently, the principles of patient experience and PCC have been applied to care for people with LTCs throughout a number of policy documents. For instance, the '*National Service Framework for LTCs'* (Department of Health, 2005a) outlined several standards of care for people with LTCs, including the need to improve interaction between healthcare professionals and patients and implementation of accessible person-centred services. The current '*NHS and Social Care LTCs Model'* (Department of Health, 2007b) emphasises more personalised services by taking a patient-centred approach to long-term health care. The consultation document, '*Personalised care planning; improving care for people with LTCs'*

*(*Department of Health, 2011b), highlights the need for a seamless, holistic process of care delivery, promoting empowerment and allowing people to make informed choices.

The white paper, '*Equity and Excellence: Liberating the NHS'* (Department of Health, 2010d), places great emphasis on enhancing the quality of life for people with LTCs. Overall, the document highlights two major issues; putting patients and the public first (point 2, pp13-20) and improving health care outcomes (point 3, pp21-26). The two topics are interlinked and it is argued that current provision of care is delivered though a top-down target approach. The general aim is to provide a new foundation for health services that empowers staff and gives patients choice and personalised care. The document also establishes new strategies for improving healthcare outcomes and places great emphasis on outcomes experienced by patients, as it is seen to be a true reflection of quality.

Work by the King's Fund has also contributed to this policy agenda. In a recent report produced by the King's Fund, '*Delivering better services for people with long-term conditions'*, Coulter, Roberts and Dixon (2013) argued that the management of care for people with LTCs needs to be holistic, preventative, proactive and patient-centred. The document also highlights the need for personalised care planning to ensure each person's values and concerns are considered and help inform the way in which they are supported to live well with their condition. However, despite the extensive body of literature and policy exploring the popular concept of PCC, there is still little consensus on its meaning (Mead & Bower, 2000) and its measurement.

2.5 Origins of patient-centred care

Over the last 30 years, a broad range of definitions of PCC have been developed in the academic and clinical literature. Similar to the policy agenda, the notion of PCC is not new and has been part of health care delivery for some time. For instance, early work by the physician Sir William Osler on the practice of medicine (The Principles and Practice of Medicine, Osler, 1909) highlighted the need for good bedside manners and compassion for patients. Indeed, much of the concept of PCC focuses on the relationship between health professionals and patients and with the aim to create 'good' experiences of health care delivery. Over the years, other researchers and practitioners have provided additional definitions and depth to the concept of PCC (e.g. Balint, 1969; Byrne & Long, 1976).

One of the early definitions by Edith Balint (1969) described patient-centred medicine as *'understanding the patient as a unique human being'*. In the context of clinical consultations, Byrne and Long (1977) argued that it represents *'a style of consulting where the doctor uses the patient's knowledge and experience to guide the interaction within the consultation'*. Similarly, McWhinney (1989) described the patient-centred approach as one where *'the physician tries to enter the patient's world, to see the illness through the patient's eyes'*. Laine and Davidoff (1996), argue that PCC is indeed about *'closely congruent with, and responsive to patients' wants, needs and preferences'*.

Others have provided more detailed descriptions of this concept of PCC. For instance, Stewart, Brown, Weston et al. (1995) identified six related components of PCC; exploring both the disease and the illness experience, understanding the whole person, finding common ground

regarding management, incorporating prevention and health promotion, enhancing the doctor-patient relationship, and being realistic about personal limitations and issues such as availability of time and resources. Other factors that have emerged over time include providing information to patients and involving them in the decision making process (Grol, Whitfield, Maeseneer et al., 1990; Winefield et al, 1996).

In a narrative review, Mead & Bower (2000) highlighted five key conceptualised patient-centred aspects of the doctor-patient relationship; the biopsychosocial perspective, the patient-as-person, sharing power and responsibility, the therapeutic alliance, and the doctor-as-person. They argue that 'patient-centred' medicine differs greatly from the biomedical model; a model which centres on the patient's reports of symptoms (indication of the existence of a disease) and focuses on identifying and treating the disease entities. Subsequently, the patient's illness is often reduced to a set of signs and symptoms with the aim to restore/improve health and bring the patient back to 'normal' state.

By understanding the patient's illness in general and their personal experience of illness, health professionals can be sensitive to patients' preferences for information, encourage patient involvement and respond appropriately to shared decision-making. This allows for a fundamental therapeutic alliance where doctor and patient develop common goals in order to enhance the personal bond. In this mode, health professionals also have an awareness of how their personal qualities and subjectivity influences the practice of medicine.

In practice, the concept of PCC has become established within rehabilitation and disabilities social care provision (e.g. Cott, 2004; Macleod & Mcpherson, 2007) and in approaches to the delivery of health care (Carr & Higginson, 2001; McCormack & McCance, 2006), where it is often referred to as patient-centeredness or person-centred care. Indeed, the terms 'patient' and 'person' are often used interchangeably in the literature, but it is worth noting that the medical viewpoint, since the 1950's, has been enhanced with reflection on the patients' subjective experience and has subsequently adopted many of the conceptual bases of a patient-centred approach (Leplege et al., 2007).

Nowadays, patient-centred care is often regarded as the desirable way of delivering health care (McCormack, 2004) and many institutions have presented their own framework of PCC (e.g. Institute of Medicine, World Health Organisation, Department of Health). These frameworks aim to outline aspects of care that are most important to patients (described as domains) and can be used to help define questions to ask patients in patient reported surveys in order to capture real time feedback, The development work varies for each framework but may consist of interviews or surveys with patients and health care professionals about their experiences and aspects of health care delivery that are important to them These frameworks appear similar and overlapping in some aspects and a full appraisal of the existing frameworks of PCC is much needed in order to gather a better understanding of the origin of this concept and its definition. Therefore, the concept of PCC is further explored in chapter 3.

It has also been suggested that PCC is about two different aspects of health care delivery; the 'what' and the 'how' (The King's Fund, 2011; Robert et al., 2011). The 'what' (or

transactional) refers to what happens to patients and the steps of the process that take place between patients and health care staff, whilst the 'how' (or relational) refers to the tone, manner and language of interactions. This distinction is also apparent in the literature where PCC can be about the individual clinical encounters between health professionals and patients (e.g. Mead & Bower) or more towards to the organisational level of health care delivery.

In addition, it may be that PCC has different meaning in different settings, depending on the nature of the condition and the health services bring provided (Goodrich & Cornwell, 2008). For instance, in cancer services, PCC could be about the strategic goal underpinning the re-organisation of primary, secondary and tertiary services into networks designed around patients' clinical needs. For patient organisations and consumer groups, patient-centred usually means services that listen to patients, take their views seriously and attend to the 'fundamentals' of 'basic' or 'simple' aspects of care: dignity and respect for individuals, well-organised care, clean wards and nutritious food.

In LTCs, it can apply to approaches to management that explore what patients think, believe, and expect, and their subsequent confidence about disease management (Bauman, Fardy & Harris, 2003). However, the range of health and social problems experienced by people with LTCs are complex, multi-faceted and often vary over of time. Currently, there is no adaptation of the concept of PCC for care for people with LTCs and the ways in which PCC can be evaluated with this population is underexplored.

2.6 Measuring patient experience and patient-centred care

Several attempts have been made to define what really matters to patients about their health care and the best approaches to measurement. Traditionally, patients' views on health care performance were captured through the measurement of 'patient satisfaction'; a broad and often ill-defined concept (Hall & Dorman, 1988; Fitzpatrick & Hopkins, 1983; Sitzia & Wood 1998; Fitzpatrick, 1991).

Earlier work by Ware, Snyder, Wright et al. (1983) and Fitzpatrick (1991) has particularly emphasized access and availability of health care, communication with health care professionals and the effectiveness of treatment and care to be essential domains in the measure of patient satisfaction. However, there is still little consensus on the core components of patient satisfaction and its measurement.

The notion of patient satisfaction becomes more ambiguous if it refers to multiple health care events and interactions over long periods (Valentine, De Silva, Kawabata et al., 2003). Coulter, Fitzpatrick & Cornwell (2009) argued that patient satisfaction ratings reflect at least four factors:

- The personal preferences of the patient
- The patient's expectations
- Response tendencies due to personal characteristics
- The quality of care received

These inherent limitations in assessing patient satisfaction may at times make it difficult to interpret results and make inferences about the quality of health care (Calnan, 1988). Firstly, measure of satisfaction may simply capture general attitudes rather than recall of actual event (Revicki, 2004). Research has also indicated that many respondents readily provide positive evaluations but have more difficulty providing negative evaluations of their care (e.g. Fitzpatrick, 2002; Jenkinson, Coulter, Buster et al., 2002), compared with the more wide-ranging opinion that can be detected using qualitative research methods (Staniszewska & Henderson, 2004).

Finally, patient satisfaction questionnaires have been criticised for failing to discriminate effectively between good and bad practice as they rarely ask patients about the personal value of services received (Cleary, Edgman-Levitan, McMullen et al., 1992). For instance, patients can be satisfied with lower quality care and, similarly, they can be dissatisfied with care that is considered to be high quality by other indicators (Cleary, 1998). Consequently, satisfaction does not imply that all aspects of care were successfully delivered and may often present a limited and optimistic picture of patient experience of healthcare services (Jenkinson et al., 2002).

The absence of a solid conceptual base and consistent measurement approaches for patient satisfaction over the last decade has led to a proliferation of survey measures that focus exclusively on ‘patient experience’ in addition to evaluations of care (Edgman-Levitan & Cleary, 1996; Cleary et al., 1992; Bleich, Ozaltin & Murray, 2009). These questionnaires do not ask about attitudes and evaluations, but instead ask patients to recall whether certain

processes occurred during an episode of health care (Jenkinson et al., 2002). By examination of specific issues, these measures may provide a better guide of performance in the health care system and highlight areas which can be addressed. However, it should be noted that these measures are still subjective measures of experience and, although they aim to systematically capture aspects of care, may not provide a wholly accurate description of quality of care (The Intelligent Board, 2010).

2.7 Measuring patient experience in the NHS

Patient reported outcome measures (PROMs) are self-reported measures used by patients to provide feedback on their health and quality of life (QoL) (Browne, Jamieson & Lewsey, 2007). PROMs are well established and have been used widely in clinical trial or clinical settings. Currently, PROMs are being used in the NHS to evaluate the outcomes of hip or knee replacements, varicose vein surgery, and groin hernia surgery[2]. As part of this programme, the NHS asks patients about their health and QoL before and after a procedure in order to capture the effectiveness of that procedure. PROMs are also mentioned in various national policy documents (e.g. Department of Health, 2010b, 2010d) and the NHS Outcomes Framework's second domain for improvement is to enhance the QoL for people with LTCs as assessed by PROMs, particularly the generic measure EQ-5D (Department of Health, 2010e).

[2] http://www.nhs.uk/NHSEngland/thenhs/records/proms/Pages/aboutproms.aspx

Patient reported experience measures (PREMs) aim to capture experiences of care or 'what actually happened' rather than the outcomes of care, e.g. national outpatient or GP surveys. Generally, PREMs are at an earlier stage of development than PROMs and there is less literature, recognition and policy around PREMs. Many condition specific PROMs (e.g. asthma, diabetes, arthritis) are in existence with extensive validation and support for their use in clinical trials and the NHS, however, the use of PREMs to evaluate care for people with LTCs remains relatively unexplored.

Traditionally, evaluations of healthcare tended to be largely focused on capturing healthcare resource use and costs, rather than patient experience of healthcare. The *'Performance Assessment Framework'* (PAF) introduced in 1999 (Department of Health, 1999) marked the change in direction by seeking to measure aspects of quality of care through a range of domains (or indicators), including clinical effectiveness of care, patient experience and patient safety.

Measuring patient experience has now becomes an integral part of health care regulation and improvement. For instance, in primary care, GP payments are partly linked to the patient satisfaction survey results (QOF[3]) and in secondary care, NHS hospitals measure patient experience as part of the national regulation by the Care Quality Commission[4]. Much of this work is co-ordinated by the Picker Institute Europe, a not-for-profit organisation that develops

[3] http://www.ic.nhs.uk/statistics-and-data-collections/audits-and-performance/the-quality-and-outcomes-framework

[4] http://www.cqc.org.uk/

and implements surveys throughout the health services. Their involvement includes patient and staff surveys conducted as part of the NHS patient survey programme, which aims to gather views and experiences about the care they received in a number of settings[5].

The 'National GP Patient Survey' (run by Ipsos Mori on behalf of NHS England) is mailed out twice a year to over 1.3 million people registered with a GP in England in order to assess patient experience of their local NHS services[6]. The survey is described as an opportunity for patients to experiences of their GP practice to inform where improvements are needed. Equally, the NHS friends and family test[7] was introduced in 2013 which seeks feedback on the care and treatment that was received by patients by directly asking patients whether they would recommend hospital wards, A&E departments and maternity services to their friends and family if they needed similar care or treatment. Overall, the question of how well the NHS is performing is high on the agenda as a 'patient-centred NHS' must first and foremost know what impact it is having on patients.

However, more recent policy debate has called for an additional overarching measure of patient experience and quality of care. For example, the NHS Outcomes Framework for 2010/2011 (Department of Health, 2010e) extended Darzi's three domains of quality (patient experience, patient safety and clinical effectiveness) to be driven by a comprehensive set of outcome

[5] http://www.nhssurveys.org/

[6] http://www.gp-patient.co.uk/info/

[7] http://www.nhs.uk/NHSEngland/AboutNHSservices/Pages/nhs-friends-and-family-test.aspx

indicators; some identified and others in development. Simultaneously, the '*Transparency in Outcomes'* document (Department of Health, 2010a) highlighted the need for a self-reported measure to capture patients' perceived benefits of care they received. In domain 4, the document referred to a long term need for an outcome indicator that focuses directly on the outcome that matter most to patients:

> *'These questions would ask patients whether they received the care and services they need, and its overall quality (for example whether it met their requirements, enabled them to maintain their health, or enhanced their quality of life).'*
>
> (Department of Health 2010a pp32-33).

The Department of Health proposed a two-step approach for this task: a short-term interim approach and a long-term approach. The short term approach proposed monitoring performance in patient-reported experience, based in five themes: 1) access and waiting, 2) safe, high quality coordinated care, 3) better information and more choice, 4) building closer relationships, and 5) clean, friendly comfortable space. The long-term approach proposed to develop an overarching outcome indicator based on a set of core questions that could potentially be included within all surveys, based on the outcomes that matter most to patients (3.44).

However, there is a concern as to whether the currently existing approaches and the newly proposed self-reported measures are sufficient or relevant to evaluating care for people with LTCs.

2.8 Adequacy of existing approaches to measure experience and outcomes

With the growing prevalence of LTCs, there is a need for an effective patient-reported evaluation of care for people with LTCs. There is much emphasis on service design, principles of good care, and perceived benefits of a more involved and participatory approach to care. However, the measurement of the quality of services for people with complex health needs and multiple conditions poses specific challenges, particularly if these are to be used as indicators of the quality of services.

There is a concern that existing patient experience measures have derived largely from more hospital based or acute hospital episodes, without focus on core aspects of PCC or key experiences that matter to people with LTCs. A self-reported measure of health care for people with LTCs needs to consider specific experiences that matter to these patients, which may be different to those of acute or treatable conditions. It is questionable as to whether these specific experiences have been adequately captured in the patient experience and PCC frameworks. For instance, PCC to people with LTCs may not be about cleanliness of hospitals or receiving respect and dignity from health professionals, but more about empowering patients to be able to look after themselves and manage their condition better.

Despite the plethora of patient experience measures, existing measures do not directly address these issues. . Such a measure would be a) more relevant to the care of people with LTCs to capture experiences of care that matter to patients and b) generic in nature and applicable across different LTCs to better capture the complexity of health problems. In addition, ideally this measure would focus on capturing aspects of PCC which is highly placed in current policy

agenda. It is worth exploring the development of such a measure, to examine the constructs that would underpin its content and evaluate its feasibility in patients with LTCs.

2.9 Conclusion

The impact of LTCs is evident on both the health care services and on the individual. Improving quality of care is a major health policy drive and much emphasis has been put on the importance of positive patient experience and services that deliver PCC. However, the concept of PCC is ill defined and may not capture aspects of care that is particularly important in the management of LTCs.

The overview of policy presented above highlights the importance attached by policy makers to raise the quality of health services, however despite the many policy initiatives and drive to improve care for people with LTCs, evaluations have shown that quality of care has remained variable across different LTCs. There is a clear need for more co-ordinated services for chronic disease enablement and evaluation of quality of care received, in terms of tools to collectively measure health experiences of people with LTCs.

Chapter 3 further explores the concept of PCC and evaluates the existing frameworks of patient experience and PCC through the method of conceptual synthesis in order to present an overarching framework of PCC.

3 Conceptual Synthesis of Existing Frameworks of Patient Experience and Patient-Centred Care

3.1 Introduction

3.1.1 Background and rationale

As discussed in chapter 2, several documents and initiatives have emphasised the importance of positive patient experience and PCC. The two concepts share many of the same basic principles and overall aim to provide good quality health care for patients and service users. In fact, it can be argued that PCC should make for good patient experience and vice versa.

However, it can be argued that some aspects of patient experience are more 'transactional' (e.g. Robert et al. 2011) and less self-evidently around the concept of PCC or 'relational' aspects of health care delivery. For instance, aspects of the environment (such as cleanliness) and car parking at hospital is more about availability of resources and less in the control of health care professionals that provide care. In addition, it may be that patients consider care to be holistic and patient-centred even with the absence of ample parking or clean facilities. Nevertheless, a better understanding of the concepts and frameworks of patient experience is needed to gather a better understanding of the concept of PCC.

This chapter examines existing frameworks of health care delivery (particularly in terms of care that is patient-centred) to evaluate how these frameworks are similar, how they differ from

one another, and to explore the possibility of synthesising key concepts from these frameworks to create an overarching framework of PCC. The search mainly focuses on identifying frameworks of patient experience and PCC as these concepts were considered to be closely related and important in the optimal delivery of health care.

3.1.2 Objectives

The specific objectives of this chapter were:

1. To identify existing frameworks of patient experience and PCC in order to evaluate their commonalities and differences.
2. To assess the possibility of synthesising and combining existing frameworks to create an overarching framework of PCC.

3.2 Methods

The approach taken to review the frameworks identified in this chapter was informed by Critical Interpretive Synthesis (CIS) techniques, but adapted to suit the purpose of this chapter. In this chapter, the method is described as Conceptual Synthesis.

The method of CIS was originally developed by Dixon-Woods, Cavers, Agarwal et al., (2006) and used in their literature review, *access to healthcare by vulnerable patient groups,* with the aim of pulling together both quantitative and qualitative literature. Dixon-Woods and colleagues argued that the method of CIS offers a sensitised approach compared to the process of conventional systematic review techniques. Without a strict focus on selective sampling,

CIS allows the researcher to further understand a topic by drawing on relevant literature and interrogating the findings through a philosophical and theoretical interpretation. The method is particularly useful in instances where traditional aggregation of data (in a search for an answer about what works best) is not a suitable methodology.

The possibility of conducting a systematic review was also explored for this chapter. The conventional systematic review methodology can be limited in certain circumstances, particularly for the purpose of this chapter where the aims were to synthesise and combine concepts and principals rather than the result of empirical research. The literature and frameworks around patient experience and PCC are large, diverse and complex in nature. Much of the literature is of mixed methodology, including both qualitative and quantitative methods as well as theoretical and policy documents/statements. Reviewing a variety of frameworks required a more flexible approach and a critical analysis of a composite body of literature, rather than the aggregation of data to see what works best. Therefore, an approach based on the method of CIS was particularly suitable for this chapter.

The method of CIS was adopted for this purpose, originally proposed by Dixon-Woods and colleagues and subsequently adapted by Entwistle, Firnigl, Ryan et al. (2012) for synthesis of qualitative literature. The approach in this chapter followed the adaptation of CIS by Entwistle et al. (2012) and aimed to synthesise concepts of patient experience and PCC; abstracting from a variety of independent frameworks to arrive at a higher level interpretation and meaning. The approach was defined as a ‘conceptual synthesis’ as it still drew on methods that were

developed to interrogate data. However the aims of this chapter were not to look at empirical data, but rather to synthesise concepts and frameworks.

An example of an adapted CIS methodology with similar theoretical aims was presented recently in a review by Entwistle et al. (2012) of *experiences of health care delivery that matter to service users*. Using a methodological adaptation of CIS with a more purposed approach, Entwistle and colleagues selected only 3 distinctively different frameworks for their synthesis. Table 1 presents Entwistle's interpretation of CIS and the key characteristics of this approach.

Table 1. Key characteristics of Critical Interpretive Synthesis (CIS) (Entwistle et al., 2012).

Purpose	To further understanding of a topic/question by drawing on broadly relevant literature to develop concepts and theories that integrate those concepts. The topic might not be precisely bounded, and the initial question might be refined as the review progresses.
Process	The process of CIS is iterative, interactive, dynamic and recursive, with recognition of a need for flexibility and reflexivity. Searching, sampling, critique and analysis may happen concurrently.
Search strategy	Formal bibliographic searches may feature, but use will also be made of the research team's awareness of relevant literature from various fields and sources. The strategy may evolve organically.
Sampling	Sampling of studies may be selective and purposive (not necessarily aiming for comprehensive identification and inclusion of all relevant literature). Inclusion criteria can be flexible and to some extent emergent. Reflexivity informs sampling. Ongoing selection of potentially relevant literature is informed by emerging theoretical framework.
Quality appraisal	Some formal appraisal of methodological quality may be appropriate, but judgements about the credibility and contribution of studies may be deferred until synthesis, as methodologically weak papers may still prove theoretically or conceptually insightful.
Data analysis	Inductive – aims towards the development of a synthesizing argument. CIS involves an interrogation rather than aggregation of concepts and themes. Formal data extraction may be useful but is not essential to the approach.
Findings/results	CIS results in the generation of a 'synthesizing argument' linking existing constructs from the findings to 'synthetic constructs' (new constructs generated through synthesis). This network of relationships and categories is submitted to rigorous scrutiny as the review progresses.
Discussion, contribution	CIS aims to offer a theoretically sound and useful account that has explanatory power and is demonstrably grounded in the evidence. It explicitly acknowledges the 'authorial voice' and that some aspects of its production will not be auditable or reproducible.

The interpretation of CIS presented by Entwistle and colleagues was particularly helpful for the methodology adopted in this chapter. For instance, a structured search and review methodology similar to that of ‘search strategy’ and ‘sampling’ was adopted, presented in Table 1. A formal bibliographic search was conducted using appropriate search terms and the frameworks identified by the searches were selectively sampled, without the aim of comprehensively identifying and including all relevant literature.

The methodology and findings of this approach were regularly shared and discussed with supervisors to assure that the process remained reflective and informed. Indeed, the methodology of CIS can be highly interpretive; however appropriate documentation and transparency of methodology allow s it to be re-producible.

The conceptual synthesis also allowed for reflection on the identified frameworks; to understand their message and interpret what they were trying to capture, how they might be related to the concept of PCC and how they might relate to each other. This involved extracting each framework and interrogating its domains for a deeper understanding and meaning. For instance, if the domain ‘information’ was an important part of a patient experience framework, it was important to understand what information meant to the patient and health care professionals and what aspects of information were particularly important and relevant to the framework.

The development of a ‘synthesis argument’ informed the way each domain was linked to a ‘synthetic construct’ (in the form of a higher domain and framework of PCC generated through the synthesis) and how domains linked to each other. The synthesis argument was revised based on feedback from an expert panel with specialist expertise in the area of primary care and public health. The expert panel consisted of supervisors and a specialist advisor with experience in analysing patient experience frameworks. The final overall framework of PCC and its constructed domains were presented in a table format.

3.2.1 Review sources and sampling

The search was conducted using three main sources:

- A bibliographical search using search engines
- A hand searching strategy of relevant policy and guidance documents
- A supplementary search of the reference lists of relevant articles

Bibliographical search engine strategy

Search strategies were developed for the Ovid search (up to January 2011) to identify studies reporting on frameworks of patient experience of health care and PCC (see Appendix 2 for search strategy). Ovid search engine explores a number of relevant databases, including AMED (Allied and Complementary Medicine), EMBASE, PsycInfo, Ovid MEDLINE(R) In-Process and Other Non-Indexed Citations and Ovid MEDLINE(R).

Hand researching strategy

Hand searching of the titles of key policy and health guidance documents (up to January 2011) was conducted. The following policy publication forums were selected for this search:

- The Department of Health
- The Kings Fund
- The World Health Organization
- The Institute of Medicine
- The Picker Institute
- The National Institute for Health and Care Excellence
- The National Institute for Health research: Health technology Assessment Programme

Supplementary search of references

A supplementary hand search of reference lists of relevant articles was conducted in order to capture relevant frameworks. The aim of this search was to identify additional frameworks that may not have been available through the bibliographical search or hand search of relevant policy and guidance documents.

3.2.2 Search terms

Search terms were developed for the Ovid search. These terms were revised with the assistance of an Information Specialist based at the Bodleian Library (University of Oxford), with particular expertise in development of search strategies and identification of appropriate search. Several search terms were used for the synthesis including; patient experience, patient satisfaction, patient-centre care, person-centred care, person-centredness.

3.2.3 Definition of frameworks

A framework was defined as a text that provided an apparently comprehensive or inclusive set of distinct domains of patient experience or PCC, with the attempt to be a complete list of things that matter to patients (rather than a selective identification of a few).

3.2.4 Selection of frameworks

The selection of frameworks was a process driven by the relevance of the content of each framework, rather than methodological rigour of published papers and policy documents. Purposive sampling was used to capture a wide range of different frameworks and themes. Newer frameworks (that had been derived from original frameworks) were only considered if they proposed additional domains not covered by existing frameworks.

Another aim was to include a diverse range of frameworks from a range of healthcare conditions and settings (including frameworks for inpatient hospital care, palliative care and care for people with LTCs) in order to investigate different interpretations and adaptations of the concept of patient experience and PCC.

3.3 Results

3.3.1 Frameworks identified

The bibliographic search identified 3 frameworks and all 3 were included in the synthesis. The hand search identified 5 frameworks, of which 4 were included in the synthesis. The supplementary search identified a total of 7 frameworks, of which 3 were included in the synthesis. A total of 15 frameworks were identified overall and 10 were included in this synthesis. Frameworks were excluded if they were derived from original frameworks (and did not offer additional domains) or if they were adequately covered by a review of PCC frameworks (see Excluded frameworks). The number of relevant articles identified through each source is shown in Table 2.

Table 2. Number of frameworks identified through the three search strategies.

Source	**Number of frameworks identified**	**Number of frameworks included in review**
OVID (up to Jan 2011)	3	3
Hand search	5	4
Supplementary search of references	7	3
Total	15	10

3.3.2 Frameworks included in the synthesis

Each framework and its content are discussed in more details below. Frameworks included in the synthesis were:

Gerteis's framework of PCC and additional frameworks derived from Gerteis

1. Gerteis et al. (1993) framework of PCC
2. The Picker principles of PCC (1987)
3. Institute of Medicine (IoM, 2001)

Frameworks presented by World Health Organisation (WHO)

4. World Health Organisation (WHO, 2003)
5. World Health Organisation 'General Principles of Good Chronic Care' (WHO, 2004)

Frameworks of patient-centred relationships

6. Stewart et al. (1995) framework of person-centred relationship
7. Mead and Bower (2000) framework of person-centred relationship

Additional frameworks

8. SENSES framework (Nolan et al., 2001)
9. National Health Council (NHC, 2004)
10. Cronin (2004) review of PCC

3.3.2.1 Gerteis's framework of PCC and additional frameworks derived from Gerteis

Gerteis et al (1993) framework of PCC

In 1993, Gerteis and colleagues presented a comprehensive insight into experiences and needs of patients, based on primary research funded by the Picker/Commonwealth programme for PCC. The framework was developed through a set of three US studies which explored patient and family experience of hospital care.

The first study consisted of three focus groups with recently discharged patients (and their families) who had received either medical or surgical treatment. A questionnaire was developed from the findings and the second study involved telephone interviews about the questionnaire with 50 patients and family members from 5 different hospitals. Additional focus groups were also conducted with medical and non-medical staff. The final study involved a nationwide survey in order to assess the quality of care. The survey was designed based on the Gerteis framework of PCC. A total of 6455 patients and 2000 'care partners' were interviewed. Centres that had particularly good reports of patient experience were visited in order to gather a better understanding of their methods of health care delivery.

The results and subsequent framework were presented in *'Through the Patient's Eyes; Understanding and Promoting Patient-Centred Care'*, where PCC was defined as an approach that consciously adopts the patient's perspective. Although the focus was mainly to inform how health care policy, standards and regulations could be more patient-centred, Gerteis et al. also presented a framework for PCC consisting of 8 domains:

- Respect for patients' values, preferences and expressed needs.
- Co-ordination and integration of care.
- Information, communication and education.
- Shared decision making and support for self-care.
- Physical comfort.
- Emotional support and alleviation of fear and anxiety.
- Involvement of family and friends.

- Continuity of care and smooth transition across service boundaries.

These eight dimensions of PCC have been subject to further research for some time; however the findings in this area have been inconsistent and often focused on one dimension of care, rather than the entirety of PCC (Goodrich & Cornwell, 2008). Nevertheless, the Gerteis framework of PCC has been widely adopted and credited, particularly by two of the most commonly quoted frameworks; the Picker Institute principles of PCC (1987) and the Institute of Medicine framework of PCC (IoM, 2001). More recently, the Gerteis framework was adopted by the NHS in their development of the NHS patient experience framework (Department of Health, 2011a).

The Picker principles of PCC (1987) [8]

As noted above, the framework of PCC presented by Gerteis was also adopted by The Picker Commonwealth Program for PCC (later became known as The Picker Institute), who originally funded the investigation. The domains presented in the Gerteis framework were renamed in 1987 as the 'Picker principles of PCC' and an additional domain of 'access to care' was added. The following eight principles were proposed:

- Respect for patient-centred values, preferences, and expressed needs; *including an awareness of quality-of-life issues, involvement in decision-making, dignity, and attention to patient needs and autonomy.*

[8] http://cgp.pickerinstitute.org/?page_id=1319

- Coordination and integration; *of care across clinical, ancillary, and support services and in the context of receiving "frontline" care.*
- Information, communication, and education; *on clinical status, progress, prognosis, and processes of care in order to facilitate autonomy, self-care, and health promotion.*
- Physical comfort; *including pain management, help with activities of daily living, and clean and comfortable surroundings.*
- Emotional support and alleviation of fear and anxiety; *about such issues as clinical status, prognosis, and the impact of illness on patients, their families and their finances*.
- Involvement of family and friends; *in decision-making and awareness and accommodation of their needs as caregivers.*
- Transition and continuity; *as regards information that will help patients care for themselves away from a clinical setting, and coordination, planning, and support to ease transitions.*
- Access to care; *with attention to time spent waiting for admission or time between admission and placement in a room in the inpatient setting, and waiting time for an appointment or visit in the outpatient setting.*

The principles of PCC presented by Picker have also informed the development of the NHS national patient survey programme[9] developed by the Picker Institute: an annual performance

[9] http://www.nhssurveys.org/

monitoring survey which obtains data from samples of patients in each NHS trust with the aim to gather information about experiences of the NHS care[10].

The Institute of Medicine (IoM, 2001)

As mentioned above, the framework of PCC presented by the IoM was informed and developed from previous work by Gerteis's framework of PCC. The work presented by IoM also highlights that the concept of PCC is multi-dimensional and encompasses all aspects of how services are delivered to patients. To date, this definition is preferred by the King's Fund 'Point of Care' programme (e.g. Coulter et al., 2009) and Goodrich and Cornwell (2008) have praised it as being the most useful and comprehensive definition of PCC. In this framework, the dimensions of PCC were defined as:

- Compassion, empathy and responsiveness to needs, values and expressed preferences.
- Co-ordination and integration.
- Information, communication and education.
- Physical comfort; *properties of the physical environment (design, light, space, furniture and equipment, accessibility); management of the environment (warmth, cleanliness, smells, noise); and staff responsiveness to individual patients.*
- Emotional support relieving fear and anxiety.
- Involvement of family and friends; *involvement in caring for individual patients, and group involvement in governance, service design and service planning.*

[10] NHS national patient survey programme http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/Browsable/DH_5578969

Although the IoM framework of PCC is similar to Gerteis framework and Picker principles, it adds an additional domain of 'compassion, empathy and responsiveness to individual needs, values and expressed preferences' which was not included in the other two frameworks. It was therefore included in the synthesis.

3.3.2.2 Frameworks presented by the World Health Organisation (WHO)

The World Health Organisation (WHO, 2003)

A broad literature review by the WHO (Gostin, Hodge, Valentine et al., 2003) developed domains of responsiveness (people's actual experience of the health care system) based on the areas of quality of care and patient satisfaction, including the examination of several survey instruments. Eight domains were identified that most comprehensively captured responsiveness:

- Autonomy; *involvement in decisions, getting information about treatments and tests.*
- Choice; *choice of health care provider.*
- Communication; *clarity of communication, getting enough time to ask questions about health problems and treatment.*
- Confidentiality; *confidentiality of personal information, ensuring patients can talk privately to health care providers.*
- Dignity; *respectful treatment and communication, being greeted and talked to respectfully, having privacy respected during examinations and treatment.*
- Prompt attention; *convenient travel and short waiting times.*

- Quality of basic amenities; *surroundings, cleanliness of facilities and having enough space.*
- Access to family and community support; *contact with outside world and maintenance of regular activities, family and friends can easily visit.*

Although the main focus of the framework was to capture responsiveness and not specifically PCC, it still presented several domains that were similar to the frameworks presented by Gerteis, Picker and IoM (such as communication and support and access). In addition to these, the WHO framework highlighted additional domains, such as choice, confidentiality and dignity, which may be of importance to delivering PCC.

World Health Organisation (WHO) 'General Principles of Good Chronic Care' (2004)

In 2004, WHO presented one of four modules prepared by the Integrated Management of Adolescent and Adult Illness (IMAI) team, covering general principles of good chronic care that are relevant to the management of all chronic conditions. In the document, it is proposed that the following principles can be used in managing many diseases:

- Develop a treatment partnership with your patient.
- Focus on your patient's concern and priorities.
- Use the 5A's: Assess, Advise, Agree, Assist, and Arrange.
- Educate patient on disease and support patient self-management.
- Organise proactive follow-up.
- Involve "expert-patients", peer educators and support staff in your health facility.
- Link the patient to community-based resources and support.

- Use written information – registers, treatment plan, treatment cards and written information for patients – to document, monitor, and remind.
- Work as a clinical team.
- Assure continuity of care.

Although not specified as a framework and intended to interim guidelines for first level facility health workers, it is the only set of domains identified by this synthesis that focuses on chronic care. In addition, the principles covered by this document are similar to those of patient experience and PCC.

3.3.2.3 Frameworks of patient-centred relationship with health professionals

A number of frameworks have attempted to specifically define the patient-centred relationship between healthcare professionals and patients. These frameworks focus less on the structural aspects of care (e.g. environment and access to care) and instead offer a greater insight into the interactions that patients have with health professionals.

Stewart et al. (1995)

In 1995, Stewart, Brown, Weston et al. presented six interactive components of the patient-centred clinical method that aim to clarify important factors in effective clinical care:

- Exploring both disease and the patients' illness experience.
- Understand the whole person.
- Finding common ground regarding management.
- Incorporating prevention and health promotion.

- Enhancing the patient-doctor relationship.
- Being realistic.

Mead and Bower (2000)

Also focused on the relationship between patients and clinicians (in particular primary care doctors), Mead and Bower (2000) suggested five conceptual dimensions of patient-centredness:

- The bio-psychosocial perspective; *a perspective on illness that includes consideration of social and psychological (as well as biomedical) factors.*
- The 'patient-as-person'; *understanding the personal meaning of the illness for each individual patient.*
- Sharing power and responsibility; *sensitivity to patients' preferences for information and shared decision-making and responding appropriately to these.*
- The therapeutic alliance; *developing common therapeutic goals and enhancing the personal bond between doctor and patient.*
- The 'doctor-as-person'; *awareness of the influence of the personal qualities and subjectivity of the doctor on the practice of medicine.*

Both frameworks emphasise the importance of understanding the patient and seeing them as a person with an illness or condition, rather than treating just the illness itself. The therapeutic alliance is also a feature in both frameworks, in terms of finding common ground and goals for management. Although the main focus of these frameworks is patient-centred relationships, they were both considered significant contributors to the field of PCC research and included as separate frameworks in the synthesis.

3.3.2.4 Additional frameworks

Several additional frameworks were identified as part of this synthesis that perhaps offer an alternative perspective to the concept of patient experience and PCC.

The SENSES framework (Nolan et al., 2001)

The SENSES framework was originally developed as a means of providing a rationale for care within longer terms institutional settings, but has over the years been adapted for understanding good quality care in acute hospital settings for older people (e.g. Davies et al, 1999). According to Nolan et al., (2003):

> *"The framework captures the subjective and perceptual dimensions of caring relationships and reflects both the interpersonal processes involved and the intrapersonal experiences of giving and receiving care"*

The general idea is that all parties involved in caring for an individual (importantly including professionals care staff) should experience a relation that is supportive and offers a sense of:

- Security; *to feel safe within relationships.*
- Belonging; *to feel part of things.*
- Continuity; *to experience links and consistency.*
- Purpose; *to have potentially valuable goal(s.).*
- Achievement; *to make progress towards desired goal(s).*
- Significance; *to feel that you matter.*

Although it is clear that these experiences do vary across different groups such as patients, carers and family (Davies et al., 1999), they are nonetheless the fundamental basics for building relationships that are nourishing for all individuals involved. In addition, the framework places great emphasis on purpose and achievement, which is something that is not widely covered by other frameworks. It was therefore included in the synthesis.

National Health Council (NHC, 2004)

The National Health Council (NHC) is a not for profit US based association of health organisations, including the American Cancer Society, the American Health association, the American Diabetes Association and the Alzheimer's Association. The mission of the NHC is described as the following:

> *"To provide a united voice for the millions of people living with chronic diseases and disabilities and their family caregivers. The NHC envisions a world in which all people receive health care that meets their personal needs and goals."*

In 2004, the NHC presented three themes and three principles of PCC (IAPO, 2005). The council defined PCC as the following:

> "*Patient-centred care is quality health care achieved through a partnership informed and respected patients and their families, and a co-ordinated health care team."*

The three themes of PCC were stated as the following:

- Care over time that involves the patient's family.

- Information that is shared and accessible.
- Respect for the patient's needs, values and preferences.

The three principals of PCC were stated as the following:

- Patients and their families manage their health care in partnership with co-ordinated health care team that recognises respects and acts upon their goals, needs, values, preferences, cultural wishes, and/or other factors identified by patients and their families.
- Patients and their families receive evidence-based, cost-effective quality care that maximises health, alleviates discomfort and is safe and free from avoidable errors.
- Patients and their families have the ability to obtain and understand health information and services, and make appropriate health decisions.

Although the development work for this framework is not available for review, it appears that the framework was developed based on health outcomes for people with a range of conditions, including LTCs. The framework offers important aspects of PCC involving patients and their families and was therefore included in the synthesis.

Cronin (2004)

In 2004, Carol Cronin (Executive director, Informed Patient Institute) undertook a review of 9 existing concepts of patient-centred healthcare as part of an internal review for the NHC (mentioned on the previous page). The review highlighted a number of frequently occurring dimensions that appeared in multiple definitions, including:

- Education and shared knowledge.
- Involvement of family and friends.
- Collaboration/team management.
- Holistic/sensitive to non-medical or spiritual issues.
- Respect for patient's needs and wants.
- Free flow/accessibility of information.

The work conducted by Cronin was published in the second edition *review of definitions and principles associated with patient-centred health* care by the International Alliance of Patients' Organizations (IAPO, 2007). Although Cronin's report was not fully published and accessible for this synthesis, the IAPO review indicated that 3 of the 9 frameworks which were considered by Cronin included the *Picker/Commonwealth Dimensions of PCC*, the *Institute for Patient- and Family-Centred Care Model of Patient- and Family Centred Care*, and the *Planetree Model of PCC* (the latter two frameworks were excluded from this synthesis but are discussed later in this chapter). The framework offers the additional domain of holistic/sensitive approach to non-medical or spiritual issues and, according the previously mentioned inclusion criteria, it was therefore included in the synthesis.

3.4 Development of an overarching framework of PCC

3.4.1 Development of framework

With a deeper understanding of the domains and concepts behind each of the 10 frameworks included in this synthesis, it was possible to investigate their similarities and differences. This involved reflecting in detail on each domain, what it was aiming to cover and how it was related to other similar domains. Similar domains were then grouped if they were thought to be related, overlapping or covering the same topic. The process of grouping domains was not mutually exclusive and one domain could be part of several different groups.

This was an iterative process and placement of each domain was challenged throughout the process. Supervisors were included in this process and results were frequently discussed with them in order to establish agreement on placement of the domains.

Once domains were grouped together, a common meaning was developed for that group. For instance, all domains that referred to ‘communication’ were grouped together to try and understand what communication means to patients and how communication can be part of PCC. Each group was then considered as an overarching domain of PCC and part of a new framework of PCC.

Each domain was then entered into Table 3. From this process, nine domains of PCC were constructed:

1. Access, availability and choice
2. Information, communication and education
3. Relationship with health professionals
4. Involvement in care
5. Respect and dignity
6. Responsiveness to individual needs and differences
7. Consistency, continuity and co-ordination
8. Effectiveness of treatment and care
9. Physical environment

It is worth noting that, as expected, many of the domains included in this synthesis were similar to each other and overlapping. Some domains also covered several aspects of care and can be interpreted as having more than one meaning. For instance, the domain '*information that is shared and accessible'* can be interpreted to refer to communication, information and access to information and communication. These factors were taken into consideration during the synthesis development of Table 3. Hence, domains that were thought to fit under more than one overarching domain of PCC are presented in *Italic*.

Each domain is discussed separately below in terms of frequency of occurrence and meaning to the framework of PCC.

Access, availability and choice

This domain was covered by 5 of the frameworks included in this synthesis. It refers to availability and access to health care overall, but also to particular aspects of care such as access to information and communication with health professionals. Therefore, there is great overlap between this domain and the domain of 'information, communication and education'. The domain also covers patient choice; to be able to have access to the type of health care or health care provider they chose. In an ideal PCC scenario, a patient would have prompt access to care, healthcare professionals and health care information of their liking with minimal waiting times.

Information, communication and education

This domain was covered by 8 of the frameworks included in this synthesis. It covers aspects of information, including general and basic information about conditions, advice on management and treatment and the way in which the information is shared between health professionals and patients. As mentioned above, access to information, communication and education was reported as a priority for PCC. In addition, this domain is also linked to 'responsiveness of individual needs and preferences' as the amount of information, communication and education required or desired by each patient may vary greatly.

Relationship with health professionals

This domain was covered by 4 of the frameworks included in this synthesis. It aims to capture all aspects of the therapeutic relationship between the patient and the health professionals involved. The main feature of this domain is about understanding the patient as a person and

building a relationship where both the patient and the health professionals feel secure and can contribute to. Of course the opportunity to build a relationship is dependent on a certain level of continuity and access to the same health professionals, but gathering a better understating of a patient also allows for greater respect for their choices and responsiveness to their needs.

Involvement in care

This domain was covered by all of the frameworks included in this synthesis. One of the pre-requisites for PCC is above all that the patient is involved decisions and management of their care alongside health professionals. In addition, it may be important to some patients (not all) to have their family or carers involved in as well.

Respect and dignity

This domain was covered by 8 of the frameworks included in this synthesis. It is about respect for patient choice, needs and preferences. The domain also refers to care received in hospital settings, particularly in cases where patient dignity may be at risk (such as being washed or fed by a nurse).

Responsiveness to Individual needs and preferences

This domain was covered by 7 of the frameworks included in this synthesis. Closely related to the domains relationship with health professionals and respect and dignity, it places emphasis on being responsive to needs and preferences. For instance, some patients may prefer a great amount of information, whilst others are happy to simply not know and just be treated. Equally, some patients may require a great deal of emotional support and it may be important to them to

be treated with compassion by health professionals, whilst others prefer to just deal with the situation by themselves. The domain acknowledges that all individuals are different and equally their health care approach should be tailored to their needs.

Consistency, continuity and co-ordination

This domain was covered by 7 of the frameworks included in this synthesis. This domain is about the way in which health professionals structure care around the patient. It involves planning care, communicating within the team and ensuring smooth transition between services. It is also about offering patients the choice of seeing the same health professionals so that a therapeutic alliance may be achieved.

Effectiveness of treatment and care

This domain was covered by 3 of the frameworks included in this synthesis. Interestingly, effectiveness of treatment (or outcomes of care) was not a major feature of PCC. This is understandable as care can be patient-centred in all aspects but the outcome of treatment may be dependent on other circumstances (such as type of condition and treatments available). Therefore, this domain refers to achievements within healthcare and treatment that are attainable and that have perhaps been set by the patient and health care professional(s) though discussions about what is important to the patient and finding common ground.

Physical environment

This domain was covered by 4 of the frameworks included in this synthesis. This domain refers to aspects of the physical environment such as access to clean facilities and basic amnesties. It also refers to physical comfort of the patients, for instance in a hospital care setting.

Overall, none of the frameworks included all of the overarching domains of PCC. However, there were many similarities between the frameworks and much overlap between their domains.

Table 3. Development of an overarching framework of PCC.

PATIENT-CENTRED CARE									
Frameworks	**Access, availability and choice**	**Information, communication and education**	**Relationship with health professionals**	**Involvement in care**	**Respect and dignity**	**Responsiveness to individual needs and preferences**	**Consistency, continuity and co-ordination**	**Effectiveness of treatment and care**	**Physical environment**
Gerteis et al. (1993) framework of PCC		Information, communication and education		Shared decision making, Involvement of family and friends, I*ntegration of care*	Respect for patients' values, preferences and expressed needs	Emotional support and alleviation of fear and anxiety, Support for self-care	Co-ordination of care, Continuity of care and smooth transition across service boundaries		Physical comfort
The Picker principles of PCC	Access to care	Information, communication, and education		Integration, Involvement of family and friends	Respect for patient-centred values, preferences, and expressed needs	Emotional support and alleviation of fear and anxiety	Coordination, Transition and continuity		Physical comfort
Institute of Medicine (IoM) framework of PCC (2001)		Information, communication and education	*Compassion*	Involvement of family and friends, Integration	*Compassion*	*Compassion*, empathy and responsiveness to needs, values and expressed preferences Emotional support, Relieving fear and anxiety	Co-ordination		Physical comfort
World Health Organisation (WHO) framework of responsiveness(2003)	*Choice,* Prompt attention, Access to family and community support	*Autonomy,* Communication *Confidentiality Dignity*		*Autonomy, Choice*	*Confidentiality Dignity*				Quality of basic amenities

Frameworks	Access, availability and choice	Information, communication and education	Relationship with health professionals	Involvement in care	Respect and dignity	Responsiveness to individual needs and preferences	Consistency, continuity and co-ordination	Effectiveness of treatment and care	Physical environment
World Health Organisation (WHO) 'general principles of good care' (2003)	*Assess, Arrange*	Advise, Educate patient, *Support patient self-management,* Use written information and remind, *Link the patient to community-based resources and support*	Develop a treatment partnership	Involve "expert-patients", *Link the patient to community-based resources and support Support patient self-management,*	Agree	Focus on your patient's concern and priorities, Assist *Link the patient to community-based resources and support*	Organise proactive follow-up, Continuity of care, Work as a clinical team *Arrange,* Assure *Link the patient to community-based resources and support*	*Support patient self-management*	
Stewart et al. (1995) framework of person-centred relationship		*Incorporating prevention and health promotion*	Understand the whole person, Enhancing the patient-doctor relationship	*Finding common ground regarding management*		Exploring disease and patients' illness experience,	*Incorporating prevention and health promotion*	*Finding common ground,* Being realistic *management.*	
Mead & Bower (2000) framework of person-centred relationship			The therapeutic alliance, the doctor-as-person	Sharing power and responsibility	*The patient-as-person The bio-psychosocial perspective*	*The patient-as-person, The bio-psychosocial perspective*			
The SENSES (Nolan, 2001)			Security	Belonging *Significance*	*Significance*	Purpose	Continuity	Achievement	
National Health Council (NHC, 2004)	*Information that is shared and accessible*	*Information that is shared and accessible*		Care over time that involves the patient's family	Respect for the patient's needs, values and preferences				
Cronin (2004) review of PCC	*Free flow/accessibility of information*	Education and shared knowledge, *Free flow/accessibility of information*		Involvement of family and friends	Holistic/sensitive to non-medical or spiritual issues, Respect for patient's needs and wants		Collaboration/team management		

3.5 Excluded frameworks

A few frameworks were excluded from the synthesis, mainly if they were derived from original frameworks (and did not offer additional domains) or if they were adequately covered by a review of PCC frameworks.

3.5.1 Frameworks derived from Gerteis et al. (1993) or the Picker institute

A number of frameworks that were excluded from this synthesis were in some way either related to or drew on Gerteis et al. (1993) framework of PCC. These frameworks were excluded from the synthesis as they did not present any additional domains or further insights into the existing domains of PCC. The excluded frameworks are discussed in more detail below.

Coulter (2005)

As mentioned above, the definition of PCC used by the Picker Institute is based on the elements outlined by Gerteis et al. (1993). Similarly, in a series of articles examining the government's planned market reforms to healthcare provisions, Coulter (2005) described the following healthcare aspirations of patients:

- Fast access to reliable health advice.
- Effective treatment delivered by trusted professionals.
- Participation in decision and respect for preferences.
- Clear, comprehensible information and support for self-care.
- Attention to physical and environmental needs.
- Emotional support, empathy, and respect.

- Involvement of, and support for, family and carers.
- Continuity of care and smooth transition.

Robb and Seddon (2006)

A review by Robb and Seddon on behalf of Effective Practice Informatics and Quality (EPIQ), argued that the phrase "nothing about me without me" articulates the ideal concept of PCC, where patients and health professionals work together as "full partners to design and implement change" (Delbanco et al, 2001). Similar to the review presented by Cronin (2004), Robb and Seddon did not clearly specify which frameworks or concepts of PCC were considered for their evaluation, but rather named The Picker Institute as an inspiration. The review identified the following common concepts of PCC:

- Informing and involving patients
- Eliciting and respecting patient preferences
- Engaging patients in the care process
- Treating patients with dignity
- Designing care processes to suit patient needs, not providers
- Ready access to health information
- Continuity of care

Shaller (2007)

In 2007, the Picker institute commissioned Dale Shaller (Shaller consulting) to investigate nine influential frameworks for PCC in the US (including Picker/Commonwealth Programme for

Patient-centred care, the Institute for Patient- and Family-Centred Care and the Planetree Association). The investigation highlighted six common core properties of PCC:

- Education and shared knowledge.
- Involvement of family and friends.
- Collaboration and team management.
- Sensitivity and non-medical and spiritual dimensions of care.
- Respect for patients needs and preferences.
- Free flow and accessibility of information.

3.5.2 Frameworks reviewed by Cronin (2004)

The following two frameworks, the *Institute for Patient- and Family-Centred Care Model* and the *Planetree Model of patient-centred care* were included in reviews by Cronin (2004) and Shaller (2007). Upon further investigation, it was considered that they did not add any additional domains of PCC and were therefore excluded from the synthesis. These are presented below.

Institute for Patient- and Family-Centred Care Model

Founded in 1992, the Institute for Patient- and Family-Centred Care aims to incorporate the principles of patient and family centred care in all aspects of care for patients, including health care and social care. The institute recognises PCC as an innovative approach to care delivery and highlights the importance of a mutually beneficial relationship between patients, their families and their health care providers. The core concepts of patient- and family-centred care as suggested by the institute include:

- Dignity and respect*; health care practitioners listen to and honour patient and family perspectives and choices. Patient and family knowledge, values, beliefs and cultural backgrounds are incorporated into the planning and delivery of care.*
- Information-sharing; *health care practitioners communicate and share complete and unbiased information with patients and families in ways that are affirming and useful. Patients and families receive timely, complete, and accurate information in order to effectively participate in care and decision-making.*
- Participation; *patients and families are encouraged and supported in participating in care and decision-making at the level they choose.*
- Collaboration; *patients and families are also included on an institution wide basis. Health care leaders collaborate with patients and families in policy and program development, implementation, and evaluation; in health care facility design; in professional education; and in the delivery of care.*

Planetree Model of patient-centred care

Founded by a patient in 1978, the Planetree organisation aims to define the concept of PCC by focusing first and foremost on the needs of patients. Their model of PCC offers a more holistic approach to care that cultivates the healing of mind, body, and spirit (Shaller, 2007). The 9 elements of the PCC model are:

- Explicitly recognising the importance of human interaction in terms of personalised care, kindness, and being 'present' with patients.
- Informing and empowering diverse patient populations though consumer-oriented health libraries and patient education.

- Integrating health partnerships with family and friends in all aspects of care.
- Attending to the nurturing aspects of food and nutrition.
- Incorporating spirituality and inner resources for healing into care of patients.
- Incorporating massage into human touch,
- Incorporating arts (music, visual art forms) into the healing process.
- Incorporating complementary and alternative practices into conventional care.
- Creating healing environments through architecture and design.

3.6 Additional frameworks identified post synthesis

A number of new patient experience frameworks emerged since the completion of the conceptual synthesis. It was necessary to investigate the content of these frameworks and assess whether any additional domains could be added to the synthesis. These frameworks are discussed in more detail below.

NHS Patient Experience Framework (Department of Health, 2012)

Published in 2012, the NHS patient experience framework aims to guide the measurement of patient experience across the NHS. The development work was endorsed by the Department of Health and approved by the NHS National Quality Board (NQB). This framework outlined elements which are considered critical to patient experience of NHS Services:

- Respect for patient-centred values, preferences and expressed needs; *including cultural issues, the dignity, privacy and independence of patients and service users, and awareness of quality of life issues and shared decision making.*
- Co-ordination and integration of care; *across the health and social care system.*
- Information, communication, and education*; on clinical status, progress, prognosis, and processes of care in order to facilitate the autonomy, self-care and health promotion.*
- Physical comfort; *including pain management, help with activities of daily living, and clean and comfortable surroundings.*
- Emotional support; *and alleviation of fear and anxiety about such issues as clinical status, prognosis, and the impact of illness on patients, their families and their finances.*
- Welcoming the involvement of family and friends; *on whom patients and service users rely, in decision-making and demonstrating awareness and accommodation of their needs as care-givers.*
- Transition and continuity; *as regards information that will help patients care for themselves away from a clinical setting, and co-ordination, planning and support to ease transitions.*
- Access to care; *with attention for example, to time spent waiting for admissions or time between admission and placement in a room in an in-patient setting, and waiting time for an appointment or visit in the out-patient, primary care or social care setting.*

Upon further investigation, it appeared that development of the framework was based on previous work by Gerteis, Picker and IoM framework of PCC. Although the NHS patient

experience framework does not add any new or additional domains of PCC, it supports previous findings in this area and presents these in a more public setting.

National Institute for Health and Care Excellence patient experience quality standard (NICE, 2012)

Developed in 2012, the NICE patient experience quality standard aimed to define best practice and provide the NHS with clear commissioning guidance on the components of good patient experience. Interestingly, the development of the NICE quality standard was not guided by Gerteis framework, but was instead guided by the development of a new framework of patient experience; the Warwick Patient Experience Framework (Staniszewska, 2012). The development of this overarching framework included a review of existing patient experience frameworks, a scoping study capturing generic themes and sub-themes of experiences (from 3 clinical areas including cardiovascular disease, diabetes, and cancer), and validity and acceptability testing by the guideline development group.

Similar to this chapter, the framework development adopted elements of a systematic review methodology, including development of search strategies, identification of papers through inclusion and exclusion criteria and extraction of data from identified articles. The key dimensions of the Warwick patient experience frameworks were described as:

- Patient as active participant.
- Responsiveness of services; an individualised approach.
- Continuity of care and relationships.
- Lived experiences.

- Communication.
- Information.
- Support.

These themes provided a basis from which the NICE quality standard was developed. The quality standard presented specific and concise quality statements to provide the public, health/social care professionals, and commissioners with definitions of high-quality care. The list of quality statements included:

- Statement 1. *Patients are treated with dignity, kindness, compassion, courtesy, respect, understanding and honesty.*
- Statement 2. *Patients experience effective interactions with staff who have demonstrated competency in relevant communication skills.*
- Statement 3. *Patients are introduced to all healthcare professionals involved in their care, and are made aware of the roles and responsibilities of the members of the healthcare team.*
- Statement 4. *Patients have opportunities to discuss their health beliefs, concerns and preferences to inform their individualised care.*
- Statement 5. *Patients are supported by healthcare professionals to understand relevant treatment options, including benefits, risks and potential consequences.*
- Statement 6. *Patients are actively involved in shared decision making and supported by healthcare professionals to make fully informed choices about investigations, treatment and care that reflect what is important to them.*

- Statement 7. *Patients are made aware that they have the right to choose, accept or decline treatment and these decisions are respected and supported.*
- Statement 8. *Patients are made aware that they can ask for a second opinion.*
- Statement 9. *Patients experience care that is tailored to their needs and personal preferences, taking into account their circumstances, their ability to access services and their coexisting conditions.*
- Statement 10. *Patients have their physical and psychological needs regularly assessed and addressed, including nutrition, hydration, pain relief, personal hygiene and anxiety.*
- Statement 11. *Patients experience continuity of care delivered, whenever possible, by the same healthcare professional or team throughout a single episode of care.*
- Statement 12. *Patients experience coordinated care with clear and accurate information exchange between relevant health and social care professionals.*
- Statement 13. *Patients' preferences for sharing information with their partner, family members and/or carers are established, respected and reviewed throughout their care.*
- Statement 14. *Patients are made aware of who to contact, how to contact them and when to make contact about their ongoing healthcare needs.*

After further consideration and discussion with an advisory panel (including supervisors), the Warwick framework of PCC was excluded from the synthesis as it was not considered to add any new domains of PCC to existing findings. Nevertheless, the domains presented by the framework were considered to fit within existing proposed domains of PCC.

3.7 Revision and final framework of patient-centred care

The findings from the synthesis (table 3) were presented to an expert panel (including supervisors) with specialist expertise in the area of primary care and public health for feedback. After some discussion, it was considered that the domain on physical environment may not be an integral part of offering PCC, but instead reflects the 'transactional' quality of structures and processes in hospitals settings. For instance, aspects of the 'environment' (e.g. cleanliness, availability of staff etc.) appears to be an important component of patient experience, but the key aims of a patient-centred approach might be to provide more holistic care, increase patient satisfaction and reduce anxiety levels (Dewing, 2004; McCormack & McCance, 2006). As a result, the domain of physical comfort was excluded from the final overarching framework of PCC.

The final framework is presented in Table 4 below. It must be clarified that, as expected, the framework does not offer any new or additional domains to what is already presented in the literature and policy. Instead it draws together a more comprehensive vision of PCC than any individual framework.

Table 4. Final framework of patient-centred care.

Patient-Centred Care
• Access, availability and choice • Information, communication and education • Relationship with health professionals • Involvement in care • Respect and dignity • Responsiveness to Individual needs and preferences • Consistency, continuity and co-ordination • Effectiveness of treatment and care

3.8 Discussion

3.8.1 Summary of main findings

The method of conceptual synthesis was used to identify and review existing domains of patient experience and PCC. The combined bibliographic and hand searches identified a total of 15 frameworks, of which 10 were included in the synthesis. There were 4 main groups of frameworks; those derived from Gerteis framework of PCC, frameworks presented by WHO, frameworks of patient-centred relationships and additional frameworks of patient experience that offered an alternative perspective to health care delivery. Many of the included frameworks reviewed were based or derived from Gerteis framework of PCC, a framework that still holds much value and influence in this field of research and policy.

Further interpretation of these frameworks in this chapter revealed that many of them lacked appropriate development work i.e. the involvement of appropriate patient groups and health care professionals in the development phase of the framework. Indeed, it was often not clear how domains of a framework were generated and the types of validation work that were carried out in order to establish the framework as conclusive and comprehensive. As a result, many of the frameworks appear to lack depth and do not fully address experiences of care of PCC that could be important to patients and health care professionals alike.

Overall, the frameworks included in this synthesis shared many of the same concepts and domains of PCC. The results of the synthesis yielded an overarching framework of PCC consisting of 8 domains which are considered important in the delivery of PCC to

all patients. The synthesis did not identify any additional framework of PCC, but excluded some aspects of structure of care that were considered less important in PCC services.

3.8.2 Strengths and limitations

The conceptual synthesis used a systematic and comprehensive search strategy without any language restrictions. Full-text versions of articles, papers or reports that were felt to be relevant were obtained and reviewed, even if they development of presentation of a framework was not mentioned in the aims. However it was not always possible to access relevant reports, particular if they were only internal findings presented to local government agencies.

The main limitation in conducting this review was the identification of relevant frameworks. The original bibliographic search did not identify many frameworks of patient experience and PCC; however this is believed to be due to the fact that many frameworks were presented in policy documents or public reports, and therefore not identifiable through standard database searches. In addition, the majority of frameworks included in this synthesis were based on generic findings of PCC and it was only possible to examine one framework specific to care for people with LTCs.

3.8.3 Conclusion

The main aim of this chapter was to identify existing frameworks of health care delivery and, through the process of conceptual synthesis, explore the possibility of combining these frameworks into an overarching framework of PCC. This chapter has provided an

overarching framework of PCC which will be used to inform subsequent stages of the thesis.

It must however be noted that this framework and its domains were derived from generic frameworks of patient experience and PCC, often drawn from hospital care, and therefore may not specifically apply to care for people with LTCs. Nevertheless, the 8 emerging domains provide a strong conceptual basis for PCC overall. The next step was to investigate how these findings compared to what people with LTCs believed to be important about their care. Chapter 4 examines this through secondary analysis of qualitative patient interviews.

4 Secondary Analysis of Qualitative Interviews

4.1 Introduction

4.1.1 Background and rationale

The conceptual synthesis (chapter 3) highlighted a generic overarching framework of PCC consisting of 8 domains. However, the conceptual synthesis did not identify any LTCs specific frameworks of PCC. It can be argued that care for people with LTCs is inherently different from the management of acute episodes of care. Consequently, the domains identified from the synthesis may not be fully applicable to the healthcare needs of people with LTCs.

Many of the frameworks identified in the synthesis were developed with the help and input of patients and their families. Similarly, the development of a LTCs specific framework of PCC should include the views and experiences of people with LTCs, particularly in terms of what they believe is important about their care. It was possible to pursue this aim through secondary analysis of interviews with people with LTCs conducted by the Health Experience Research Group at University of Oxford.

The function of the secondary analysis of patient interviews was to enable an independent investigation of a new research question that differed from the questions pursued in the primary study. This process was conducted through the mode of 'informal data sharing' where the data was obtained directly from the primary researchers/organisation (the Health Experience Research Group) by request of the independent investigator (Heaton, 2004).

This chapter presents what a broad sample of people with LTCs believed to be important about their health care from personal experiences. An additional aim was to evaluate whether the findings from the analysis of patient interviews would differ from the domains identified in the conceptual synthesis and if so, how they differed.

4.1.2 Objectives

The specific objectives of this chapter were:

1. To conduct secondary analysis of qualitative interviews with people with LTCs to identify domains of PCC.
2. To evaluate how the domains derived from secondary analysis differ from the domains derived from the conceptual synthesis.
3. To use these findings to inform the development of a PCC experience questionnaire for people with LTCs.

4.2 Methods

4.2.1 Primary data set

The primary data set was a collection of relatively unstructured narrative interviews with people with LTCs throughout the UK. The interviews were conducted by researchers from the Health Experience Research Group at the Nuffield Department of Primary Care Health Sciences, University of Oxford.

Recruitment

Recruitment was conducted through a number of different routes including GPs and hospital consultants, support groups and newsletters, advertising in the press and on websites and by word of mouth. Patients were given a recruitment pack containing additional information about the project and asked to reply if they were interested in taking part.

A 'purposive/maximum variation sampling' (Patton, 1990; Coyne, 1997) approach was adopted, meaning that the researchers continued to collect interviews until it was considered that the findings had adequately represented core experiences of people within the UK. This method also helped ensure that the interviews captured a wide range of experiences and views from people with a variety of backgrounds.

Interview preparation

Before interviews commenced, information regarding that specific condition was gathered by the researchers. This was obtained from a variety of sources such as published books, papers and reviews of clinical evidence and from an advisory panel. The preparation process ensured that relevant issues for that particular condition were included in the interview guide and also helped in the identification of sample population that will were included.

Interview process

Approximately 40-50 patients were interviewed for each condition. All interviews were audio recorded for analysis and if the respondents were happy to consent, interviews were also video recorded.

The interviews were open-ended and usually consisted of two parts. The first part was unstructured and respondents were asked to tell their story without prompts and interruptions from the researcher, enabling them to tell their own accounts and raise things that matter to them. In part two, the researcher pursued the interview by asking additional questions, often prompted by issues that the respondent raised earlier or sourced from previous literature reviews. Consistent with good qualitative research practice, the interview guide was adapted and refined based on discussion about the emerging themes from the initial interviews. This interaction between collecting and analysing as well as the generation of new ideas enabled the researchers to fully explore important issues in the respondents' stories.

Each study was supported by an expert advisory panel (including patients, health professionals and researchers with a special interest in the topic) that provided advice to the researchers throughout the project. These steps and the process of analysis are described in detail in Ziebland and McPherson (2006).

Once the interviews had been fully transcribed, they were returned to the respondents for a review. Participants were given the opportunity to take out sections of their transcript that they did not wish to share. Consequently this was removed from the final version of their transcript.

Data sharing

Upon agreement of the respondents, the transcripts were made available to researchers/academics at the University of Oxford, and other universities under licence

from Oxford. This approval allowed for the material to be used for teaching, broadcasting, research, and other publications. Summaries of findings and extracts from the interviews are available online and contribute to the collection of 'Health and illness experiences' on the Health Talk website which is run by the DIPEx charity.

4.2.2 Selection of long-term conditions

Five LTCs were included for secondary analysis; rheumatoid arthritis, type 2 diabetes, asthma, heart failure and epilepsy. These were chosen from a number of conditions available from the primary dataset.

The selection process aimed to include a range of LTCs that were considered to offer contrast in terms of severity of disease, urgency of health care and types of impact. For instance, the experience of pain is well known to patients with rheumatoid arthritis and is a factor that affects daily living. Pain is less spoken of in type 2 diabetes where patients are much more prone to discuss their diet and exercise regime.

Treatment for these conditions may also vary from on-going (e.g. type 2 diabetes) to episodic where it may not be necessary to take medication at all times (e.g. asthma). However, the LTCs included in the analysis are all common conditions that have a great impact on patients and the health care system. This rationale allowed for the selection of LTCs that were considered to provide a diverse range of experiences. The first twenty interviews of each condition were selected and analysed, giving a total pooled sample of 100 interviews. This was conducted to achieve a form of random selection of interviews and to avoid possible selection bias.

4.2.3 Respondents

Table 5 presents respondent demographics in more detail. Of the 100 patient interviews included in the secondary analysis, 44 were male and 56 were female. All respondents were over the age of 18 years and the mean age was 54.1 years. Patients with Epilepsy had the lowest mean age at 40.3 years and patients with heart failure had the highest mean age at 70.7. Overall, 70 patients were of white (British, Irish and other European) ethnicity, 3 were white other, and 3 were Asian (including Pakistani and Punjabi). A total of 66 patients were married, 2 had long-term partners, 18 were single, 6 were divorced, 1 was separated, and 4 were widowed. Wide ranges of occupational status were reported, ranging from professionals and semi-skilled to manual occupations.

Table 5. Patient characteristics for qualitative interviews.

	Rheumatoid Arthritis n=20	**Type 2 Diabetes n=20**	**Heart Failure n=20**	**Epilepsy n=20**	**Asthma n=20**	**Total**
Sex						
Male	5	12	13	9	5	44
Female	15	8	7	11	15	56
Age (at interview)						
<50	6	3	1	15	8	33
>50	14	17	19	5	12	67
Mean	54.1	59.1	70.7	40.3	46.4	54.1
Ethnicity						
White (British, Irish, Other)	17	16	17	-	20	70
White/Other	3	-	-	-	-	3
Asian (Pakistani, Punjabi)	-	3	-	-	-	3
Not completed	-	-	3	20	-	23
Marital status						
Married	16	14	18	9	9	66
Partner	1	1	-	-	-	2
Single	-	1	-	9	8	18
Divorced	1	2	-	1	2	6
Separated	-	1	-	-	-	1
Widowed	1	1	2	-	-	4
Not completed	1	-	-	1	1	3

4.2.4 Analytic approach

Secondary qualitative analysis is an increasingly used approach in social research. It involves using pre-existing data (e.g. from archives or from researchers own back catalogue) that has originally been collected for other research purposes (Miller, 1982; Dale et al., 1988; Heaton, 2004). This is often conducted to investigate a new research question and the new investigation may be led by the original researcher(s) or an 'outside' researcher with no involvement in the primary research.

As mentioned earlier, the function of the secondary analysis in this case was to enable an independent investigation of a new research question through the mode of 'informal data sharing'. According to Heaton's (2000) five categories of secondary analysis presented in Table 6, this study falls into the categories of Supra-analysis, Amplified analysis and Supplementary analysis.

Table 6. Types of secondary analysis of qualitative data (Heaton, 2004)

Supra analysis	Transcends the focus of the primary study from which the data was derived, examining new empirical, theoretical or methodological questions.
Supplementary analysis	A more in-depth investigation of an emergent issue or aspect of the data which was not considered or fully addressed in the primary study.
Re-analysis	Data re-analysed to verify and corroborate primary analysis of qualitative data sets.
Amplified analysis	Combines data from two or more primary studies for purposes of comparison or in order to enlarge a sample.
Assorted analysis	Combines secondary analysis of research data with primary research and/or analysis of naturalistic qualitative data.

The method of 'Supra Analysis' is used when the aims of the primary study are transcended. In this instance, the primary consisted of open ended exploratory

interviews with people with LTCs. The process of supra analysis involves examining the data from a new perspective with the investigation of new theoretical, empirical and methodological questions. In this chapter, the interviews were approached with the intention to collect personal experiences of PCC, which differed from the purpose of the primary data collection.

The use of 'amplified analysis' was included to re-use several different data sets for examining common or divergent themes across the different populations. This method allows for comparison of PCC themes and aids in determining whether these themes are consistent across the range of LTCs.

It can be argued that the analysis also contained elements of 'supplementary analysis' as it involves more in-depth focus on several emerging themes and issues from the primary data collection. The purpose of the primary research was more wide ranging and it is possible that some issues may not have been dealt with in depth. Even though the primary research was not designed to address these issues directly, it is possible that the two approaches may have overlapped and that some attention was given to these topics. Nevertheless, these topics will be further investigated by the secondary analysis and therefore extending original findings.

4.2.5 Benefits and disadvantages of secondary analysis approach

There are some potential gains as well as practical problems associated with secondary qualitative analysis. There are conflicting attitudes about the use of secondary qualitative analysis and some argue that it remains problematic and ill-defined (Hammersley, 2010). A great deal of this debate has been in regards to methodological

issues surrounding re-examination of primary data. The two main concerns are generally 'lack of contextual knowledge' and 'fit of data' to the new research question (Savage, 2005; Moore, 2006; Hammersley, 2010). Both of these issues needed to be addressed before commencing with the new research question.

Fit of data

Fit of data refers to the content of the primary data and how relevant it is to the new research question. In this instance, it was necessary to first establish that the data was indeed fit for the requirements of this research. Although the primary interviews were not designed to address PCC issues directly, these interviews were open-ended and aimed to capture a variety of experiences of living with a LTC. This included a great deal of interaction with the health services, especially during the process of diagnosis and treatment. It can also be argued that without directly asking the respondents about their views of PCC (which can sometimes be viewed as an abstract term), they were given a chance to talk about health experiences that are of value and importance to them. Respondents will generally also have been prompted to talk about health experiences as this is a great part of living with a LTC. Before the 100 interviews were selected for secondary analysis, a sample of 20 interviews was randomly chosen to explore fit of data and to ensure that the analysis would produce valuable content. Overall, the general approach of the primary interviews allowed for rich data for secondary qualitative analysis.

Lack of contextual knowledge

Lack of context is another potential issue that may be encountered. This refers to the lack of involvement of the secondary researcher in the primary data collection, which may affect interpretation of the data, and in turn conclusions.

One way that this may be reflected in secondary analysis is that it was sometimes difficult to interpret feelings and expressions through the written word which may have been much more apparent to the primary researcher that was present at the interview. Hence, the written transcript may not offer a full insight into the respondents' story and experiences. However, several patient interviews were video recorded and available from the primary research team. These videos were used during the process of secondary analysis and provided better insight into the experiences of interviewees.

Another way that this may have affected the secondary analysis is through the loss of 'bank of knowledge' by the secondary researcher (West & Oldfather, 1995; Locock & Brown, 2010). This refers to the experience and knowledge acquired by the primary researcher through meeting with each respondent and simply being present in their environment (e.g. meeting with them, sitting in their living room, having a cup of tea etc.). This may have allowed for an affiliation between the interviewer and the respondent, allowing the researcher to acquire knowledge about the respondent and the context of their story. Although this is an experience that can't be replicated by the secondary researcher, the benefit of working closely with the primary researchers may have aided in overcoming this disadvantage and allowed for better understating of the primary data.

Potential benefits

Uncertainties with the use of secondary analysis are well debated; however, Moore (2006; 2007) argues that these issues are not only limited to secondary analysis and that their impact is not as severe, particularly as all study data is established and re-used within the research process. Indeed, once these potential issues of secondary analysis are acknowledged, the benefits of this approach can be discussed. For instance, Savage (2005) argued that:

> *"It is indeed clear that published studies report only a small amount of the relevant data collected, and that there is significant potential for re-analysing material left for other purposes."*

There are several positive aspects that can be associated with this particular method, specifically in terms of time and ethics. For instance, it can be argued that secondary qualitative analysis of already collected data saves considerable time and costs, which can in turn allow for deeper analysis and understanding of the primary data. Neither was it necessary to apply for ethical approval as the interviews were already collected, consented for analysis and approved for sharing. This was not a generic benefit of the primary data, but specific to this thesis.

The positive ethical dimensions can also be applied to the idea of over burdening people by asking them to participate in more research and interviewing, which may not be necessary if there is existing data that is fit for purpose.

Moreover, with access to the original researchers that were involved in the collection and analysis of the primary data, there was a great source of knowledge that could be drawn upon. Indeed, an approachable research team can help with the understanding and interpretation of original data, especially within the process of coding and analysis. In addition, with the availability of some video recordings of interview and the availability of these interviews on the 'Health Talk Online' website, the issues of contextual knowledge may have been counteracted allowing for much better insight into the respondents' expression of their experience.

4.2.6 Data analysis software

The qualitative data software programme NVIVO was used for coding. This is not an automated analysis programme but instead assists with selecting, labelling, linking and organising data segments. It allows the researcher to generate codes (knows as Nodes) and maintains selected text within the relevant codes. When coded, the content of that code can be viewed and used for further analysis.

4.3 Process of secondary analysis

4.3.1 Coding framework

Interviews were coded using a thematic content analysis approach, looking for both anticipated and emergent themes. The primary coding framework consisted of a set of anticipated domains that were identified from the conceptual synthesis, presented in Table **7**. However, the aim was to allow the data to speak for itself, starting from a blank sheet and coding a variety of different experiences.

Table 7. Primary coding framework.

Primary coding framework of patient-centred care
• Access, availability and choice • Information, communication and education • Relationship with health professionals • Involvement in care • Respect and dignity • Responsiveness to Individual needs and preferences • Consistency, continuity and co-ordination • Effectiveness of treatment and care

These domains provided a perspective of what was expected from the secondary analysis based on the existing literature. However, the aim was to not place too much emphasis on the findings from the literature review, but to approach the interviews with a broader view of the definition of PCC. Hence, these domains were compared with what the respondents actually experienced and the framework was expanded and revised as new codes were discovered in the secondary analysis.

This process of constant comparison helped expand the coding framework; comparing codes and examining how these may relate to each other. This was done after each interview and after discussion with supervisors. As new insights were identified, they were linked to the existing framework. Previously coded interviews were re-visited every time new codes were added to the framework in order to capture experiences that were not recorded in the first instance. If the new insights were not compatible, then both the insights and the framework were challenged and revised. Similarly, domains of the framework were challenged if no support was found from the qualitative analysis. This process is described in more detail below.

Codebook

A ‘codebook’ was created for every long-term condition. This document contained all the codes that emerged from that condition and a brief definition. This codebook was updated to include more detail about PCC domains and the addition of ‘inclusion’ and ‘exclusion’ criteria and an ‘example extract’ from interviews. An illustration of a codebook is presented in appendix 3.

Analytic memo

An ‘analytic memo’ document was created for each condition. The document contained a selection of notes e.g. reflections, data connections and hypothesis to help the researcher better understand and think about the data. This was considered to be an integral part of the analytical process and was continuously updated throughout the coding process. An illustration of the analytic memo is presented in appendix 4.

4.3.2 Initial coding

The coding process began with reading a few rheumatoid arthritis transcripts. This was a step to become familiar with the style of the interview and the topics covered. The interviews were transferred into a table in Microsoft which allowed for notes to be made on the right hand side of the text.

Assigning codes

The coding process began instantly and guiding notes were made on the side of each paragraph. Text selected for coding could be as short as a single sentence or even entire paragraphs. The researcher would read the text and consider the respondent to be talking

about a certain experience that they had and code it by assigning it with a name. For example, respondents often talked about the experience of pain caused by their rheumatoid arthritis and this would be coded as ‘pain caused by condition’.

Similarly respondents would talk about ways to relieve the pain, either by medicine or alternative treatments. In this case, the experience could be coded as several different themes such as ‘pain relief’ and ‘medication’ or ‘alternative treatment’. Text segments were not restricted to one single code, but instead were noted as all codes that it would possibly refer to; hence one sentence/paragraph could be coded under several different codes.

Parallel coding with senior researcher

The initial coding process and analysis was discussed with supervisors. It was agreed that one interview should be coded by hand by the researcher and similarly by a more senior researcher from the Health Experiences Research Group. The aim of this process was to ensure that fairly similar codes were being assigned by both researchers (whilst allowing for subjective interpretation) and to allow an open discussion about interpretation and meaning of experiences.

Although some have argued that the inclusion of an additional analyst can improve the consistency or reliability of the analysis (e.g. Waitzkin 1991), the appropriateness of the concept and application of a second pair of eyes in qualitative research is questioned (Armstrong, Gosling, Weinman et al, 1997; Pope, Ziebland & Mays, 2000), specifically when applied to unstructured, interactive interviews where all participants are not asked the same questions (Corbin & Morse, 2003). However, in this instance the researchers

felt that it would be helpful to the process of secondary analysis, especially as the senior researcher was part of the primary research team.

Interview number 6 was selected for analysis. The researcher would read each sentence/paragraph and take time to think about what the respondent was trying to express. The text would be assigned one or several codes on the right hand marginal. At the end of the analysis, a discussion took place between the two researchers to compare notes.

This session was beneficial in many ways. Firstly, it was an opportunity to confirm a number of codes with a senior researcher and this allowed for confidence in analysis. This also allowed for discussion about potentially problematic codes and the meeting helped clarify these and provided better understanding of the coding process.

Similarly, the senior researcher had coded additional themes. This is believed to be mostly due to the different backgrounds of the two researchers (health psychology vs. sociology) which allowed for more codes to be generated. Overall, there was good agreement between the two researchers and most of the codes that were suggested by the senior researcher were included in the analysis.

4.3.3 Development of categories

A total of 20 rheumatoid arthritis interviews were transferred to NVIVO programme where they could be more easily handled and coded. Coding started with interviews 1-5, creating new codes as they emerged. These codes were assigned with an appropriate name. An amount of text that was thought to refer to a particular experience would be

selected and dragged to the appropriate code[11]. This would contain the text within that node and allows for it to be reviewed at a later date. Specific attention was given to experiences of receiving health care or interactions with health care professions and any findings were referred back to the coding framework. Interviews 6-10 were also coded using this method.

The codes covered many aspects of living with rheumatoid arthritis. Many of the domains of the primary coding framework were confirmed in the coding process and a number of codes were expanded to include sub-codes. Some codes were merged together (as they were thought to be capturing similar experiences) and some were expanded with the addition of new codes. After coding 10 interviews, the codes were grouped into categories[12]. This process provided more structure and gave better understanding of the codes.

This set of categories was then applied to the rest of the 10 rheumatoid arthritis interviews. However, new codes were added if they had not been captured previously and thought to be relevant. Coding of the subsequent 10 rheumatoid arthritis interviews added little in terms of new codes; generally information would fall into the codes discovered in the first few interviews. Table 8 presents a list of codes and categories identified from 20 rheumatoid arthritis interviews. The process and list of codes were discussed further with supervisors before coding further interviews.

[11] Codes were created as 'free nodes' in Nvivo

[12] Known as 'tree nodes' in Nvivo

Coding of type 2 Diabetes

After discussion with supervisors, it was agreed that the coding process should be repeated with the first 10 type 2 diabetes interviews. This meant starting again with the primary framework, coding all experiences and later building structure with categories.

Similar codes to those captured from the rheumatoid arthritis interviews also emerged during coding of type 2 diabetes interviews as both sets of patients were found to have much in common. Where they did differ was mostly in regards to condition specific effects and needs of each condition. For instance, ‘pain’ was shown to be a great influencing factor in patients with rheumatoid arthritis and had great effects on treatment and medication. However, this was not the case with patients with type 2 diabetes; instead ‘diet’ was frequently discussed as a way of maintenance and treatment.

Table 8. List of codes and categorised extracted from rheumatoid arthritis interviews.

Diagnosis

- Early signs of illness
- Process of diagnosis
- Doctor could not identify illness
- Doctor uncertain about condition
- Wrong diagnosis
- Feelings about diagnosis
    - Relief over diagnosis
    - Relief that condition is not worse

Treatment

- Medication
    - Improvement due to medication
    - Medication side effects
- Surgery
- Pain control
- Side effects of treatment for condition
- Alternative or related treatments

Impact of condition

- Mental health
    - Irritation over loss of ability
- Physical health
    - Condition inhibiting physical activity
- Work
- Loved ones
- Changes in daily activity
- Causing financial issues

Support

- Family and friends
- Local council
- Other patients
- Arthritis support groups

Family

- Support from family and friends
- Family involved in care
- Family adapting to changes

Research

- Own research

Living with disease

- Acceptance of condition
- Appreciating own health
- Coping
- Self-management
- QoL
- Humour
- Loss of independence
    - Feeling guilt over dependence
- Pain caused by condition
- Use of aid
- Diet
- Exercise
- Seeking normality
- Preparing self mentally for future
- Private about condition

Worry

- Future (general)
- Future health conditions
- Medication

Interaction from health services (PCC?)

- Access, availability and choice
- Communication
- Information and Education
- Relationship with health professionals
    - Belief/Trust/Risk, Disagreement, Empathy/Compassion
    - Support from health professionals
- Involvement in care
    - Choice/decision making
    - Patient/family involvement
- Respect and responsiveness to individual needs and preferences
- Consistency, continuity and co-ordination
    - Monitoring health
- Effectiveness of treatment and care

Furthermore, pain often resulted in patients with rheumatoid arthritis seeking more help and having more frequent interactions with health professionals, whereas type 2 diabetes patients were often self-managing their condition with the help of their diet. These issues quickly became apparent through the use of analytic memo document.

After the first 10 type 2 diabetes interviews were coded, the results were again discussed with supervisors. It was agreed that many similar codes and categories had emerged from type 2 diabetes and rheumatoid arthritis interviews and that future coding should focus on capturing the category of PCC. This required a revision of the coding framework which was then applied to the subsequent 10 type 2 diabetes interviews as well the three remaining LTCs.

4.3.4 Revised coding framework

The coding framework was revised after coding of 30 interviews (20 rheumatoid arthritis and 10 type 2 diabetes interviews). The framework revision was influenced by the codebook and the reflection and notes document, but also discussion with supervisors. It was agreed with supervisors that coding of the remaining interviews would only focus on capturing experiences of PCC. There was a discussion as to which categories should be considered under the umbrella term of PCC and what these categories were aiming to cover.

After some reflection on the codes and the content of the patient interviews, it was felt that people with LTCs placed a great deal of emphasis on interactions with health professionals. For instance, many of the codes relating to receiving health care were about communication, involvement and relationship building with health professionals.

Similarly, the outcome of care was talked about in terms of monitoring and maintenance of condition with the aid of health professionals, rather than outcomes of surgery for instance.

The new framework consisted of 7 codes and further sub-codes (Table 9). Many of the codes were similar to those identified in the conceptual synthesis, however, some codes were merged and some were expanded. For instance, the domain 'communication' is often reported in the literature alongside the domain 'information and education' as the two are thought to be similar and overlapping (IoM, 2001; Goodrich & Cornwell, 2008; Coulter et al., 2009). However 'communication' and 'information and education' were kept separate during the coding and analysis to gather better insight into each one independently.

The codes 'respect and dignity' and 'responsiveness to individual needs and preferences' were merged into one code; 'respect and responsiveness to individual needs and preferences'. It was felt that people with LTCs talked about respect and dignity in a different way. Respect and dignity were still important factors, but more in terms of respect for choices and individual preferences (e.g. management of treatment), rather than the more common care assumptions of dignity as privacy and personal bodily care. The word 'dignity' was never used in the interviews and may have little resonance for people with LTCs. However, the basic concept is still important and is believed to manifest in a different way for people with LTCs as discussed above.

The code 'involvement in health' was dissolved and instead included as a sub-code under respect and responsiveness to individual needs and preferences' and

‘communication’, and ‘information and education’. It was felt that involvement in care is an essential part of PCC and as it is integrated into many different aspects of care, it would be good to code it in with some context (e.g. involvement through communication).

The new coding framework was applied to the 3 remaining conditions; heart failure, epilepsy and asthma. No changes were applied to this framework during the subsequent coding process.

Table 9. Revised Coding Framework of patient-centred care.

Patient-centred care

• Access, availability and choice
  o Access to care and communication
  o Availability of health professionals
  o Choice of care provider
 	
• Communication
  o Access to communication
  o Communication/presentation style
  o Exchange of information
  o Involvement in care
 	
• Information and education
  o Gathering information (e.g. research)
  o Conflicting information
  o Lack of information
  o Quality of information
  o Consistent information
  o Management of information
  o Involvement in care
 	
• Relationship with health professionals
  o Disagreement
  o Trust/belief/risk
  o Support and encouragement
  o Patience
  o Empathy and compassion
  o Support from health professionals
 	
• Respect and responsiveness to individual needs and preferences
  o Involvement in care
  o Choice and control
  o Patient family/carer involvement
  o Health professional involvement
 	
• Consistency, continuity and co-ordination (also between different parts of service)
  o Monitoring health
 	
• Effectiveness of treatment and care
  o Maintenance and control (of condition)
  o Expectations
  o Competence of health professionals

4.3.5 The OSOP tool

Once the coding framework had been revised and all the interviews had been coded, 'One Sheet Of Paper' (OSOP) was used for further in depth exploration of codes extracted from patient interviews. The central question to the analysis was:

'What do people say about aspects of PCC?'

OSOPs are widely used by researchers at the Health Experiences Research Group at University of Oxford (Ziebland & McPherson, 2006). It is a tool that can be used by qualitative researchers in order to help clarify codes and link concept together. The process is similar to that of a visual mind-map technique where the researcher creates a 'visual representation' of the data on a single page. This analytic process allows the researcher to unpack and link common patterns and themes within the existing data whilst generating new insights, meaning and understandings.

An OSOP was created for 5 of the 7 codes in the revised coding framework. These included; communication, information and education, relationship with health professionals, respect and responsiveness to individual needs and preferences, and consistency, continuity and co-ordination. An OSOP was not created for the codes 'access, availability and choice' and 'effectiveness of treatment and care' as it was thought during the final coding process that these concept were adequately captures in other codes.

A NVIVO report was generated for each code, which contained all the related text. This text was them summarised into an OSOP. Each OSOP explored and unpacked each code (e.g. communication) and various sub-codes (e.g. access to communication). It was

then possible to link and group codes into broader ‘themes’ to tell a story about common patterns and themes. This processes also ensured that all coded data were considered in the analysis, which is significant to the method of qualitative research (Miles & Huberman, 1994). An illustration of an OSOP is presented in Appendix 5.

4.3.6 Generic results and revision of analysis

Findings from the OSOP suggested that a great amount of the generated themes were similar to those reported in existing literature and PCC frameworks, as we might expect. It appeared that many of the things that matter to patients with LTCs are general issues that matter to a broad range of patients.

For instance, communication emerged as an important theme both in the conceptual synthesis and in the secondary analysis. A range of presentation styles were mentioned by patients, such as gentle, forceful, tactful, blunt, honest and patronising. Patients varied in their preference for presentation style; some patients preferred health professionals to be honest and blunt whilst others appreciated a gentler approach. Not surprisingly, patients clearly preferred health professionals who showed interest in them and their condition and mentioned several characteristics of an engaged health professional, which included:

- Allowing time for patients to ask questions and voice concerns.
- Paying attention to what the patient is saying (e.g. listening to concerns/making eye contact).
- Willingness to explain and clarify/ensuring that information is understood.
- Relieving worries and fears.

It can be argued that these findings are likely to be important to many patients, but may hold a different meaning or weight of importance for those with LTCs. Another example is having a good and respectful relationship with your health professional, which is again likely to be important to many patients, but for those with LTCs the long term nature of their encounters with healthcare may make the quality of that relationship much more important than for those who see a doctor only occasionally. In other cases, these experiences are more exclusively related to LTCs.

It is perhaps not surprising that the analysis generated many similar themes to those reported in existing PCC frameworks. Many of these themes may ultimately be important to all patients receiving medical care and not just to patients with LTCs. Nevertheless, the results from the analysis provided confirmatory evidence for existing PCC frameworks and empirical evidence that have previously been reviewed in the introductory chapter.

However, it can be argued that some of the themes covered in PCC frameworks are too generic for care for people with LTCs, particularly as they were not specifically developed for people with LTCs. Therefore, it was considered that further steps in the analysis should focus on how these generic PCC domains differ or are interpreted in the context of LTCs. The purpose of the exploratory analysis was to tease out themes that are not currently captured by PCC frameworks and perhaps hold a distinctive meaning when applied to care for patient with LTCs, rather than acute or curable conditions.

4.3.7 Exploratory analysis

The purpose of this next step of analysis was to apply a much more focused approach to exploring how the meaning of these themes differ for people with LTCs, compared to those with a curable or acute condition. This was a process of reflection on what health services are expected to do for patients in order to help them live well with their condition.

In the process of exploratory analysis, each OSOP was re-visited to analyse what aspects of PCC are distinctive to people with LTCs. As part of the focused approach, two specific questions were applied:

1. How do these experiences of PCC differ in people with LTCs?
2. What experiences of PCC allows people with LTCs to live well with their condition?

The first filter was to evaluate more specifically how the themes identified from the OSOP differ in care for people with LTCs. For instance, how is 'access to communication' different in LTCs? What does good 'communication' look like in LTCs? For instance, 'no one told me' was a theme that was frequently reported across all aspects of care, but it may be of more importance in the care of LTCs as patients are asked to be responsible for managing their own condition.

The second filter was to appraise the factors that contribute to people with LTCs living in the way that they value (or the way they want to) with their condition(s). It was explored in terms what respondents said and how important their experiences were for the ultimate goal of living well with their condition. These experiences are perhaps even

more relevant to people living with LTCs as they highlight issues surrounding long-term care and quality of life.

The second filter was obtained from Entwistle's paper on experiences of healthcare delivery that matter to service users (Entwistle et al., 2011). In their paper, Entwistle et al. conducted a broad-based review and a critical interpretive synthesis of research literature in order to identify and evaluate experiences of healthcare delivery which matter to people. The 'capabilities approach' (Sen, 2009), was adopted for the analysis to produce a 'conceptual map of experiences of health care delivery'. The conceptual map highlighted several components of what is meant by capabilities that are believed to help enable patients '*to be and do what I have reason to value being and doing, within and beyond my health care encounters*'. These included:

- Live well in the way that I value and that I want to.
- Engaging in meaningful activity in daily life.
- Get the help I need, when I need it.
- Develop my capabilities for autonomy and self-care.

The concept of *'live well with health problems that cannot be fully cured'* was considered to be particularly relevant to the ultimate goal and outcome of care for patients with LTCs. This statement encapsulates themes such as coping, hope, enjoyment and most importantly quality of life. With this insight, it was decided that the exploratory analysis would filter the analysis with the capabilities approach, which would also help distinguish experiences of health care delivery that matter to patients with LTCs.

The inclusion of both filters in the more focused approach provided a better insight into the lives of people with LTCs and helped evaluate the idea of 'living well with my condition' (which may differ from the perspective of health professionals).

4.3.8 Themes generated from the analysis

Several themes of PCC emerged from the analyses that were considered most important to people with LTCs. The final list included:

- Methods of communication, exchange and co-ordination in care for people with LTCs.
- Consistent and tailored information that supports education in LTCs.
- Respectful partnership with health professionals in LTCs.
- Involving patients, respecting their decision and responding to individual needs and preferences in LTCs.
- Continuity, consistency and co-ordination of care in LTCs.

The above themes focus on how health care services can support patients with LTCs to achieve the best outcomes for them. This is about ways in which patients learn to live well with their condition and how they go about finding strategies to maintain their quality of life. In the setting of LTCs, there may not be clear improved health outcomes in the same sense as in other areas of health.

Consequently, what is discussed formally in terms of outcomes in previous PCC frameworks is not necessarily very helpful in care for patients with LTCs. Best outcomes may also differ from what is described in standard

textbooks/guidelines/policy, and is perhaps more about what the individual patient believes to be the best outcome for them.

4.4 Results

This section summarises the results from the secondary analysis of qualitative interviews. Results are presented separately for each theme (see methods). These sections aim to discuss experiences that are particularly important or relevant in care for patients with LTCs. Some of these experiences will of course also apply to general care, but perhaps carry a different value or meaning when applied to long-term health care.

4.4.1 Methods of communication, exchange and co-ordination in care for people with long-term conditions

Good communication is an essential part of health care delivery to all patients, but to people with LTCs it is crucial for self-management and treatment. Patients with LTCs often have extensive, long term interactions with different parts of the health services, particularly so if they have co-morbidities.

Information is of course hugely important for how patients understand and manage their condition, but communication is about more than just imparting information and is perhaps more about how patients and health professionals interact, rather than the content of what was said during consultations. It implies something more relational and two-way where health professionals and individual are both involved in exchanging information and sharing decisions. Communication can also cover a wider range of issues, such as the patient's emotional and social needs.

There were two areas of care for patients with LTCs where the meaning of communication was particularly distinct. These were:

- Communication, exchange and co-ordination of information between health professionals
- Having access to alternative methods of communication and interaction (consultations between consultations)

Patients talked about how **communication between different health professionals** affected their experience and their ability to live well with their condition. As patients often have contact with several different parts of the health services, they also rely on these services to communicate and update each other about the patient's condition. Delays in communication between specialists, GPs and other professionals might result in a delay in treatment:

> *I felt "Well, he could have said that [information about starting new medication] over the phone to my GP", "Why I waited all this time to see him?" "Perhaps I could have started on this earlier?" I just found that aspect of it very frustrating.*
> (Patient with rheumatoid arthritis)

Inevitably, the amount of information and the way in which patients wish to receive it from health professionals will vary. Perhaps what is important in care for patients with LTCs is considering the patient as an expert in their condition and offering them alternative ways of communicating with health professionals, so they have the opportunity to seek information in a way that suits their circumstances and enables them

to live well with their condition. Communication for people with LTCs is therefore not just about how information is presented, but also about alternative means and access to communication when needed.

Exchange and co-ordination of information between health services can give health professionals a 'full picture' of the patient. In turn, the appointment time may be better spent and fewer burdens are imposed on the patient (e.g. recounting their medical history):

> *You get a letter to the consultant, that says "This patient banged her head two weeks ago, investigate please." It should be able to say to the doctor, send some secure email to the consultant saying "This woman has a history of X, Y and Z, she has now banged her head, da, da, da, she is allergic to whatever," so they have the full picture and you don't have to spend three appointments redoing your stuff, which another part of the hospital has already got it anyway. It's so bizarre.* (Patient with epilepsy)

Communication between services can also be helpful during episodes of acute care for patients with long-term conditions. In these instances, it is useful for staff to be aware of the patient's history and existing conditions in order to provide effective treatment:

> *I've now got a yellow community folder which basically is provided by a community matron who, between you and me, is about much use as a chocolate tea pot, and in this folder it's got my management plan, my drugs, all my history and everything in it so I can just give it to the ambulance men. I don't have to,*

they will say, what your date of birth, your address, your phone number or any of that, you just give it to them and say, "It's all in there, all my allergies are in there, contact details of people, everything". The other thing that I've been able to set up since I've been down here is I have a management plan written by my consultant because what's happening was when you go into A&E there's this text book protocol of how you mange an asthmatic and over the years we've discovered, trial and error, what works with me and what doesn't and my consultant's view is why re-invent the wheel? So I now have it written down. It says, when Jenny turns up in A&E you should have done this, this and this, so you should do this, clinically reassess then do this and then reassess and do this, and it's sort of written, and it is slightly different to what the text book for the junior doctor says, but it's what works for me. It has helped because the doctors sort of say, "Oh, you come with instructions". Fair enough just do what it says, it's fine.
(Patient with asthma)

Better communication between health services could also ensure that patients receive **consistent information** about their treatment. This is particularly important for patients who have more than one LTC, but can equally apply when someone has one LTC but may at different times be advised by their GP, a specialist nurse, a consultant, and others such as physiotherapists or pharmacists. Receiving conflicting information about treatment could be especially worrying, as this patient with epilepsy explained:

I take 1000mgs a day and I don't know, it just makes my head feel fuzzy. Also my consultant up in [town] wants me to come off sodium valproate and yet my

consultant psychiatrist here doesn't want me to come off that. So I just wonder why we've got conflict of opinions but nobody, no explanation.

(Patient with epilepsy)

Having access and being able to communicate with health professionals during difficult times was a commonly raised topic. Several alternative forms of communication were mentioned that go beyond the standard face to face consultations. For instance, quick telephone consultations appeared to be particularly important in conditions where the person's health state can change quite rapidly and even become life-threatening (in this instance conditions such as epilepsy, asthma and heart failure), but could also provide on-going support, monitoring and reassurance. In effect, what many patients with LTCs value is the ability to have 'consultations between consultations', both in relation to more urgent matters and for patients who wish to gather more in-depth knowledge of their condition. This can help overcome the limitations and inflexibility of standard consultations. The example below shows how frequent telephone consultations were used for a short period to monitor the effect of changes in treatment with minimum disruption to the person's daily life:

The other thing that he did that was very helpful to me, although I know that other people have a different view, is that we set up a system of sort of telephone consultations. So he would be in touch with me probably once a fortnight, every time he put me on a new inhaler he'd ring me two or three weeks later to see how I was getting on. That worked for me because I was travelling all over the country. So I had consultations with my doctor in coffee breaks during meetings, once when I was on the top a hill in Yorkshire when I was on holiday. That

worked really well. Once or twice when I was really not feeling terribly good he would ask me to go and see him and I would just drop everything and wherever I was and make my way back home and go and see him. As I say, that was helpful.

(Patient with asthma)

Quick consultations can also be an effective method for answering burning questions and simultaneously reduce patient burden (i.e. having to visit the clinic). These consultations were described as helpful for discussing changes in treatment/dosage during different stages of condition:

It's really useful because a lot of times when you're recovering you're like, "Well, am I ready to reduce the doses back down again?" and rather than going into the surgery and waiting and then having a ten minute appointment you can just have a phone call that's like two minutes of, this is how I am, this is how long I've been at this level, is it OK to reduce down? How fast should I reduce it down? How long should I do it over?

(Patient with asthma)

Similarly, several patients talked about having access to health professionals in case they required more information about their condition or treatment. Some patients mentioned that they were encouraged by health professionals to 'get in touch' between consultations and if they had any general or urgent enquiries:

What I think is not always taken into consideration is that people are very anxious when they go to a rheumatology clinic and however hard you try to listen, I think

people forget what they've been told sometimes. Recently I've been to a hospital, which I was extremely impressed by, because on my initial consultation with a surgeon, I was given the name and a telephone number and hours that I could contact a nurse on his team. So that when I got home, and I thought to myself, what did he say about that? How long was it? What would I be doing after I'd had the operation? I had a, a name and a telephone number and days that this person worked and the hours that I could ring and I thought that was fantastic. I probably wouldn't need it, but there are lots of people that I think need that sort of service because you're obviously anxious when you go.

(Patient with rheumatoid arthritis)

Being able to effectively communicate with health professionals is also essential for building a partnership relationship with health providers. For instance, in order to be able to build a relationship that goes beyond standard consultations, a patient first has to be **encouraged and given the opportunity to access health professionals** when needed:

GP and the nurse, they always say, "If you want to know anything, if you're concerned about anything, just give us a phone call. You can come straight in. That's not a problem at all.

(Patient with type 2 diabetes)

There is a degree of trust involved when health professionals offer patients alternative means of communication, such as emails or personal telephone numbers. The benefits are that busy professionals are able to quickly respond to enquiries at a time that is

convenient (to the health professional), something that many patients appreciate:

> *It's just fantastic. I've got a telephone number of her [nurse], including her personal mobile number that I can contact her anytime, and I have contacted her on a Saturday or a Sunday. I've contacted her when I've felt rough on a couple of occasions and she came up to see me here. When I felt I couldn't get the car out and drive down, it's only down the road, but she's been to see me. She's been like an angel, and she said anytime I wanted to speak to her to ring her, it didn't matter when, how, and I say she's been extremely good.*
>
> (Patient with heart failure)

Of course, this process still relies on health professionals being willing to engage in this way, trusting the patient not to misuse this understanding. Equally, providing the patient with alternative means of communication means that the patient feels trusted in the partnership:

I *I suppose the first thing is the medical side, that must be reassuring that you can get hold of him [doctor] as and when? But can you contact him in the middle of the night if you're worried? So there are limits?*

R *There are limits, its only office. I have got a mobile number but it's never been stressed or stated that I should phone at any time, so I don't know if I would be abusing the service. Because maybe like everyone else, when it comes 6 o'clock at night he switches off, he's got a family life. So if I'm in real desperate straits I could phone him, but I have been very lucky with emergency services as well. If*

there is a problem, and obviously I'm not the one that phones it's my wife, she quite rightly explains the situation and then they come quickly.

(Patient with heart failure)

However, alternative ways of communicating with health professionals can also be dependent on the **availability of staff**. Standard consultation times are agreed on in advance whereas quick consultations or response from health professionals can rely on their accessibility and engagements. Being unable to get hold of health professionals can cause deep distress as well as delays in identifying symptom deterioration:

I saw the surgeon again and this was in the February and he told me that I would be in hospital and have my operation before the end of April. In fact, it just went on and on and on. Nothing happened in April, I was told that I could phone and they would give me an update and this went on right until about November. I just got to a point where I knew that unless something was done quickly I just wasn't going to be here. My son was so worried about me that he phoned the surgeon; couldn't speak to the surgeon; spoke to the secretary who said that she would have a word with the surgeon, but she didn't think I would be in hospital before January. So I went nearly a year, again I was in bed most of the time. I couldn't do anything, I was of no help whatsoever and I've always tried to be very positive about the complaint, and I just found that my morale was going down and my son said, 'We can see you deteriorating daily'. So the next thing was I went to the doctor's and I just burst into tears and we went through the rigmarole of 'when did he say you'd be in?' and he said, 'Right. We can't let this go on', 'You go home and I'll ring you later'. But apparently he rang, couldn't speak to the

surgeon because he was in theatre, explained the position to the secretary who said did I mind being in hospital over Christmas? So I said 'no, I didn't because quite frankly the way I feel at the moment I don't think I'll be here at Christmas'.
(Patient with heart failure)

Even though I'd had three flare ups I still feel there's a lot I don't know about the condition, you can only learn so much from the leaflets, you have your own particular questions you need to ask and you might only see them once every 6 months, you've got to ask then when you do. If you miss your chance then there's nobody else you can ask really. My own GP's very good but he's not a specialist in that particular condition so you do feel you need to draw on their knowledge and experience and that's a really important time when you see the consultant.
(Patient with rheumatoid arthritis)

4.4.2 Consistent and tailored information that supports education in long-term conditions

Patients with LTCs are often expected to play an active part in managing their symptoms and medication, and are also more likely to need and want to develop a degree of expertise in their condition. They may therefore require different information to those patients undergoing treatment for more acute illnesses. For instance, for conditions requiring surgery, patients need clear information about risks and outcomes to better reach a decision, whereas information to support self-management is more crucial to patients with LTCs.

As patients with LTCs ultimately have to take care of themselves, it is important to consider not just if information was provided but also whether the content was useful and if it helped patients manage and live well with their condition.

There were five main areas of care for patients with LTCs where information and education were particularly relevant. These included:

- Information (or lack of information) to help patients live well with condition
- Consistent and reinforced information
- Tailored information
- Informed about treatment decisions and changes
- Information about risks/understanding how condition may develop (e.g. symptom change)

Lack of information to support self-management was frequently reported by patients across all five LTCs. Patients often used the phrase ‘no one told me’ when they talked about this topic. This is of course not unique to LTCs; we know there are many cases where lack of information is a problem in healthcare. However, taking an example of appendicitis, provided surgery is performed well and promptly, a lack of information is unlikely to have lasting health consequences even if it may be seen as disrespectful and disempowering. In LTCs, by contrast, a lack of information can cause continuing problems with quality of life and symptom control, and potentially even be life-threatening.

Lack of information also suggests a breakdown in communication; implying that certain topics or issues were either not discussed or not drawn to the person’s attention in a way

they could make sense of. In relation to medication, it may be that the patient experienced side effects which were not explained or communicated to them:

> *The Methotrexate injections actually put me into an early menopause at aged 40. My periods stopped almost immediately after the first injection. Which apparently is not unusual because this is a cancer drug and but no-one really told me that and so I had about 10 years of hot flushes which were fairly unpleasant.*
>
> (Patient with rheumatoid arthritis)

Some patients talked about the reasons behind this perceived lack of communication of information from health professionals. Some suggested that health professionals had simply forgotten to share relevant information or they had assumed that the patient already had this knowledge:

> *The doctor said, 'Of course, you know that you've got asthma?' I said, 'No I don't'. [laughs] So that was four years ago. My doctor told me that there were chest infections. But I don't know, it must have been this asthma I suppose. I used to go to him twice or three times a year for treatment for my chest.*
>
> (Patient with heart failure)

It may be difficult for health professionals to assess information needs of patients and similarly, patients who want to be seen as experts in their condition may also be 'victims' of assumption about their level of expertise. For instance, one type 2 patient talked about how some health professionals assumed that, as someone who had had type

2 diabetes long-term, he already had certain knowledge about possible complications arising from his condition:

I: *When you came back from holiday and asked your GP [about blurred vision], how did they respond when you described your symptoms?*

R: *They were surprised that I didn't realise [that blurred vision was a possible side effect of diabetes]. This led to a few exchange of words to be honest with you, I've got no knowledge of the subject as such but they assumed because I'd been diabetic for a couple of years that I knew this. So whether it was assumptions on their part that they thought that I'd been imparted with this knowledge somewhere along the line or it had happened to me before, but it was a new experience and one I didn't really relish too much. That was probably the way it was meant that it was a wee bit of a surprise in their part that I didn't know what was happening to me, because I was diabetic and that I should know this. So there's a breakdown somewhere in communications.*

(Patient with type 2 diabetes)

In contrast, some patients suggested that perhaps they did not have time to absorb all of the information presented to them (information overload) and that they didn't take it all on board at the time. This also relates to how and when information was presented to patients by health professionals and emphasises the need for information to be re-inforced over time. Information overload may be an issue for patients with acute conditions as well, however, important information about condition and treatment may be more crucial to people with LTCs and vital to their self-management. For instance,

information received shortly after diagnosis can be difficult to absorb and may need re-inforcing over time:

> *I know that generally speaking my GP was very good, calming, explained everything to me several times, very reassuring, but I can't remember any of what he said apart from the fact you've got diabetes. I think looking back I was actually in shock.*
>
> (Patient with type 2 diabetes)

However, lack of information was not always talked about in a negative way and some patients preferred to not be told too much. It is possible that patients who prefer a more paternalistic relationship with health professionals are 'happy not to know' and preferred to leave it up to the professionals to take care of them and their condition:

> *I haven't tried to look it [treatment] up at all. I think sometimes a little knowledge is dangerous, you're better just in the dark and leaving it up to your GP to look after you. If you're happy with your GP it's a big help.*
>
> (Patient with heart failure)

> *I've never thought that I needed it [information about treatment]. Because every time I've been to see the diabetic clinic they've said, "Everything looks fine. You're doing well." So I thought, "If it ain't broke, don't fix it."*
>
> (Patient with type 2 diabetes)

Receiving conflicting or inconsistent information can be confusing and frustrating to all patients, but it may have particular consequences for patients with LTCs. Consistent and reinforced information may be particularly valuable to patients with LTCs as patients have to manage their own condition and vital information about treatment may be forgotten over time. A few patients talked about the advantages of having information reinforced to them by health professionals, and again emphasised at later stages:

> *The diabetic nurse could explain it very nicely. They give you plenty of written information, but there's nothing like someone sitting there and going through your bits and pieces. She explained about what I should be eating, what I shouldn't be eating. She also referred me to a dietician, which was very good. So now every four years I still see a dietician. On top of that I've seen the diabetic specialist nurse at the doctor, who just every now and then reminds you, especially if your weight's gone up a little bit, of why it could have gone up and what to do to get it back down.*
>
> (Patient with type 2 diabetes)

> *When the nurse came up on to the ward and went over it with me, it was extremely good. Right from the word go, she settled me down. She went over everything and then she came back later when I'd came home and went over it again. Because very often, when you are initially diagnosed it is a lot to take in and that second follow up meant that she could re-enforce what she had already told you, or you could ask questions about things you hadn't really taken in at that particular time.*
>
> (Patient with type 2 diabetes)

Lack of **tailored information or recommendations to the patient's individual circumstances** may mean that patients cannot or will not follow the advice of health professionals. One patient with heart failure talked about how he could not follow his doctor's advice as this would mean that he could lose his disability benefits:

> *The sad thing about the whole situation is there's two trains of thought - my cardiologist, my cardiac nurse etcetera, tell me, 'Exercise, go out into the garden, do what you can, push yourself as long as your recovery time is short then that's fine because you'll cope and your heart will go back.' Unfortunately, I'm on disability now because of the state I'm in. If I happened to do what the cardiologist tells me and somebody sees me doing it, they'll take away my disability. It's a real catch 22 and somebody has got to sit down to think about what goes on here. My cardiologist tells me to 'go and pick up leaves', 'dig about the garden if you can', 'do gentle gardening, it'll help you, it'll make your heart work, it will keep your muscles going'. But if the people who pay me disabled benefits see me doing that then I will be put, I will be stamped as 'not disabled' and they will take the benefits away.*
>
> (Patient with heart failure)

One patient with type 2 diabetes remarked on how she had given up on monitoring her diabetes as the recommendation from the doctor was too much to handle:

> *The doctor says that, "Every day you should test your sugar". But I don't do that. He's also given me a book to write in. In the morning, before eating you should*

test your sugar. Then after food, after two hours, you have to check again. (laughs) It's too much for me. So I stopped it.

(Patient with type 2 diabetes)

Another topic that several patients talked about was their desire to be **involved in treatment decisions** and being **informed of changes** to their care. This is particularly important in care for LTCs as treatments plans are likely to change, often as a result of medication side effects or changing symptoms. Of course, this is not just about the patient being told what is going to happen, but more about health professionals providing reasons for decisions and involving patient ins their care:

I sort of didn't feel like I fully understood why things were different or why I was keeping on medication now and hadn't been before. There were probably really good reasons for it but I sort of wanted to know it. Also with the medication, I felt with hindsight, obviously the Methotrexate worked well and there must have been a reason why I wasn't put on that to start with but I don't know why the consultant made those choices and I wasn't in any position to ask about that, I felt. I wouldn't have questioned what he said, he's the expert, but I would have just liked to have known what the reasons for it were rather than just being given the medication. Then obviously if it didn't work another one might have been tried but, why was I given that and not that? I would have liked to have known a bit more about it.

(Patient with rheumatoid arthritis)

I went back to hospital to have an angiogram and they then discovered that I'd got aortic incompetence as well and the plan was that they would replace two valves. But when it came to it, when I actually went in to have it, I had a wonderful surgeon and he said, 'I won't replace either valve if I think that your own valves are stout enough to take you on a bit longer because medical science is just changing so rapidly'. I was young, I think I was about 36 at the time and when it came to it, he didn't replace. He said, 'When I've got your heart in my hand, I'll be able to see exactly what's what and I promise you that I won't put one in unless I really feel that it's the last straw'. So I woke up in the intensive care unit with him sitting on my bed telling me that 'no, he hadn't replaced the valves', that he thought I could go on a bit longer, which I did.

(Patient with heart failure)

Similarly, patients talked about the importance of being informed by health professionals about **future health risks and how their condition may develop over time**. Typically, this involved health professionals proving patients with an understanding of how symptoms may change as the condition progresses and preparing patients for possible future treatments:

He [doctor] said, "You've gone from nowhere to being this very diabetic very quickly. The first few months we were fighting this". He said, "It was progressing and we were battling as, it was changing all the time." He expects that it will progress further in the future, and he expects looking at the medicines he's had to give me, that I will end up being an injector.

(Patient with type 2 diabetes)

Information about the future could also be in relation to life events and choices not directly related to the condition, for instance planning for a pregnancy. As one woman with epilepsy demonstrated, health professionals involved in her care provided her with information and advice about potential side effects of the medication that she was taking at the time:

> *I don't actually really want children in the future but I was told that if I did decide at some point in my life to have children then I would have to come off the medication. Because people on like large quantities of medicine have a higher change of having a child who is slightly deformed or brain damaged.*
> (Patient with epilepsy)

However, there are some difficulties involved in providing patients with information about potential things that may happen in the future. It is of course essential that this information is tailored to the condition and circumstances of each patient, but even then it may be difficult for health professionals to accurately predict what may happen over time. Some patients talked about losing trust in health professionals after re-evaluating the information that they were provided with some time ago:

> *It [diabetes] is progressive and eventually I might have to go onto tablets and eventually might even have to go onto insulin. It might develop into type 1 diabetes. That there's a possibility that my eyesight might be affected, that other parts of the body will be affected, the feet. Which again, having been to the chiropodist and she's looked at the, my feet and said, "They're absolutely fine.*

There's nothing to worry about, nothing to be concerned about." So all these things that I've been told might happen aren't happening. Therefore it makes it more difficult to take it seriously.

(Patient with type 2 diabetes)

The amount of times people, especially doctors, insensitively would say, "most kids grow out of this, you'll have grown out of this by the time you're 14 or 15". I thought, "Well, that's bollocks for a start" [laughs] because you knew that there were kids in the school who were 16 or 17, sometimes who were still really ill and they hadn't grown out of it. Sometimes I felt, and probably was, much more intelligent than the people who were supposedly looking after me.

(Patient with asthma)

4.4.3 Respectful partnership with health professionals in long-term conditions

Whilst having a good relationship with health professionals is of course important to all patients, again patients with LTCs may have distinctive requirements of these relationships. It may be that supporting people to self-manage their condition and develop their own expertise can lead to improved outcomes. But to achieve this requires not only the one-way provision of information (as discussed above) but also the creation of a more equal partnership, in which the professional respects and fosters the individual's expertise, and the individual feels able to call on good, trusted advice and reassurance. Not all people with LTCs will want to play such an active part in their care, but they are nonetheless bound into a long-term relationship with health services because of their condition.

Two major themes emerged from the analysis. These included:

- Respectful partnership (trust in competence of health professional and patient)
- Emotional support and understanding (impact of condition on the patient's life)

Patients frequently commented on characteristics of health professionals. These traits on their own are not particularly important or different in LTCs; however, during the analysis it became apparent that by describing characteristics of health professionals, patients also passed judgement on their **perceived trust in the competence of health professionals**. These comments were of course based on observed competence and not actual measured proficiency of professionals. However, it may be that patients who have become experts in their condition judge competence differently and are in a better position to do so than many other patients:

> *I'm sure that the care teams, both at the GP's and the hospital, would very quickly spot anything that wasn't correct, and either take remedial action or make you aware of it and get you too adjusted in some way.*
>
> (Patient with type 2 diabetes)

> *I've been very lucky with a very honourable doctor, GP. I really would like to thank her very much for all her help and care and attention over the years. I think it must be much more difficult if you haven't got a good relationship with your GP.*
>
> (Patient with epilepsy)

Patients appeared to be talking about a sense of partnership and mutual exchange between them and health professionals. Perceived competence appeared to be related to how much **patients trust health professionals** involved in their care and equally, how much **health professionals trust patients**. But this is a two way relationship; patient trusting professionals (when there is something wrong with their health) to provide the right information and to advice properly, and in turn **health professionals trusting patients** when they say there is something wrong and that they are not managing well:

> *I was taken home in the car, my wife sent for the doctor. The doctor came, which was a trainee doctor. He was just temporary at the practice and he more or less didn't believe me. He was a little bit argy-bargy and he wouldn't give me a sick certificate or anything to explain why I wasn't going to work. My wife got very annoyed with him and she phoned the surgery and we got our own doctor. He came and he said, 'Definitely, there's something', and after having a day's rest he said, 'Do you think you'd be strong enough to come to the surgery for an ECG?' So I said 'yes', so someone had to take me.*
>
> (Patient with heart failure)

A relationship in which patients trust the advice they are given by health professionals is also more likely to lead to greater adherence and improved quality of life and symptom control:

> *I feel if I'd questioned it, I would have had a choice. But I have complete faith in the people that look after me. I've never felt any need. If somebody says to you look this is a hard drug, I think you should take this, or try it on this dose, you're*

going to have to have a blood test every four weeks because I want to monitor the this, then you feel confident about that because you know in four weeks you'll have a blood test and when the results come back, it's going to tell the rheumatologist whether it suits you or not. The way it's been presented to me, has been the correct way, and I've, I've never felt any need to say why, I've just thought, right if you think it's a good idea. It's always been adequately explained to me and I've been quite happy with everything I've taken. Maybe that's not a good thing, but it suited me fine and I've not been let down.

(Patient with rheumatoid arthritis)

Another important aspect of a trusting partnership between patients and health professionals is providing **emotional support and understanding**. Living with a LTC will inevitably have an impact on quality of life. This is about health professionals recognising that living with a LTC is difficult on a personal level and offer realistic, kind advice whilst being supportive, encouraging and reassuring about issues that may affect patients.

My diabetic nurse, she very aware that obviously I am a diabetic, but that I still work, that I have to fit in my family life, that I have to fit in things that crop up unexpectedly. So she's very good, sort of talking to me about that, and giving me advice on how I could deal with different situations, but again without being patronising, which is quite nice.

(Patient with type 2 diabetes)

Really part of this disease is the psychological aspect. But it's almost invariably completely ignored. It is very depressing and you don't feel like doing exercises whereas if you had a physiotherapist say once a month "Come on", "How are you doing?", "What's going on for you?", "Which joints are being a problem this month, or this day, or this week?" "Why don't you try this?" It's much more encouraging to feel that some individual health professional is taking a genuine on going regular interest in me. I don't know how other people feel about it, but just speaking from my own experience.

(Patient with rheumatoid arthritis)

4.4.4 Involving patients, respecting their decisions and responding to individual needs and preferences in long-term conditions

Achieving good outcomes in patients with LTCs is more about controlling or managing the condition rather than curing it. As Entwistle et al. (2011) explains (using a capabilities approach to understand PCC), a good outcome is that which enables the individual to live as well as possible with the condition, to be able to do things they value doing and be the person they want to be. This means that the individual has to be closely involved in defining what is a good outcome for them, given their symptoms, and working out with professionals how treatment can best respond to their individual needs.

The main areas that patients talked about included:

- Control over condition
    - Negotiations and arrangements with health professionals to get the right medication balance

    - Maintaining and improving quality of life as judged by the patient
- Evaluation of current treatment/medication
- Presenting alternative treatments options
- Deep understanding of the patient (my needs - not everyone's the same)
- Monitoring health and altering follow-up times to suit the individual and stages of condition

As mentioned previously, good outcomes in LTCs vary by condition and patient and may not necessarily be a textbook standard. In some instances, a good outcome becomes a trade-off where patients are willing to live with some side effects, as long the effects that impact their quality of life the most are dealt with efficiently:

> *I had been helped by the introduction of a new drug in the early 90s. I was pretty zombified with various different drugs, and Lamictal came on the scene. This drug was the one that changed my life, although it hasn't stopped the fits, I have about a fit every two weeks, it has made life much more bearable in between fits and I am not a zombie anymore.*
>
> (Patient with epilepsy)

By understanding preferences and involving patients in their care, health professionals can gather a better understanding of what is important to the individual person and what they believe is a good outcome for them. Having the right information is an important pre-requisite for patient involvement (see information). However, it is not enough simply to provide information, but health professionals also have to make sure that the patient is involved in the decision making process. There are several ways of doing this

and some patients talked about feeling able to have **negotiations with health professionals** about their treatment:

> *I said to my GP in January, "I want one last try to get these [weight and blood sugar] under control" and he said "Okay, but you've said that before" and I said, "No, I really mean it this time. I will, and then if I don't get it under control, I will start insulin, and you can put that on my card, I will do that" and he let me do that and he hasn't sort of pressured me into stuff that I didn't want to do. The increase of medication has been negotiated.*
>
> (Patient with type 2 diabetes)

> *I think my GP did handle it well, because they were aware of how reluctant I was about taking the tablet, and that's when they did give me the window, saying, "Okay. We'll give you x number of months and if you come back with another chest infection, we'll have to act". I think they were very good and I think they were a bit reluctant too. They didn't want to be just dishing them [medication] out.*
>
> (Patient with asthma)

As shown above, negotiations allow the patient to be involved in their care and have a say in the treatments that they believe work best for them. In this sort of partnership, arrangements about care and treatment can be set up between health professionals and patients. Again, trust and confidence are important factors for both parties (see relationship with health professionals), especially for health professionals to see the patient as an expert and trust them to treat and manage themselves:

I also feel quite lucky about the self-control of my medication, because I think that there's all this stuff about the expert patient and the patient knows best? So I feel quite lucky that I've got a GP that's allowed me to do that rather than having to kind of live with the symptoms or keep having to go back all the time. I have control. I know the minimum but I can then vary the maximum depending on how I feel about it, and I think that's really good, because it does give you some control over what you do and when you do it.

(Patient with asthma)

I regularly have it [joints] monitored at the hospital and x-rayed. The decision there between myself and the surgeon is that if it carries on feeling OK and doesn't change on the x-rays I can carry on indefinitely like that. But if there's any major sign to me that anything's getting worse or if the x-ray shows more damage, then I have to go in immediately, because otherwise it makes the surgeon's job that much more difficult and my chances of a good operation to re-do it are reduced if I don't take a sensible attitude to the operations.

(Patient with rheumatoid arthritis)

My asthma has just generally gone worse, but when in winter if I get a cold, then they give you an asthma plan, and I've got a cold or something and I'm just a bit worse, you can just increase this medication to that level and see how that goes for a few weeks. Then if that works and it clears and it copes, then you can reduce it down again. You don't have to even go back to the surgery because they know that is what they've agreed with you. They're happy for you to do that on your

own, if you're happy to do it. It's really nice because they're kind of like, "Well, if you're happy doing that you just do that and you just call us when there's a problem". But if you're kind of not sure, you can just ring them up and say, "Well, this is how I'm feeling, I'm not sure whether I need to increase that one" and they'll go, "Yeah, let's try it for a week" or "let's come in and have a listen".

(Patient with asthma)

Evaluating current treatment and medication is an important aspect of receiving long-term care. In many LTCs, treatment is a case of trial and error and medication is often taken for longer period of time; therefore requiring continuous evaluation and monitoring. This process involves professionals (or sometimes patients) presenting alternative methods of treatment and allowing time for discussion, or alternatively a joint exploration by the health professional and the patient. However, if treatment is inefficient and left unevaluated it can lead to further health problems and have serious impact on everyday life of the patient:

Years went by, I was about 15 or 16, and I was still seeing this consultant at [hospital] once a year. He'd look up and say "Hello, how many fits have you had?" and he'd look back down again and say "Right carry on with the drugs." I was still having seizures on the drugs, I was having about six a year and I would have a seizure and then take a day to recover and then went back to school.

(Patient with epilepsy)

Presenting alternative treatment options requires health professionals to engage and listen to patient concerns and to investigate reports that they consider to be worrying.

Generally in care for people with LTCs, presenting alternatives is about getting the right medication balance for individual patients. Again, some of this relies on the perceived competence of health professionals, but also about health professionals trusting that patients know their condition(s) well and know when they need to seek help for additional problems:

> *I never went onto tablets at all. Straight away they put me onto a drip and I was on quite a high dose originally and then it boiled down. So like everything it balanced out once I got back onto a normal level of eating, my normal life virtually. I had the initial follow up of course, and then every three months for the first 12 months I went to the clinic. I was getting support from my own doctor but also I went to the clinic, and they checked me over and they did all my blood tests and all this. They finally settled on a regime and the amount of insulin that I was taking, that suited my lifestyle.*
>
> (Patient with type 2 diabetes)

> *My condition seems to have settled down now, because at the moment I'm getting a lot of help from my neurologist because we've been trying to mix a newer drug in with the Sodium Valproate. They've been trying to find a correct balance for me. It's been a correct combination of many different types of drugs and now we're finally, we've hopefully found the correct drug for me that is working. It's finding and actually stopping these seizures, keeping them at bay so that they're not coming back any more.*
>
> (Patient with epilepsy)

G**athering a deeper understanding of a patient** may help health professionals in being more responsive to the patients' needs and preferences and help tailor their care. This is perhaps more important in LTCs as patients have more extensive contact with the health services and therefore are more affected by the degree of continuity of care. Gathering thorough information from patients also helps create a better doctor/patient relationship:

> *I'm still on medication, I'm not going to come off it because it frightens me the minute I stop medication that I'll have a major seizure. The doctor that I see, he's willing to leave me on the medication for as long as I want. I could decrease it if I want to, but I can get my independence with driving round if I want to. I'm feeling stronger in myself.*
>
> (Patient with epilepsy)

> *You could go to a couple of weddings following each other, engagements anything. Then when you go for bloods, because the bloods go back over a certain period of time, they don't take into consideration what's happened in the last three months. They don't look at it that way. That again annoys me with the medical profession. They say, "Oh your bloods are up. They don't as you, "Why do you think your bloods are up?" or, "Why do you think your bloods have gone down". They don't. They just go, "Well take another tablet".*
>
> (Patient with type 2 diabetes)

Gathering an understanding of patient needs can also be useful in determining how involved patients want to be in their care and the decision making process. This is also

about recognising personal patient preferences and acknowledging their individual needs:

> *What I would ask an expert would be "Why don't you involve patients in your decision making at every stage? Why don't you ask patients what they want and what they feel they need because the patient is the expert in their own disease?" Because absolutely every patient is a complete individual and there are no two patients that match each other completely. I think doctors could learn a huge amount by listening more to patients.*
>
> (Patient with rheumatoid arthritis)

> *All asthmatics are different; don't stick us all in the same box. Don't assume that we'll all have the same attitude to things and that you can treat us all the same way. It's great when acknowledged that you have the condition and you've lived with it and what you're doing. I mean, I've got A&E well trained now. When I go in there they say, "What do you want, what do you need?" Because they know that I know, that I've lived with this for a long time so I will say to them "Can you listen to this? Am I wheezy? Am I this, am I that?" and they'll say, yes, whatever, and they'll treat me. Lots of people, a lot of medical professionals will say that "Oh, it's your condition, you're the expert", and then they completely ignore you. Then I think, well, hang on, you just told me that I'm the expert and that I lived with it, and I am. The classic thing, my brother, he's a junior doctor at the minute, and he acknowledges that he knows nothing about that [asthma] or that he knows very little. I know a lot more about asthma than he does, and - accept the knowledge, use it. Sometimes you get junior doctors who will just blank you.*

You've asked them something and they'll just blank you, and you're like well, what's the point? I know what's happening, I know my body, I know how I feel, and I know what will help.

(Patient with asthma)

Similarly, trust and respect for personal choice is important, especially in instances where patients refuse new treatments suggested to them by health professionals. This can be for a variety of reasons, such as little or no improvement in health status, medication side effects or simply other personal life circumstances/reasons. In these instances, it is important that health professionals value the patient's opinion and decision as an expert in their condition:

The consultant gave me a list [of medication] and I had to try one lot for 3 weeks, then another lot for 3 weeks and then try another one. But the ones that the consultant put me on suited me and when I come off, because you had to go on them for 3 weeks then you had to come off it was 3 days before you started another lot, presumably to get them out of your system. I did say to my husband that the Meloxicam kept everything under control so I wanted to stay on those ones and I was a bit worried about "Do I ring up the consultant and say I'm sorry but I haven't done what you've asked me to do because I prefer these ones." When I went back in there I was a bit sheepish and I did say to him "That list you gave me, I didn't bother with the other ones. I found these ones and when I came off them I found I was a lot worse. I said to my doctor, 'Is it all right if I stick with these?' and my doctor was like, 'Well, it's you, so yeah". In that aspect, I did have control.

(Patient with rheumatoid arthritis)

When you try to talk to the doctors they don't want to know, they don't care what you think. Every time I've gone up there, they say your bloods are up and I say, "Okay then, give me three months and when I come back for more bloods. If they're still up in three months' time, then fine, we'll talk about more medication. If they're down, leave me as I am." "Yeah, okay then." I've done that for the last eighteen months and my medication hasn't changed. Because then the next three months I've watched what I've been doing and if I have been unfortunate to have a wedding or an engagement party, you watch what you are doing, if it's in that period of time. You can still go out, enjoy yourself, but don't push yourself that little bit further. Then you go back in and your bloods are back down again. So they are happy and you are happy, but a lot of doctors will say, "Well, no I'm sorry. You take this now" and you've got no choice in it, because if you don't listen to the doctor or you don't accept what the doctor is doing, then he won't treat you. You can't go to another surgery or another medical practice because they don't want you. So you're stuck with the medical practice you've got. Basically, you either take a chance and say, "I'm not taking the medicines, end of story", or you just bide by what they tell you. I think that is wrong, I think you should have more of a say in what your actual medication is, or how it is prescribed to you anyway.

(Patient with type 2 diabetes)

Another important aspect of patient involvement and good outcomes is **monitoring health and doing this based on individual patient needs**. Even routine check-ups can be altered and negotiated to suit the individual person and the state of their condition:

> *I'd gone every four months [to hospital appointment], and then this latest little surge where they saw me after 5 or 6 weeks, and then I'm now on a 3 month one which is what it's been for a number of years. But the 3 months wasn't always necessary, it was sometime 4 months. Because it was toddling along quite nicely for a long time.*
>
> (Patient with rheumatoid arthritis)

> *The GP, I don't see until I want to. There's no regular contact. The practice diabetic nurse sees me twice a year. The consultant sees me irregularly, but he's available if the nurse needs him. If the practice nurse is worried at all, she can get me an extra appointment. I tend to go every three months to see the consultant.*
>
> (Patient with type 2 diabetes)

Patients often talked about being involved in determining follow-up times that suit them through negotiations with health professionals. Through these arrangements, patients feel trusted to report any deterioration in their health and in turn, health professionals are trusted by patients to monitor their health and detect any additional effects:

> *I've been to see him [doctor] quite a number of times because he built me up on the tablets. But the last time I seen him was almost six months ago, because he*

said leave it six month and come and see me, which I'm going to do shortly. But I have seen the nurse there, also had check up on the heart. I was there last week in fact and they check my blood pressure and they took blood samples and a sample of water. Apparently you can get liver trouble with some of these tables or kidney problems, so they have to keep a tight check on them.

(Patient with heart failure)

I see the GP fairly regularly but it's usually for other things, more minor things. In fact, I don't think I ever go to see him about the arthritis. I tend to see the rheumatologist about yearly, sometimes two yearly but I see the surgeon who did my hip revision operation every year in order to check up on the hips and knees. So he's my more regular point of contact for how I'm doing with the joints and everything.

(Patient with rheumatoid arthritis)

4.4.5 Continuity, consistency and co-ordination of care in long-term conditions

Continuity of care is important to all patients regardless of type of condition, but it can be argued that some patients with LTCs may want more from consultations as time progresses. Patients with LTCs greatly value being cared for by the same health professionals and this offers many of the benefits discussed in previous domains, such as opportunity to build a more partnership-based relationship.

Two major themes emerged from the analysis. These included:

- Continuity; not seeing the same health professional / having to explain condition and circumstances every time

- Consistency and co-ordination; receiving conflicting or inconsistent information from different health professionals

Patients frequently talked about the frustration of not seeing and discussing their condition with the same health professionals. Overall this **lack of continuity** appeared to be an important issue to many patients with LTCs, unless of course for some reason a patient did not get along with a particular health professional. The main concern of poor continuity was that patients felt that they had to explain their medical history/condition at each appointment, which can be time consuming and take focus away from the consultation. This can be particularly unsatisfying for expert patients who wish to get more out of their standard consultations:

> *I find that quite often problems arise because there is poor continuity – I've had this disease now for 22 plus years and in that time there has been an incredible turnover over all these health professionals. The only one who I remember from back then is my then registrar now Professor of rheumatology. He was able to act recently upon information that he's accumulated from knowing me all those years. What better way is there of serving a patients than by knowing them over a long period of time? That has to be true of every health professional. If you see a different occupational therapist every time you go, it's exhausting, exasperating. I feel almost like being rude, it's so exasperating to explain to a 19 year old who's never met me before. But of course it's not her fault. She's just going through things I've seen a hundred times before and they're not telling me anything new, not asking me anything new.*
>
> (Patient with rheumatoid arthritis)

They're bringing in a couple of younger doctors who are going to support them and eventually replace them. I think one's already been replaced. The frustration of seeing a doctor you're not used to seeing is the inevitable question "What medication are you taking?" and you sit there thinking, "If you turn back one page, you'll find that it was all written down the last time I was here, and if you turn back two pages, you'll see you wrote it all down when I was here the time before last. Because they ask the same questions each time.

(Patient with type 2 diabetes)

Another negative point raised by patients was that often they felt important decisions about their care can only be discussed and negotiated with high level consultants and specialists. This often means that patients are not able to get a review and evaluation of their treatment at the time of appointment:

I think probably the most frustrating time is you get to see your consultant maybe every three to six months, and if you're not happy with the results of the drug and you go to see him, but you obviously only see his registrar. They're not the ones that make the decisions about your drugs and they will tend to just say, 'well keep taking it and we'll see you in another three months.' There were two occasions I got really upset about it and I wrote to my consultant who brought me in immediately to talk to me about it. Because I really felt I was just being fobbed off and six months out, or a year out of your life is a long time and I wasn't just going to sit back and just continue in the situation I was in. But my consultant saw me straight away after that. But that's the trouble, you get a few minutes of their time

every six month and you may not see them, you may see a registrar who is not to be the same as the registrar who was there six months earlier. So you can't build any relationship up with them at all.

(Patient with rheumatoid arthritis)

They're quite good because a lot of the GP practices, they only have like one or two asthma nurses. They might have six or seven GPs and if you always see the same asthma nurse they can kind of go, "Oh yes, this is clearly a lot better than you were last time" or, "Sounds like you may be going a bit downhill, let's review what medications you're on". It's like because they see you every time.

(Patient with asthma)

However, many patients appreciated that for financial or organisational reasons, it is not always possible to see the same health professionals. At the same time, some patients mentioned that these instances should be infrequent, explained to them and that they should be offered a chance to meet with their regular health professional at a later time:

I haven't always seen the person that I expected to see, but interestingly, it's always been mentioned, "I'm sorry the person that you're expecting to see can't be here today, so I'm looking after you today, but next time you come, the person that you're expecting to see will be looking after you". That has always been true and I think that's very good because you do like to see the same person. But it's not always possible and I appreciate that sort of remark, and it's always been the truth.

(Patient with rheumatoid arthritis)

Seeing different health professionals can also have an effect of the co-ordination of care and can mean that patients receive **conflicting or inconsistent information** from different sources (previously discussed in relation to communication). Again, having clear and concise information about treatment and self-management is vital to patients with LTCs. Several patients talked about receiving conflicting information from different health professionals at the same clinic:

> *I'd been told so strongly in the initial flare up that it's so important to rest. This rest was so important and that I had to have splints, not just even lying in bed that I assumed that would happen again and it didn't. I was very unsure how much I should do, whether I should be trying to rest or whether I should be trying to do as much as I could. And I found that a little confusing. I didn't feel the medical were that clear on that at the time. The doctor would just said, "Well do what you're feel able to". But I sort of felt "Well, is it going to damage my joints when they're so inflamed, if I'm doing things?" "Should I be resting them until they've settled down a little bit more?" I didn't feel I got very clear cut advice at that stage.*
>
> (Patient with rheumatoid arthritis)

> *Different doctors have said different things. One doctor at the rheumatology clinic has said, "Look you must have this, you must come twice a year, spring and autumn, you must come for a course of hydrotherapy, to keep you moving." Yet a year later, I can go to the rheumatology clinic and see a different registrar and they'll look at me as if I'm asking for the moon.*
>
> (Patient with rheumatoid arthritis)

4.5 Comparison of generic domains of PCC and domains specific to people with LTCs

The generic framework of PCC developed from the conceptual synthesis was used to develop a coding framework for the secondary analysis of patient interviews. The secondary analysis highlighted several themes of PCC that were of importance to people with LTCs. The findings from the secondary analysis present an alternative framework of PCC that is more specific to care for people with LTCs.

The two frameworks are presented in Table 10. The main difference between the two frameworks is in regards to the depth of experiences that is covered by the LTCs specific framework of PCC. The two frameworks can be seen as working side by side; the generic framework highlighted many important domains of PCC and the LTCs specific framework aims to explain what aspects of these domains are particularly important to people with LTCs.

Table 10. Patient-centred care; domains identified from synthesis and themes identified through secondary analysis.

Generic framework of patient-centred care (domains) identified through conceptual synthesis	Long-term conditions specific framework of patient-centred care (themes) identified through secondary analysis
• Access, availability and choice • Information, communication and education • Relationship with health professionals • Involvement in care • Respect and dignity • Responsiveness to Individual needs and preferences • Consistency, continuity and co-ordination • Effectiveness of treatment and care	• Methods of communication, exchange and co-ordination in care for people with LTCs. o Having access to alternative methods of communication and interaction (consultations between consultations) o Communication, exchange and co-ordination of information between health professionals • Consistent and tailored information that supports education in LTCs. o Information (or lack of information) to help patients live well with condition o Consistent and reinforced information o Tailored information o Informed about treatment decisions and changes o Information about risks/understanding how condition may develop (e.g. symptom change) • Respectful partnership with health professionals in LTCs. o Respectful partnership (trust in competence of health professional and patient) o Emotional support and understanding (impact of condition on the patient's life) • Involving patients, respecting their decision and responding to individual needs and preferences in LTCs. o Control over condition o Evaluation of current treatment/medication o Presenting alternative treatments options o Deep understanding of the patient (my needs - not everyone's the same) o Monitoring health and altering follow-up times to suit the individual and stages of condition • Continuity, consistency and co-ordination of care in LTCs. o Continuity; not seeing the same health professional/having to explain condition and circumstances every time o Consistency and co-ordination; receiving conflicting or inconsistent information from different health professionals

4.6 Discussion

4.6.1 Summary of main findings

The method of secondary analysis of existing qualitative interviews was used to identify key experiences of care for people with LTCs. A total of 100 open-ended interviews with patients with LTCs were coded and analysed using a modified grounded theory approach, looking for both anticipated and emergent themes. Findings from the conceptual synthesis were used as a primary coding framework.

As expected, the analysis generated many generic themes that were similar to those reported in existing literature and PCC frameworks, such as communication, information and education, and responsiveness to individual needs. As a result, further analysis explored what these generic domains mean for people with LTCs and that would enable people to live well with their condition(s).

The exploratory analysis added much needed depth to the generic concepts of PCC and identified 5 themes and a number of sub-themes of PCC that were specific to care for people with LTCs. In addition, it appeared that many of the experiences that were important to people with LTCs were shared across different LTCs.

4.6.2 Strength and limitations

The secondary analysis included a large number of patient interviews across 5 different yet common LTCs. The interviews provided a rich insight into the experiences of people with LTC and it was possible to generate a great deal of codes and themes from the data. As a result, the analysis and proposed domains of PCC were driven by patient

narratives and not pre-determined categories. The use of secondary data also holds specific benefits in terms of time and patient burden, as discussed previously.

The main limitation in conducting this review was that the patient interviews did not specifically focus on experiences of health care delivery, but instead had a much broader aim which included all aspects of living with a LTC. Indeed, the primary interviews were driven by the patient narrative about their experiences and were not based on pre-determined categories. As a result, the process of secondary analysis was slow and required frequent revisions to the coding framework. However, this may also have been a further strength of the analysis, allowing for in-depth consideration to ensure that all the relevant experiences that people with LTCs considered important were considered.

4.6.3 Conclusions

This chapter aimed to identify experiences of PCC from patient narrative interviews and compare these with the domains identified in the conceptual synthesis.

Several of the domains developed through the conceptual interpretative synthesis were revised during the analysis. Overall, there was a high degree of consensus on the experiences of care across different LTCs, suggesting that similar strategies can be pursued and measured across a range of LTCs.

The result was a LTC specific framework of PCC which reflects the things that are important to people with LTCs. It was also discussed how and why these themes may hold a distinctive meaning when applied to long-term care. The LTC specific

framework is seen as an extension to the generic PCC framework, presenting themes that are of specific important to care for people with LTCs.

These themes were taken forward to the next stage, and further evaluated with people with LTCs. The next steps involved testing of the LTCs specific themes, through item generation for items for a patient-centred LTCs specific measure and subsequent cognitive interviewing with people with LTCs. Chapter 5 presents the process of item generation.

5 Item generation for a generic patient-centred care experience questionnaire for people with long-term conditions

5.1 Introduction

5.1.1 Background and rationale

This chapter presents the process of item generation for a generic PCC experience questionnaire for people with LTCs, based on themes identified in the secondary analysis.

There is a great deal of guidance on the process of item generation for patient-reported measures. Much emphasis is placed upon the use of mixed methods (Kerr, Nixon & Wild, 2010); including both empirical findings (literature) and patient views (Fayers & Hays, Streiner & Norman, FDA, 2009). A clear and well defined conceptual framework is essential to the development of patient-reported measures and traditionally, item generation is informed by the relevant literature and existing health measures (Steiner & Norman, 2008). The US Food and Drug Administration (FDA, 2009) advocates for patients to be included from early stages of design in order to strengthen the conceptual framework, capture relevant and meaningful domains, and ensure the correct terminology has been used for items. These important steps were considered and adopted in the development process.

5.1.2 Objectives

The specific objectives of this chapter were:

1. To construct a set of meaningful and relevant items of PCC for people with LTCs relating to themes generated from the secondary analysis of patient interviews.
2. To present the process of development and iterations of items for a generic PCC experience questionnaire for people with LTCs.

5.2 Methods

5.2.1 Existing patient experience measures

A number of existing patient experience measures were used for guidance in the process of item generation, mainly for wording and structure rather than content. For instance, the introduction was evaluated for wording, the items and response options were explored for tone and wording, and the length of questionnaires were considered. The structure, domains and item generation of these measures were studied in detail and special attention was given to the wording of items and how they reflected the corresponding domains.

Overall, there was little guidance on the development work of these questionnaires, particularly around how themes were converted to questions. It must be acknowledged that these questionnaires are all relatively new and therefore may be lacking in supportive literature and validation work. Nevertheless, the existence of these

questionnaires further supports the need for such measures to capture patient experience and PCC.

The patient experience measures used for guidance included:

- The NHS patient surveys (Picker Institute).
- The Outcomes and Experience Questionnaire (OEQ).
- The Long-Term Conditions 6 (LTC6) questionnaire.

The NHS patient surveys (Picker Institute)

The Picker Institute Europe is a not-for-profit organisation that specialises in measuring patient experiences (using patient experience surveys and focus groups) for the purpose of providers and commissioners. An example of this is the NHS national patient survey programme[13] (developed by the Picker Institute) which aims to annually monitor NHS care and performance[14].

The Picker surveys adopts a fairly detailed framework of patient experience and asks questions on most aspects of care, including choice of provider, access and waiting times, confidence and trust in health professionals, information and communication, involvement in treatment decisions, availability of staff when needed, hygiene, cleanliness and hand-washing, food and physical environment, access to records and

[13] http://www.nhssurveys.org/

[14] NHS national patient survey programme http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/Browsable/DH_5578969

medical communications, being treated with dignity and respect, and overall satisfaction. The response options are tailored for each question in the survey.

The Outcomes and Experience Questionnaire (OEQ)

Commissioned by the Department of Health and developed by the University of Oxford, the OEQ is a short general-purpose questionnaire, with the aim of integrating patients' perceptions of a specific recent in-patient hospital stay into a short single measure.

The first of its kind, the measure aims to combine two complementary aspects of patients' reports; Patient Reported Outcomes (PROs) and Patient Reported Experiences (PREs) of services. To capture outcomes, the questionnaire asks about the perceived value, relevance, and benefits to the patient of the episode of care. To capture experiences of care, it asks about the core clinical and therapeutic experiences in relation to the same hospital stay. Item response varies across the questions.

The LTC6 questionnaire

Since the start of this thesis, a long term conditions specific questionnaire has been presented by the Department of Health. The questionnaire was developed by the Quality Innovation Productivity and Prevention (QIPP)[15], part of the Department of Health "Quality & Productivity" programme[16], which aims to place quality of care at the heart of the NHS and improve care for people with LTCs.

[15] http://www.dh.gov.uk/en/Healthcare/Qualityandproductivity/QIPPworkstreams/index.htm

[16] http://www.dh.gov.uk/en/Healthcare/Qualityandproductivity/index.htm

The Long Term Conditions 6 (LTC6) is a 6-item questionnaire for people with LTCs receiving care in the NHS. It aims to assess the quality of care and support received over the last 12 months and how patients perceived this to have helped them better manages their condition. The topics covered include communication, patient involvement, information, support from health care team, co-ordination of care and a global question asks about overall confidence to manage own health. Item response varies across the questions.

A copy of the questionnaire is included in a recent document produced by the Royal College of General Practitioners (RCGP)[17] and it is stated on page 27:

> *"From the Quality Innovation Productivity and Prevention (QIPP) programme (the LTC 6): Six questions for patients which cover the most important aspects of care for someone with diabetes (Appendix A2.1).*

The questionnaire is also mentioned in a policy documents. For instance the 'NHS South Central: Strategic and Operational Integrated Plan' (2011/12 to 2014/15)[18] states on page 39 under 'Quality' that improved patient experience will be assessed by the LTC6 questionnaire. The questionnaire is also mentioned in the '*NHS East of England: Commissioning Framework*' (2011/12)[19] where it is stated that 100% uptake of LTC6

[17] Care Planning, Improving the Lives of People with Long Term Conditions (2011) http://www.rcgp.org.uk/PDF/CIRC_Care_Planning.pdf

[18] http://www.southcentral.nhs.uk/wp-content/uploads/2011/05/HA11-043-SHA-Strategic-and-Operational-Integrated-Plan.pdf

[19] https://www.eoe.nhs.uk/downloadFile.php?doc_url=1298035122_jRvw_commissioning_framework_2011-12.pdf

questionnaire is nationally recommended. However, development work for this questionnaire is not presented and it is not clear how it was derived.

5.2.2 Item generation

Item development started with themes generated from the secondary analysis with the aim to generate meaningful items for each theme. Item generation was guided by the patient interviews and the extracts for each theme. It was important to capture significant experiences of care that could be revised into items for a questionnaire.

5.2.3 Expert panel review

Refinement of the questionnaire and subsequent items was conducted with the assistance of an advisory board, consisting of 3 academics (including both supervisors) which brought together a combination of expertise in primary care, public health and questionnaire development and validation.

The advisory board were presented with the findings from the secondary analysis of patient interviews and the initial suggested items. During the meeting, reviewers were asked to provide feedback on:

- Overall structure of the patient experience questionnaire, including introduction and layout.
- Relevance of items to original themes.
- Relevance and acceptability of items to people with LTCs.
- Wording and presentation of items and response options.
- Missing or additional items for consideration.

The feedback and critique offered by the advisory panel were taken into consideration and the questionnaire and its items were revised accordingly. The results were presented back to the advisory board for further feedback. Overall, there were 2 rounds of expert panel review with the advisory board.

5.3 Results

This section presents the steps taken to generate items based on the themes identified in the secondary analysis of patient interviews.

5.3.1 Item generation

Several themes identified from the secondary analysis generated more than 1 item and several items were associated with more than one theme. An additional section was added to the questionnaire which asked about respondent demographics in order to gather a better understanding of each respondent and their answers. The initial questionnaire, version 0.1 (dated 1st Jan 2013), consisted of an introduction to the questionnaire and 2 subsequent sections; section 1 asked about views and experiences of healthcare and consisted of 17 items and section 2 asked about patient demographics and consisted 6 items (see appendix 6). Several items contained more than 1 question, for example presented as question 1a, 1b, and 1c. Overall the first draft consisted of 30 questions.

5.3.2 Response options

Tailored response options were developed for each question, with specific consideration to how the question was developed for each question. For instance, if the question asked

'how helpful was…', then the word helpful was reflected in the response options which offered the choice of 'very helpful', 'helpful', 'not very helpful', and 'not at all helpful'. The response options also aimed to be well balanced and were tailored to provide two positive options (e.g. very helpful and helpful) and two negative (not very helpful and not at all helpful).

5.3.3 Expert panel refinement

Round 1 feedback and revisions

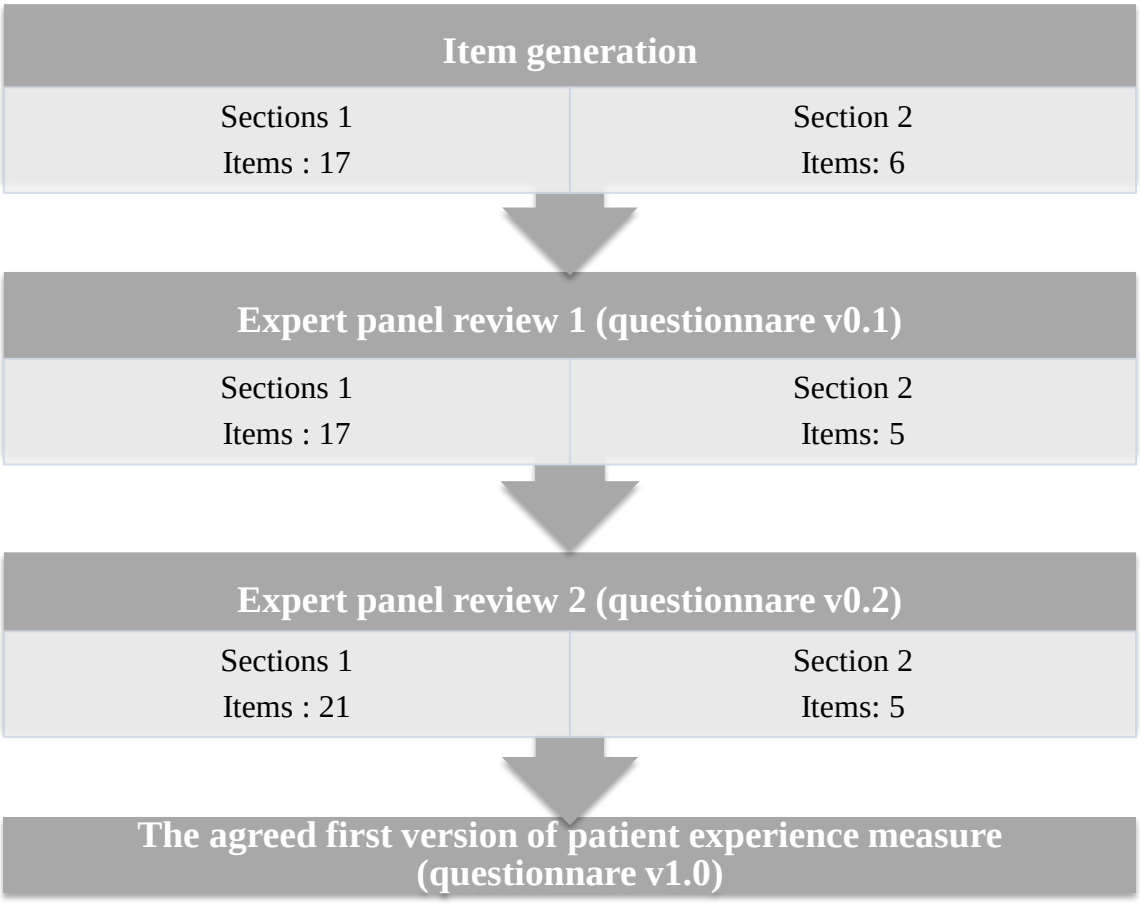
The expert panel were presented with version 0.1 of the questionnaire. Reviewers offered amendments to a number of items and response options, mainly in regards to wording in order to improve clarity. It was also suggested that the item regarding ethnicity should include response options more in line with Oxford University guidelines. Amendments were made to all 17 items in section 1. No items were removed but one item regarding medication and treatment was split into two items as it was considered to be asking about two separate issues.

Round 2 feedback and revisions

The expert panel were presented with version 0.2 of the questionnaire which had been revised based on their feedback from the previous meeting. The feedback was mainly around the order of items and further clarity of 2 items and their response options. In addition, it was suggested that the questionnaire should include additional items about monitoring health. It was suggested that an additional item regarding changes to treatment should be split into two items as it was considered to be asking about two separate issues. No items were removed.

After 2 rounds of discussions it was felt that a consensus was reached regarding item inclusion and overall construction of the questionnaire. Results from the advisory panel and item revision at each stage are demonstrated in Figure 1.

Figure 1: Item generation and refinement process.



5.3.4 The agreed first version of questionnaire and items

The agreed first questionnaire, version 1.0 (dated 1st Feb 2013), consisted of an introduction and 2 subsequent sections; section 1 asked about views and experiences of healthcare and consisted of 21 items and section 2 asked about patient demographics

and consisted 5 items. Several items contained more than 1 question and overall the questionnaire consisted of 33 questions. (see appendix 7).

Introduction to the questionnaire

The front page of the questionnaire consisted of the name of the questionnaire, version number and date. The introduction presented the purpose of the questionnaire and an explanation of how to complete it.

Section 1: Views and experiences of healthcare

This section included all of the items generated from the secondary analysis. These are presented below separate for each theme.

Theme 1: Methods of communication, exchange and co-ordination in care for people with LTCs.

Areas of PCC	Items
Having access to alternative methods of communication and interaction (consultations between consultations)	• Were you offered different ways of contacting staff in between standard appointment times and services? (e.g. email or telephone number) • If you did contact staff outside of standard appointment times, how helpful were they in… o Answering your questions? o Relieving your worries and fears? o Helping you manage your condition(s)?
Communication, exchange and co-ordination of information between health professionals	• Thinking about how different staff involved in your care communicated and updated each other about your treatment… o Did you receive conflicting information from different health professionals? • Did you feel that different health professionals kept each other informed of your medical history? • Was there ever a delay in your care because of lack of communication between different health professionals?

Theme 2: Consistent and tailored information that supports education in LTCs.

Areas of PCC	Items
Information (or lack of information) to help patients live well with condition	• How useful was the information you received in helping you manage your condition(s)? • If you take lots of different medication for your condition(s), do you get enough practical help on how to take them? • If you received new medication or treatment, how helpful were the instructions you were given on how it should be used or taken?
Consistent and reinforced information	• Did you receive conflicting information from different health professionals?
Tailored information	• How useful was the information you received in helping you manage your condition(s)? • Were the advice and treatment you were given right for you?
Informed about treatment decisions and changes	• If there were any changes to your treatment, were you… o Involved in the discussion? o Understand why these changes were happening?
Information about risks/understanding how condition may develop (e.g. symptom change)	• Did you get the information you wanted about how your condition(s) may change over time? • Were you given the opportunities you wanted to discuss how your condition(s) may change over time?

Theme 3: Respectful partnership with health professionals in LTCs.

Areas of PCC	Items
Respectful partnership (trust in competence of health professional and patient)	• If you developed any new symptoms or problems, did the staff involved in your care… o Trust your judgment that something was wrong? o Get you the right treatment quickly?
Emotional support and understanding (impact of condition on the patient's life)	• Were you able to talk with staff about personal issues that were important to you? (e.g. how the condition(s) affects your family and social life) • How helpful were health professionals in helping you limit the impact of your condition(s) on your life?

Theme 4: Involving patients, respecting their decision and responding to individual needs and preferences in LTCs.

Areas of PCC	Items
Control over condition	• Were you able to discuss medication and treatment options with staff? (e.g. changes, dosage)
Evaluation of current treatment/medication	• If there were any changes to your treatment, were you… o Involved in the discussion? o Understand why these changes were happening?
Presenting alternative treatments options	• Were you able to discuss medication and treatment options with staff? (e.g. changes, dosage)
Deep understanding of the patient (my needs - not everyone's the same)	• Were you able to talk with staff about personal issues that were important to you? (e.g. how the condition(s) affects your family and social life) • Were the advice and treatment you were given right for you? • Were you able to discuss how you can adapt treatment to suit your personal situation?
Monitoring health and altering follow-up times to suit the individual and stages of condition	• In the last 12 months, have you had a full review of your condition and treatment? o If you did have a full review, how helpful was this to you? • Did you get to see a specialist nurse for your condition? • Were you given follow-up appointments when you felt you needed them?

Theme 5: Continuity, consistency and co-ordination of care in LTCs.

Areas of PCC	Items
Continuity; not seeing the same health professional/having to explain condition and circumstances every time	• Thinking about your appointments with health professionals… o How important was it for you to see the same person, rather than a different health professional(s)? o Were you given the option of seeing the same health professional(s)? • Did you feel that different health professionals kept each other informed of your medical history?
Consistency and co-ordination; receiving conflicting or inconsistent information from different health professionals	• Did you receive conflicting information from different health professionals?

Additional comments

The final item of the questionnaire asked respondents about any other comments or experiences that they wished to report. The response option for this item was in the form of an open text box.

Section 2: Patient demographics

The patient demographics section asked about age, sex, level of education, working status and ethnicity.

5.4 Conclusion

The method of item generation adopted in this chapter was based on existing guidance around the use of mixed methods in development of patient reported measures, including the use of existing patient reported measures for guidance and the involvement of an expert panel in the refinement process.

Items were developed from the themes generated from the secondary analysis and the process was guided by the patient interviews and the extracts for each theme. Overall, there were 2 rounds of expert panel review with the advisory board. The final questionnaire consisted of 2 section; views and experiences of healthcare (21 items) and patient demographics (5 items).

This chapter aimed to explore ways in which the themes identified from secondary analysis could be measured in the form of a patient experience questionnaire. The process of item generation for a PCC experience questionnaire for people with LTCs

was presented in detail. Items generated were examined for applicability and acceptability with an expert panel. The next step was to further test the measure and its items with people with LTCs and health professionals who care for this population of patients. Chapter 6 presents the process of cognitive debriefing interviews.

6 Further testing of themes and items of patient-centred care

6.1 Introduction

6.1.1 Background and rationale

The secondary analysis (chapter 4) presented a LTCs specific framework of PCC and these findings were drawn upon for item generation (chapter 5). In line with existing guidance around the involvement of relevant patient groups in the development of patient reported measures, this chapter aims to confirm findings through further interviews with people with LTCs and health professionals to examine the relevance and acceptability of a new PCC experience questionnaire for people with LTCs.

6.1.2 Objectives

The specific objectives of this chapter were:

1. To further test and confirm themes and items generated from secondary analysis though cognitive debriefing interviews with people with LTCs and health professionals.
2. To explore additional or missing themes and items that may be of importance in care for people with LTCs.
3. To report on the first stage of validation for a PCC experience questionnaire for people with LTCs.

6.2 Methods

6.2.1 Purpose and structure of debriefing interviews

Incorporating cognitive debriefing interviews ensured that the final questionnaire was developed in accordance to internationally acknowledged standards (FDA, 2009). There were two main aims of the interviews with people with LTCs and health professionals; to test and validate items generated from secondary analysis and to explore any additional or missing themes and items that may be of importance in care for people with LTCs. Both aims were explored through debriefing interviews.

The interview was conducted in 2 stages; standard cognitive debriefing approach and more open-ended approach.

Cognitive debriefing interviews (stage 1)

The method of cognitive debriefing was used to further test and validate the items of the new PCC experience questionnaire for people with LTCs. The interviews were conducted in order to establish understanding and acceptability of the items and the overall questionnaire. The objective was to determine if the items were relevant, unambiguous, and acceptable to the study population. Overall, it was important to ensure that:

- The instructions of the questionnaire were clear and easy to understand.
- Participants found all items were relevant to their condition and acceptable to answer.
- The response options were appropriate to the item stem and the response options adequately covered the potential range of agreement.

- Questionnaire validation
- The wording and terminology used was appropriate for use among a range of participants with varying levels of education.

Open-ended interviews (stage 2)

A more open-ended interview approach was used to identify additional or missing themes that respondents felt were important in care for people with LTCs. The objective was to explore experiences or items that had not been asked about in the new PCC experience questionnaire for people with LTCs.

6.2.2 Cognitive debriefing method

The method of cognitive debriefing was developed in the 1980's by a group of methodologists and psychologists with the aim of evaluating response error in questionnaires (Willis, Schecheter & Whitaker, 1999). Today, it is the most widely used method in the testing stage of questionnaire development (Tourangeau, Rasinski & Rips, 2000) and the approach has resulted in a large body of methodological research (e.g. Willis & Schechter, 1997; Sirken, Herrmann, Schechter, et al., 1999).

General approach

The general approach is to recruit relevant respondents for interviews that focus on the survey content (rather than the administration process) and study the cognitive processes that respondents use to answer survey questions (both overt and covert processes). The underlying theory of cognitive debriefing (Tourangeau, 1984) involves the following processes to ascertain:

1. General comprehension of the question; *what does the respondent believe the question is asking; what do specific words and phrases in the question mean to the respondent.*
2. Retrieval of relevant information from memory; *what does the respondent need to recall to be able to answer the question; what strategies does the respondent use to retrieve the information.*
3. Decision processes, such as motivation and social desirability; *is the respondent sufficiently motivated to accurately and thoughtfully answer the question; is the respondent motivated by social desirability in answering the question.*
4. Response processes; *can the respondent match his/her response to the question's response options.*

Methods of interview

There are two major types of cognitive interviewing methods; think-aloud and verbal probing.

The *think aloud* method originates from psychological procedures presented by Ericsson and Simon (1980), but the technique has been revised with more recent practice (Willis et al., 1999). As part of this approach, the interviewer reads each survey question to the respondent and the respondents is asked to "think aloud" when answering the questions. The process that respondents use in arriving at an answer to the question is noted and reviewed. For instance, if the respondent has trouble recalling events over the last 12 months, then it might imply that the questionnaire recall period if too long to provide adequate answers. Advantages of this method include freedom from interviewer-imposed bias, minimal interviewer training required, and the adoption of an

open-ended format. The disadvantages include issues around training for respondents (as this method is somewhat unusual for most people) and the associated resistance and burden on respondents that the technique may cause.

The *verbal probing* method is a popular alternative to the think-aloud (Willis et al, 1999), where the interviewer asks the initial survey question (and allows the respondent to answer) and then uses other related questions, known as 'probes', to gather further information about the response. Advantages of this method include control over the interview through the use of probes and ease of training for the respondent, as being asked related questions is a fairly natural process on interviews. The disadvantages include the potential for bias, as the probes may lead the respondent to particular types of responses. However, this possibility can be avoided through the careful selection of non-leading probing techniques which avoid suggestions and rather offer possibilities for further answers.

Method of interview adopted for this chapter

The method of 'retrospective verbal probing' was adopted for this chapter, a technique used by the Patient Reported Outcomes Measurement Information System (PROMIS)[20] group. As part of this method, the respondent is given the questionnaire and asked to complete it in advance of the interview. Similar to the standard probing method, the interviewer then asks each question and follows this with additional relevant questions to "probe further into the basis for the response" (Willis et al., 1999). Qualitative techniques are used to query participants' understanding of an item and their

[20] http://www.nihpromis.org/default

interpretation of the instructions and response options. The technique also enables participants to comment on the wording, meaning and relevance of the questions without being interrupted. It is suggested that the retrospective probing technique offers a more realistic presentation of items, particularly at later stages of survey development (Willis et al., 1999).

6.2.3 Ethics

Ethical approval was obtained for interviews with people with LTCs through the University of Oxford Ethics committee (Reference number MSD-IDREC-CI-2013-053).

6.2.4 Participants and recruitment process

Men and women aged 18+ were recruited if they had one or more LTCs and were able to answer a questionnaire independently. Participants were mainly from the Oxfordshire and London area. A range of recruitment methods were used including adverts placed in local newsletters and newspapers, at village halls/colleges and snowballing (see appendix 8 for advert).

Potential participants were provided with information about the research (see Appendix 9 for information sheet) and given the opportunity to ask further questions before agreeing to take part. Participants that agreed to take part in the study were asked to confirm their consent by completing a formal consent form (see Appendix 10 for consent form). They were also sent a copy of the PCC experience questionnaire and asked to complete this before the interview. All interviews were conducted by the DPhil student/researcher.

Participants were given the option of conducting the interview in person, over the telephone or by means of Internet (using Skype) and received a token payment of £20 for taking part. Overall, 25 interviews were conducted; 12 in person either at the participants home, the interviewers home or the department of Primary Care Health Sciences at University of Oxford and the remaining 13 either over the phone or via the means of Skype.

6.2.5 Interview process

The cognitive testing was conducted in three rounds of interviews; phase I (n=10), phase II (n=15) and phase III (n=7). Ten participants were recruited for phase I, and a further 15 participants were recruited for phase II. From the existing 25 participants, 6 were selected and asked to participate in phase III.

A semi-structured guide was used during the interviews. This consisted of a list of questions for each item and response options, as well as some more general questions (see Appendix 11 for interview topic guide). The debriefing questions were drawn from the retrospective verbal probing method described by Willis et al (1999).

In phase I and II, the debriefing questions were organised into four sections:

- Understanding the meaning of each item and response options.
- Understanding of general instructions and recall period.
- Overall impression and acceptability (length and presentation).
- Experiences that were missing or had not been asked about (missing domains/items).

Each cognitive debriefing interview lasted approximately 40 minutes. The interviews started with an introduction to the topic area and the development of the questionnaire. Participants were informed of the purpose of the interviews and issues regarding confidentiality and dissemination of results. They were also given time to ask any further questions before commencing the interview. All interviews were audio recorded and hand written notes were taken during the interview by the researcher.

All items of the questionnaire were approached individually. Participants were given time to read the items again, either out loud or in silence. The aim was to gather insight on how the participant had understood the items and the response options. Special emphasis was placed on terminology and wording. Participants were asked to verbalise their thoughts on how they had completed the item.

In phase III, a total of 6 participants from phase I and II were contacted and invited to comment on the revised version of the questionnaire. The questionnaire was emailed to these participants and they were provided a time period of three weeks to respond with any further comments or suggestions.

6.2.6 Analysis and revision of the questionnaire

Overall, 3 versions of the questionnaire were tested during cognitive debriefing. Version 1 (see appendix 7) was tested in phase I, version 2 (see appendix 12) was tested in phase II and version 3 (see appendix 13) was emailed to selected participants in phase III.

A modified framework analysis table was used to review findings from the cognitive debriefing (see Appendix 14 for summary table of cognitive debriefing). A separate table was created for each phase of cognitive interviews. Feedback and comments from participants were summarised by item, general feedback, missing topics/items.

Analysis was carried out at the end of each interview phase so that problems identified could be revised and retested. Items were checked for consistency of interpretation between participants and across health groups. Reoccurring problems with specific items or wording were highlighted. Interviews were conducted until it was thought all potential problems with the questionnaire and its completion had been identified and addressed.

The questionnaire was revised by the DPhil researcher with input from a team of supervisors and advisor. Issues from the cognitive interviews were raised by the researcher and discussed within the group for possible solutions and amendments.

6.2.7 Feedback from health professionals

A number of health professionals were approached and invited to review the questionnaire at each interview phase. GPs, nurses and psychologists who have contact with patients on a regular or semi-regular basis (some may also have an interest in academic research) were recruited through GP networks and contacts obtained through the department of Primary Care Health Sciences.

Interviews with health professionals were conducted alongside interviews with participants with LTCs; phase I (n=3), phase II (n=4) and phase III (n=3).

A similar recruitment process and interview process was used with health professionals with minor adjustments. Health professionals were interviewed separately, each interview lasting approximately 15 to 20 minutes. They were asked to examine the questionnaire before the interview and to provide general feedback on domains, items, relevance, presentation and feasibility (see Appendix 11 for topic guide). Interviews were analysed after each phase and comments were used to revise the questionnaire. All interviews were conducted by the DPhil student/researcher.

6.3 Results

6.3.1 Participants

People with LTCs

A total of 25 participants were recruited and interviewed; 10 males and 15 females. Participants were purposely selected to reflect a spectrum of health conditions including asthma (n=7), depression/anxiety (n=5), inflammatory bowel disease (n=3), rheumatoid arthritis (n=3), chronic pain (n=3), epilepsy (n=2), multiple sclerosis (n=1), gastric ulcers (n=1), underactive thyroid (n=1), and eczema (n=1).

Participants ranged in age from 22 to 87 years, with a mean age of 39.75 years. Overall, the mean number of years since diagnosis was 14.5 years. Three participants had more than one LTC. Characteristics of participants are summarised in Table 11. Responses to the cognitive debriefing and refinement of items are summarised below.

Table 11. Participant demographics for cognitive debriefing interviews.

	Round 1 (n=10)	**Round 2 (n=15)**	**Total (n=25)**
Sex			
Male	6	4	10
Female	4	11	15
Age			
Mean age in years	37.9	41.6	39.75
Mean years since diagnosis	12.4	16.7	14.5
Conditions			
Asthma	3	4	7
Crohn's disease	2	-	2
Depression/anxiety	3	2	5
Gastric ulcers	1	-	1
Rheumatoid arthritis	1	2	3
Epilepsy	-	2	2
Chronic pain	-	3	4
Ulcerative colitis	-	1	1
Multiple sclerosis	-	1	1
*Meniere's disease**	-	*1*	*1*
*Eczema**	*1*	-	*1*
*Underactive thyroid**	*1*	-	*1*

*Not mutually exclusive.

Health professionals

A total of 10 health professionals were recruited including general practitioners (n=3), general practitioners/clinical fellows (n=3), clinical psychologists (n=2), specialist nurse (n=1) and a paediatric specialist (n=1).

6.3.2 Overall Impressions

The opening item of the cognitive interviews aimed to capture content validity and comprehensiveness of the questionnaire. All participants, including health professionals, reported that the questionnaire had asked important and relevant questions about care for people with LTCs. One participant who was also a member of the Expert Patient Programme (EPP) commented that the questionnaire was "*thorough and relevant*" and that "*patients in the EPP programme shared these concerns about their health care*". A number of participants stated that the questionnaire covered a range of LTCs and that

"*almost everything was covered*" by the questionnaire. The items that were not covered are discussed later in 'missing topics or items'.

6.3.3 Refinement of Items by Phase

After participants had commented on their overall impressions with the questionnaire, they were asked to comment on each item and its accompanying response options individually. A series of questions were prepared to examine understanding of items, tease out potential issues with meaning and terminology and identify suggestions for re-wording.

Although the general feedback was that the questionnaire was clear and easy to answer, there were a number of suggestions on wording and clarification of terminology. Most of these comments were considered and studied, specifically if participants had also suggested ways of better capturing a concept or experience (such as rephrasing a sentence). These are discussed in more detail below. Findings from interviews with people with LTCs and health professionals are presented simultaneously.

Phase I

Version 1 (dated 1st February 2013) consisted of two sections; the first section asked about views and experiences of healthcare (21 items) and the second section asked for information about the respondent and some general demographics (5 items). Several items contained more than 1 question and overall the questionnaire contained of 33 questions.

Overall some participants were not clear about the term “health professionals” and whether this included other health staff, such as receptionist and support workers. To clarify this, an opening question was devised for version 2 that asked participants to state how many times they had seen a number of different health professionals in the last year. This question was also considered to provide insight on how involved respondents had been with the health services over the last 12 months. For better consistency, the term “staff” was changed to “health professionals” throughout the questionnaire.

On a number of items, wording was changed based on feedback from participants. For instance, on item 2 the term “when you needed them” was changed to “when you requested them” to better reflect input from respondents. For item 6, the wording was changed from “how helpful” to “how useful” and response options for items 5 and 6 were also changed to the term “useful” for better consistency.

Items 8 and 9 were revised from the information or opportunities “you wanted” to “you felt you needed” as some participants indicated that patients may not know what they want but are more aware of what they need. Similarly, items 11, 12, 13 and 14 were all changed from beginning with “were you” or “were the” to “did you feel” for better consistency.

Item 16, which asked about new medication and treatment, was revised to ask about “advice” received rather than “instructions”. It was thought that almost all medication is accompanied by written instructions whereas patients value advice from health professionals when provided with new medication.

Several participants found items 3 and 4 difficult to answer, mainly as they were not clear on the term “in between standard appointments”. Some thought this meant contacting health professionals about making appointments or ordering medication and others thought it asked about contacting staff outside of normal opening hours. After some feedback and suggestions from participants, this term was changed to “in between your usual appointments”. Participants in phase II and III were more comfortable with the change in wording.

Item 15, which asked about practical advice and help with multiple medications, received mixed comments from participants. The general consensus was that the wording suggests multiple medications, whereas practical advice might only be needed for one type of medication. Similarly, it was thought that “practical help” implies a more hands-on approach and that the term “practical advice” might be more suitable. With this feedback, item 15 was divided into two separate questions, one asking about “practical advice” and anther to capture advice about managing “more than one type of medication”.

A number of participants struggled with item18 which asked about receiving “a full review of condition and treatment” in the last 12 months. The terminology was unclear and some participants perceived this to mean any check-up or investigation done by health professionals, whilst others understood this to mean an annual appointment designated to review their condition and treatment options. With this insight, item 18 was revised to “do you feel that you’ve had a full review of your condition and treatment” to better capture what patients themselves believe to be a sufficient review.

An overall feedback from several participants was to remove the response option "a little helpful" and to add a "not applicable" option to almost all items. The argument was that care is almost always either helpful or not helpful and that some questions were simply not applicable to all respondents. Consequently, the term "a little helpful" was removed from all related items and a "N/A" option was added throughout the questionnaire. An additional response option was added for item 11, as feedback from participants indicated that perhaps some respondents "did not want to discuss" personal issues with health professionals.

In section 2, an additional item was devised, asking respondents to list the LTC(s) they have. For item 4, response option "at work" was changed to "employed" and some additional ethnic origin categories were added to item 5.

Phase II

Version 2 (dated 1st May 2013) also consisted of two sections; views and experiences of healthcare (23 items) and information about the respondent/general demographics (6 items). Several items contained more than 1 question and overall the questionnaire contained of 39 questions.

The newly devised opening item on section 1 was well received by participants with some minor comments. For instance, it was suggested that general practitioner should also be abbreviated in brackets as GP, and that a few examples could be provided in brackets for "other health professions" (such as dietician and physiotherapist). This would give respondents a better idea of what was asked.

Similar to the phase I process, several revisions were made to wording and terminology based on feedback from participants. For instance, the term “follow-up” was deleted from item 3 as it was thought to restrict the question to only follow up appointments. Item 8c was revised from “relieving” to “addressing” your worries and fears, as some participants specified that it’s not always possible to relieve concerns but that it is possible for health professionals to address these appropriately.

Items 5 and 6 which ask about receiving a full review of condition and treatment were changed back to “did you have a full annual review?”. The reason for this change was to adequately capture whether respondents had indeed received a full annual review by the health services. In addition, another item was added which asked participants if they didn’t have a full annual review, did they feel they received any kind of review. This item was thought to capture respondents that did not receive a full review but that perhaps felt that any investigations or check-ups they received were helpful.

There was still confusion about item 7, which asked respondents about contacting health professionals in between usual appointments. Some participants believed this to be asking about arranging appointment and ordering medication. After some discussion with participants and the supervisors, “to discuss your condition” was added to the sentence to clarify that the question.

Many participants responded positively to the free text box provided with item 23. Some suggested that perhaps more space should be provided so that respondents could elaborate on questions and experiences.

After removing the response option “a little helpful” in the previous phase, some participants suggested also removing “extremely helpful” as this was also thought to be outside of the helpful vs. not helpful argument. In addition, the response option “I would prefer to see the same person” was removed from item 2 and instead another option of “Not very important” was inserted. It was also thought that both revisions would allow for a more balanced response category.

As a result of discussion with several participants, it was clear that a “N/A” response option was not always necessary and that it would be replaced with more appropriate response options. One argument for this change is that “N/A” responses do not provide much useful information to researchers and health professionals and that if there is sufficient understand of why respondents would choose the “N/A” option, then these can be replaced by a specific options. For instance, the “N/A” option for item 2 was changed to “I didn’t see anyone in the last 12 months” and for item 3 it was replaced with “I didn’t need an appointment”. The “N/A “response option was removed or replaced for all items.

Some minor alterations were done to section 2. For items 4, response option “don’t know” was removed as some participants said this might be insulting to some people and that almost everyone knows their level of education. An additional response option was added to item 6 for participants that did not wish to disclose their ethnic origin.

Phase III

Version 3 (dated 1st June 2013) consisted of three sections; information about the respondent and their LTC(s) (2 items), views and experiences of healthcare (14 items),

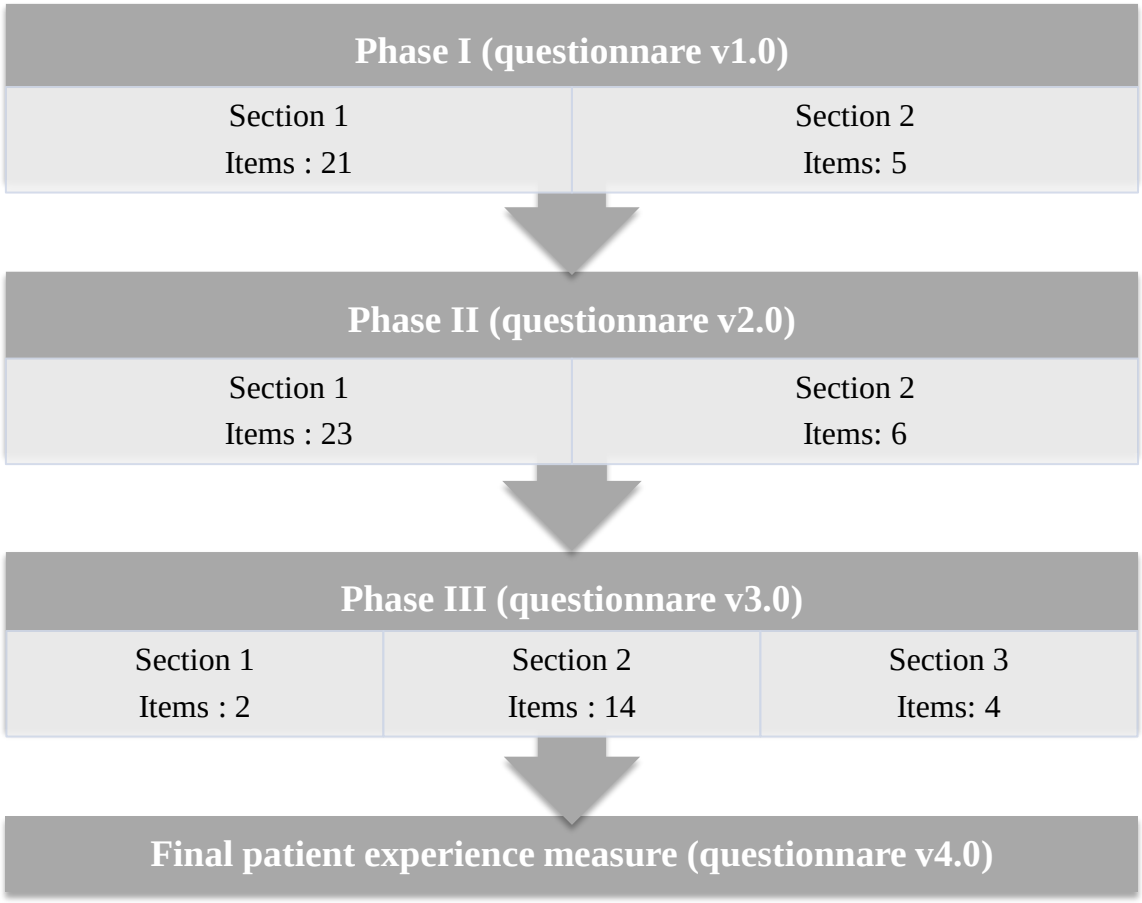
and general demographics (4 items). Several items contained more than 1 question and overall the questionnaire contained of 46 questions.

Section one was a new addition to the questionnaire, asking respondents to list LTC(s) (previously asked in section two) and how much their condition(s) had affected them physically and emotionally over the last 12 months. It was thought that this section along with item 1 in section two (asking how many times participants had seen a number of health professionals) would capture how much the respondent was affected by their condition(s) and how involved they were with health services. This would in turn provide a better insight to their subsequent answers.

An additional item was added to the end of section two, which asked participants to compare the care that they had received over the last year with care they had received in the past. The intention was to get an overall assessment of care from respondents and whether this had improved in the last 12 months.

Overall, participants responded well to version 3 of the questionnaire, with minor suggestions for wording and presentation. Figure 2 presents the item refinement process for each phase.

Figure 2: Item refinement by phase of cognitive debriefing interviews.



6.3.4 Relevance to specific long-term conditions

Overall, all participants completed the questionnaire by themselves without any issues. Many stated that the items were very relevant to them and their LTC(s) and that they could see the questionnaire being relevant to other conditions as well. However, a couple of participants stated that they struggled with some of the content of the questionnaire as their LTC had been well maintained for some time and they had very limited contact with the health services.

Similarly, some health professionals commented that although the questionnaire is very relevant to people with LTCs and captures many important aspects of care, it might be

more relevant to patients with more severe conditions that require a great deal of contact with health services. Some health professionals also mentioned that acceptability of the questionnaire and willingness to complete it will inevitably vary amongst patients. For instance, it was suggested that younger people with LTCs may feel more engaged in their health and therefore more likely to want to feedback on their healthcare.

6.3.5 General Instructions and recall period

Participants were asked to comment on the clarity of the instructions and length of recall period (12 months). Although many participants stated that the instructions were "*clear*" and "*easy to understand*", there were some further suggestions on wording. In version 3 of the questionnaire, an extra line was added which stated "*If you do not wish to answer a question, then leave it blank*". This was done to re-enforce to participants that this option was available.

There were no concerns about the 12 months recall period. Some participants preferred a longer recall period as this would mean having to complete the questionnaire less often, particularly if they did not have extensive contact with the health services. However, some participants suggested re-inforcing the idea of 12 months recall period as it can easily be forgotten. Consequently in version 3, a statement was put on the top of every page of section 2 asking participants to think or reflect upon the care they received in the last 12 months.

6.3.6 Issues around multimorbidity

A couple of participants in phase I raised the issue of multimorbidity when completing the questionnaire. The concerns were that people with more than one LTC would "*find*

it confusing" and that "*one condition may cause more trouble than the other*". This issue was raised and considered by the DPhil researcher and discussed with supervisors. However, it was thought that many people with LTCs seek care for more than one condition and that the purpose of the questionnaire is to capture experiences of care across a range of health settings. As this issue was not raised in phase II or III of cognitive debriefing, the questionnaire remained unchanged.

6.3.7 Presentation and length

There were a great deal of feedback on the presentation of the questionnaire and many participants suggested ways to improve the basic layout. In order to make the questionnaire "*look more inviting*", some participants proposed to have "*bigger text*", "*put questions into boxes*" and have "*less questions on one page*". These suggestions were all incorporated and all participants in phase III were happy with the presentation of the questionnaire.

The structure of the questionnaire was revised after each phase to provide a better flow. The order of some questions were changed and others were grouped together if they were considered to be asking about the same topic.

Reported time for completion was 10 to 15 minutes on average (range from 5 to 20 minutes). Opinions varied about the length; most participants stated that it was "*good, brief and thorough*" and that "*they had time to really think about their answers*", whilst a few commented that "*it was a bit too long*". However, participants also stated that it would be difficult to make the questionnaire shorter as it would mean leaving out relevant and important information.

6.3.8 Missing topics or items

Some participants had suggestions on other areas to ask about. Some participants suggested asking about getting second opinions or seeking herbal/alternative treatment, which would perhaps indicate a loss of confidence in health professionals and standard care. However, after some discussion it was felt that these actions may not be direct measures of PCC, but that the interactions between patient and health professionals around these issues are adequately covered in the questionnaire. For instance, seeking herbal/alternative treatment is a personal choice that may be result of helpful discussions with health professionals (covered by item 8a and 8b). It may not indicate lack of PCC, but instead that a patient wishes to try an alternative treatment option.

A few participants proposed having a question about being listened to and taken seriously, as some health professionals can be difficult to engage with during appointments (e.g. avoiding eye contact with patient and looking at the computer screen). Similarly, some participants talked about relationship with health professionals, such as feeling able to build good/reasonable relationships with health professionals and feeling at ease with them. The topic of patient engagement was raised and examined in the secondary analysis, although this was considered to be relevant to most people seeking health care and not exclusive to LTCs. However, on re-evaluation of the questionnaire in phase III, it seemed appropriate to include a question about "*being listened to*" along with existing questions about "*feeling able to talk*" and "*health professionals helping limit impact of condition*".

Other suggestions were to ask more specifically about how useful health professionals were in suggesting e.g. physiotherapy, a dietician or support groups for management of

symptoms and being open to discuss how the condition might be affecting sexual health. However, on further evaluation it appeared that these topics were already captured less explicitly by existing items.

One participant with particularly mild symptoms talked about having a question to evaluate how much respondents are actually affected by LTC(s). It was argued that this would help determine the severity experienced by respondents and also provide good insight to the subsequent answers that respondents provide. Consequently, this feedback was incorporated into version 3 of the questionnaire; section 1 asks respondents to list their LTC(s) and how much their LTC affects their daily activities and how much it affects them on an emotional level.

A health transition question was also suggested by a couple of participants, which involves asking respondents directly about how they feel their care has changed over the last 12 months, compared to the care they have received in the past. An item was devised in version 3 of the questionnaire to capture an overall assessment of health care from the patient's perspective. This was presented as the last question which asked 'Overall, how has your health care changed over the last 12 months, compared to the care you received in the past?'.

6.3.9 Final questionnaire

The final questionnaire, '*Your Experiences of Care in Long-Term Conditions*' version 4 (dated 1st August 2013, see appendix 16), consisted of 47 questions across three sections:

1. Information about the respondent and their LTC(s) (2 items, 3 questions).

2. Views and experiences of healthcare (14 items, 39 questions).
3. General demographics (5 items, 5 questions).

6.3.10 General comments from people with LTCs

Overall, people with LTCs responded positively to the questionnaire many commented that it was "*thorough*" but "*not too invasive on personal life*". Most participants stated that they would complete the questionnaire if they were asked to and that they could see the benefits of having this appraisal. Some participants favoured the ease of completing the questionnaire in a GP surgery whilst others preferred to do this in their own time (e.g. being sent the questionnaire via post or email). Some participants stated that they would not complete the questionnaire if they were asked to, however, they stated that this was merely due to personal choice (e.g. they did not see the benefit of this feedback) and not a reflection of the content or design of the questionnaire.

6.3.11 General comments from health professionals

There were also positive responses from health professionals and several mentioned that the questionnaire covered important aspects of care for people with LTCs that are currently not being evaluated in the NHS. Overall, it was felt that the questionnaire highlights areas of good care and aspects of care that may need improvement.

Some health professionals also mentioned that it would be a useful questionnaire to be used on a routine basis to evaluate how involved patients feel they are in consultations and how useful they find them. Others mentioned that the questionnaire captures feedback in a non-judgemental way both for patients and health professionals, and that this might generate more honest answers.

In contrast, several health professionals felt that one of the limitations of the questionnaire could be the difficulty in assessing care across a range of services, as people with LTCs often access care from many different sources and sometimes for different conditions. During discussions with health professionals, it was suggested that the questionnaire would be most useful in primary care/general practice to inform health professionals about aspects of care that are in need of improvement, help them understand the patients' needs better and in turn support them in managing their condition. In addition, particular attention should be given to the free text question where participants have an opportunity to describe particularly good or bad care that they may have experienced.

6.4 Discussion

6.4.1 Summary of main findings

Through the use of cognitive debriefing interviews with people with LTCs and health professionals, it was possible to further explore the themes and items generated from the secondary analysis.

Overall, there were 3 rounds of revision to the questionnaire. Refinement included suggestions on wording and clarification of terminology. Feedback from participants stated that questionnaire had asked important and relevant questions about care for people with LTCs and that it was relevant to people with a range of different LTCs. Reported time for completion of was 10 to 15 minutes on average, with most

participants reporting that it was nice and brief whilst a few participants who considered it too long. However, participants felt that all items in the questionnaire were relevant and important to people with LTCs.

Missing items that were added to the questionnaire included questions around being listened to and taken seriously by health professionals, how much respondents are actually affected by LTC(s), and how respondents feel their care has changed over the last 12 months

Most participants with LTCs commented that they would complete the questionnaire if they were asked to and that they could see the benefits of it. All health professionals stated that the questionnaire highlights areas of good care and aspects of care that may need improvement.

The final questionnaire, '*Your Experiences of Care in Long-Term Conditions*', consisted of 47 questions across three sections. Criticism of the questionnaire included its applicability to people with multiple LTCs (who may at time struggle to answer more general questions about their healthcare) and its effectiveness in assessing care across a range of services. However, health professionals felt that this was a good tool for use and evaluation of general practice.

6.4.2 Strength and limitations

It was possible to thoroughly examine the newly developed questionnaire through the use of cognitive debriefing method with people with LTCs and health professionals. During this process, every item and response options was challenged for clarity,

relevance and acceptability. Indeed, having input from both patient and professionals helped shape the questionnaire to be useful both for patients to provide feedback and for that information to be presented in a way that would be useful to health professionals.

Including people with a range of LTCs in the development process helped confirm previous findings and examine areas which were not adequately covered by the secondary analysis. It was also of particular benefit to include people with a different range of LTCs that were not captured by the secondary analysis in order to confirm that findings were applicable across a range of LTCs and help support the argument that people with LTCs have many similar healthcare needs.

The main limitation was that not all comments provided by participants could be addressed. Some statements were simply based on personal preferences of the respondents and a pragmatic approach was taken during the stages of revision. In addition, the suitability of this questionnaire for people with multimorbidity could not be fully assessed (due to the small number of participants with more than one LTC) and may need further testing and revisions. However, all participants considered the questionnaire to be clear and relevant even acknowledged that it was not possible to incorporate all of their suggestions.

6.4.3 Conclusions

This chapter aimed to test and confirm the content of a PCC experience questionnaire for people with LTCs through cognitive debriefing interviews. The findings indicated that the questionnaire is clear, relevant and acceptable to patient and professionals. The implication and wider context of these findings are discussed in chapter 7.

7 Conclusions

7.1 Summary of research findings

The main findings from this thesis are:

1. There is a policy drive to raise quality of health services for people with LTCs and to provide care that is patient-centred, there is a need for more co-ordinated services and evaluation tools to collectively measure health experiences of people with LTCs.
2. Existing frameworks of PCC and patient experience capture important domains of care but have been largely derived from generic hospital care, and therefore may not specifically apply to care for people with LTCs.
3. Secondary analysis of interviews with people with LTCs generated many generic themes of PCC similar to those reported in the literature, but added much needed depth to what these domains mean to people with LTCs and enable them to live well with their condition.
4. A new PCC experience questionnaire for people with LTCs was developed based on themes from the LTCs specific framework of PCC identified in the secondary analysis.
5. Preliminary findings from the cognitive debriefing interviews with people with LTCs and health care professionals suggest that the questionnaire is clear, relevant and acceptable to patients and professionals and offers valuable insight into the care of people with LTCs.

The background review highlighted the vast impact of LTCs on both the health care services and on the individual person, and the national policy drive to improve quality of care overall and for people with LTCs. Much emphasis has been placed on providing and evaluating care that is patient-centred, but the concept of PCC remains ill-defined in literature and policy documents. In addition, existing PROMs or PREMs may be too generic (e.g. SF-36, NHS inpatient survey) or too condition specific (e.g. PROMs for specific conditions) to provide insight into quality of care for people with LTCs.

Based on currently published frameworks of PCC and patient experience, it was possible to create an overarching framework of PCC through the method of conceptual synthesis. The framework consisted of 8 domains which enable the provision of PCC:

- Access, availability and choice
- Information, communication and education
- Relationship with health professionals
- Involvement in care
- Respect and dignity
- Responsiveness to Individual needs and preferences
- Consistency, continuity and co-ordination
- Effectiveness of treatment and care

Findings from secondary analysis of interviews with people with LTCs suggested that many of the domains from the overarching framework were also important in care for people with LTCs, but that some aspects of care were distinctly significant or held an additional meaning when applied to LTCs. The results also suggested that many of

these themes were important across different LTCs and potentially to people with multimorbidity. Themes of specific importance included:

- Methods of communication, exchange and co-ordination in care for people with LTCs.
    - Communication, exchange and co-ordination of information between health professionals
    - Having access to alternative methods of communication and interaction (consultations between consultations)
- Consistent and tailored information that supports education in LTCs.
    - Information (or lack of information) to help patients live well with condition
    - Consistent and reinforced information
    - Tailored information
    - Informed about treatment decisions and changes
    - Information about risks/understanding how condition may develop (e.g. symptom change)
- Respectful partnership with health professionals in LTCs.
    - Respectful partnership (trust in competence of health professional and patient)
    - Emotional support and understanding (impact of condition on the patient's life)
- Involving patients, respecting their decision and responding to individual needs and preferences in LTCs.
    - Control over condition

        - Negotiations and arrangements with health professionals to get the right medication balance
        - Maintaining and improving quality of life as judged by the patient
    - Evaluation of current treatment/medication
- Continuity, consistency and co-ordination of care in LTCs.
    - Continuity; not seeing the same health professional / having to explain condition and circumstances every time
    - Consistency and co-ordination; receiving conflicting or inconsistent information from different health professionals

In chapter 5, the themes identified in the secondary analysis were used to generate meaningful and relevant items for a generic PCC experience questionnaire for people with LTCs, based on existing guidance around the use of mixed methods in development of patient reported measures. Overall, there were 2 rounds of expert panel review with the advisory board. The final questionnaire consisted of 2 sections; views and experiences of healthcare (21 items) and patient demographics (5 items).

The relevance and acceptability of the newly developed PCC experience questionnaire for people with LTCs was tested through further interviews with people with LTCs and health professionals. The final questionnaire, '*Your Experiences of Care in Long-Term Conditions*' version 4 consisted of 47 questions across three sections:

1. Information about the respondent and their LTC(s) (2 items, 3 questions).
2. Views and experiences of healthcare (14 items, 39 questions).
3. General demographics (5 items, 5 questions).

Feedback from participants stated that questionnaire had asked important and relevant questions about care for people with LTCs and that it was relevant to people with a range of different LTCs. All health professionals who took part in the cognitive debriefing interviews stated that the questionnaire highlights areas of good care and aspects of care that may need improvement. However, the applicability and acceptability of the PCC questionnaire for people with multimorbidity is currently uncertain and may need further testing and revisions.

Overall, there was substantial convergence between the three different sources of evidence; the conceptual synthesis, secondary analysis, and cognitive debriefing interviews. The findings present evidence of aspects of care that are important to people with LTCs and preliminary support for how these experiences might be assessed.

7.2 Comparison with existing literature

Findings from the secondary analysis of qualitative interviews suggested that living with a LTC can impact various different aspects of an individuals' life, including the person's physical and psychological wellbeing. Equally, many people with LTCs felt that they were living normal lives and would like ongoing support in doing so. These results are in line with numerous previous research findings on the potential impact of LTCs (e.g. Goodwin et al., 2010; Department of Health, Social Services and Public Safety, 2012).

The secondary analysis also indicated that people with LTCs share many of the same experiences about their general health and the healthcare that they receive with the general population and also across different LTCs, with some condition specific considerations. With a rise in numbers of individuals with multimorbidity and the current health policy drive for more co-ordinated services for LTCs (e.g. Department of Health, 2005a), it can be argued that a more generic approach to chronic disease enablement is required. However, our current understanding of what services would look like and how 'generic' they would be is limited. In addition, the notion of providing care that is tailored and patient-centred could be at risk if the approach is too generic.

The findings from all approaches in this thesis have added to our understanding of PCC and what this could mean for people with LTCs. There are already numerous definitions and frameworks which attempt to clarify the notion of PCC (as covered in the conceptual synthesis), but none have explored what specifically PCC could mean to people with LTCs. The findings from this thesis have supported previous explanations and domains of PCC which are used to inform policy initiatives for people with LTC or more general population (e.g. Department of Health, 2005a; Department of Health, 2010d), but also helped unpack specific experiences of PCC that are important to individuals with LTCs.

This thesis has also provided preliminary support for ways in which these experiences of PCC can be captured and evaluated in healthcare settings through the use of a newly developed PREM. The questionnaire aims to capture experiences of PCC care, rather than satisfaction with care which has been criticised for failing to discriminate

effectively between good and bad practice (Cleary, Edgman-Levitan, McMullen et al., 1992).

7.3 Strengths and weaknesses

This section provides an overview of the strengths and weaknesses of the thesis.

A key strength of this thesis was the use of multiple methods to address the research objectives, which is over and above the strengths of each individual method. Each method built on previous findings and provided further insight into experiences of PCC that are important to people with LTCs

An additional strength of this thesis was the thorough and robust method of secondary analysis of qualitative patient interviews. Having access to a rich, relevant and high quality dataset of patient interviews made it possible to incorporate views from people with LTCs. These interviews provided insight into various aspects of living with a LTC, far beyond the scope of experiences of receiving health care, and added much needed depth to the concept of providing care that is personalised to each individual person. People with LTCs and health care professionals were also involved in fine tuning specific items of the PCC experience questionnaire.

A potential weakness of the thesis is that the framework for secondary analysis of the qualitative interviews was influenced by the framework that emerged from the conceptual synthesis. Although this was a deliberate approach to analysis, it may have had an unconscious effect in reproducing the framework from the conceptual synthesis.

There is a possibility that framework from the synthesis may have had a strong influence as the secondary analysis did not generate any major new domains of PCC. Instead, the framework derived from the synthesis was refined and benefited from much needed specificity.

However, the secondary analysis and the cognitive debriefing interviews were approached with the aim of teasing out the very specific ways in which the domains from the conceptual synthesis and secondary analysis were important to people with LTCs. Indeed, the cognitive debriefing interviews provided a great deal of specificity and helped clarify what exactly it was about each theme or domain that was important to people with LTCs. In addition, it might have been surprising if entirely new domains of PCC emerged from the secondary analysis that had not previously been captured in the research or policy literature.

7.4 Implications for future research

This thesis has presented experiences of PCC that are of importance to people with LTCs and demonstrated how these can be measured as part of a PCC experience questionnaire. There are several important areas for further research.

Firstly, the newly developed PCC experience questionnaire for people with LTCs needs to be further tested to examine standard features such as reliability and validity. To some extent, the first steps of validity testing has been demonstrated in this thesis, particularly ‘content validity’ which has been demonstrated through qualitative evidence from pre-testing with patients, expert opinion and literature review that

support the notion that the items in the questionnaire represent the construct being measured. Further testing for reliability, validity, acceptability and feasibility would involve examining the questionnaire in a relevant sample of patients with LTCs in order to evaluate how the instrument performs in a more testing context.

It would be useful to explore the specificity of such a generic experience questionnaire for people the LTCs and to evaluate its usefulness in evaluating care for people with multimorbidity. The issue of providing good quality care for people with multimorbidity has been raised in this thesis and although the PCC experience questionnaire has been shown to be feasible and relevant across different LTCs, its use in multimorbidity has not been fully established.

As this thesis has highlighted, there is an increasing interest in the use of PROMs and PREMs to evaluate health care and to improve health services. However, the way in which information generated from these measures are gathered, presented and utilised by patients, health professionals and health services has been widely debated and may need further consideration.

The value of a newly developed questionnaire to enhance experience and quality of care can be evaluated from two perspectives. Firstly, its impact on the everyday healthcare consultations and secondly, it's impact on more general policy initiatives. There is some support for the use of PROMs in enhancing communication between patients and clinicians (Velikova, Booth, Smith et al., 2004), encouraging shared decision making (Soreide & Soreide, 2013), and helping monitor disease progression (Gutteling, Darlington, Janssen et al., 2008). However, the use of PROMs data by healthcare

professionals to improve upon health management and outcomes is contested (e.g. Boyce & Browne, 2013; Chen, Ou & Hollis, 2013). There may be several barriers towards the uptake of PROMs data, such as practical considerations, methodological concerns and the impact of feedback on patient care (Boyce, Browne & Greenhalgh, 2014).

There also needs to be some consideration about how a new PCC experience questionnaire would be used to enhance quality of care. For instance, there is some support to suggest that health professionals value PROMs data that can be linked to individual patient care, rather than performance indicators about the care delivered to groups of patients (Boyce et al., 2014). Indeed, feedback from health professionals in the cognitive debriefing interviews highlighted that the newly developed questionnaire captures feedback in a non-judgemental way both for patients and health professionals and it is vital to ensure that the questionnaire is used accordingly.

There is also a growing recognition that structured quantitative survey data, based on well validated PROM or PREM data, collected over the years may not have the sort of impact on policy and improvement of quality of services as one might expect (e.g. Robert, Cornwell, Brearley et al. 2011). It is not clear how the vast data collected on patient outcomes and experiences could be used to make a difference in the health system or national policy. Indeed, some have argued that there is now an ‘abundance of data’ available on what matters to patient about their health care and a more concerted effort should be made to utilise this vast evidence to have a much needed positive impact on healthcare delivery (e.g. Coulter, Locock, Ziebland & Calabrese, 2014). Therefore, any future research in this area should consider the ways in which an

experience measure could contribute to both everyday consultations and policy initiatives.

7.5 Summary

It was possible to produce an overarching framework of PCC from a range of existing patient experience and PCC frameworks, whilst demonstrating some conceptual problems in understanding and evaluating the notion of PCC. Findings from this thesis suggest that an overarching questionnaire of experiences of PCC is feasible and acceptable to people with a range of different LTCs. However it has not been established whether the questionnaire would be suitable for people with multimorbidity.

Future research needs examine standard features such as reliability and validity of the newly developed PCC experience questionnaire for people with LTCs. The implications of this thesis for future research are to consider the potential use and contribution of data collected from the PCC experience questionnaire in enhancing care for people with LTCs.

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9 Appendices

Appendix 1: NHF for LTCs quality requirements

The quality requirements are based on currently available evidence including what people with long-term neurological conditions told us about their experiences and needs.

Quality requirement 1: *A person-centred service*	People with long-term neurological conditions are offered integrated assessment and planning of their health and social care needs. They are to have the information they need to make informed decisions about their care and treatment and, where appropriate, to support them to manage their condition themselves.
Quality requirement 2: *Early recognition, prompt diagnosis and treatment*	People suspected of having a neurological condition are to have prompt access to specialist neurological expertise for an accurate diagnosis and treatment as close to home as possible.
Quality requirement 3: *Emergency and acute management*	People needing hospital admission for a neurosurgical or neurological emergency are to be assessed and treated in a timely manner by teams with the appropriate neurological and resuscitation skills and facilities.
Quality requirement 4: *Early and specialist rehabilitation*	People with long-term neurological conditions who would benefit from rehabilitation are to receive timely, ongoing, high quality rehabilitation services in hospital or other specialist settings to meet their continuing and changing needs. When ready, they are to receive the help they need to return home for ongoing community rehabilitation and support.
Quality requirement 5: *Community rehabilitation and support*	People with long-term neurological conditions living at home are to have ongoing access to a comprehensive range of rehabilitation, advice and support to meet their continuing and changing needs, increase their independence and autonomy and help them to live as they wish.
Quality requirement 6: *Vocational rehabilitation*	People with long-term neurological conditions are to have access to appropriate vocational assessment, rehabilitation and ongoing support, to enable them to find, regain or remain in work and access other occupational and educational opportunities.
Quality requirement 7: *Providing equipment and*	People with long-term neurological conditions are to receive timely, appropriate assistive technology/equipment

accommodation	and adaptations to accommodation to support them to live independently, help them with their care, maintain their health and improve their quality of life.
Quality requirement 8: *Providing personal care and support*	Health and social care services work together to provide care and support to enable people with long-term neurological conditions to achieve maximum choice about living independentlyat home
Quality requirement 9: *Palliative care*	People in the later stages of long-term neurological conditions are to receive a comprehensive range of palliative care services when they need them to control symptoms, offer pain relief, and meet their needs for personal, social, psychological and spiritual support, in line with the principles of palliative care.
Quality requirement 10: *Supporting family and carers*	Carers of people with long-term neurological conditions are to have access to appropriate support and services that recognise their needs both in their role as carer and in their own right.
Quality requirement 11: *Caring for people with neurological conditions in hospital or other health and social care settings*	People with long-term neurological conditions are to have their specific neurological needs met while receiving treatment or care for other reasons in any health or social care setting.

Appendix 2: Search strategy for conceptual synthesis

The following databases were searched through search engine Ovid:

- AMED (Allied and Complementary Medicine)
- EMBASE
- PsycInfo
- Ovid MEDLINE(R)
- In-Process
- Other Non-Indexed Citations and Ovid MEDLINE(R)

The following is the complete search strategy used to search in databases using the search engine Ovid:

((person[tiab] OR patient[tiab]) adj3 (centred[tiab] OR centeredness[tiab] OR centred-care[tiab] OR experience[tiab])) OR ((patient centre*[tiab] OR patient focused[tiab]) adj3 (care[tiab]))

Appendix 3: Codebook for secondary analysis (rheumatoid arthritis example)

COPING	
Acceptance of condition	Accepting ones faith and learning to deal with consequences. Opposite of denial which can mean ignoring symptoms/condition
Adapting	Adapting to changes brought on by condition
Coping	Ways that a person learns to deal with the condition and changes in their life
Humour	Using humour to cope with condition/life/issues
QoL	Activities/changes that help increase quality of life
Realistic perception	Having a realistic perception of the future of condition/ health /physical abilities
Seeking normality	Seeking activities that make the person feel that they are living a 'normal' ordinary life (the condition does not affect or exist)
Self-management	Managing the condition by changing own behaviour/restricting certain things
Use of aid	Use of tools to ease coping with condition, e.g. seat in shower, walking stick, customised car
Wanting to gain control	Need to have control of life and take action to do this e.g. change diet

DIAGNOSIS	
Wrong diagnosis	Given incorrect diagnosis by health professionals/condition not taken seriously by HP
Process of diagnosis	Time, visits, interactions, tests etc in the process of identifying disease
Help seeking behaviour	Action of person from when first discovering symptoms to seeking medical advice/assistance
Feeling about diagnosis	Emotions the person has when they are given their diagnosis
Early signs of illness	First symptoms of possible disease and how the person reacts to this

FAMLY	
Benefits for children	e.g. Wisdom that can be passed on, children become more aware of disease, prevention of condition in children
Family adapting to changes	Family learning to live with the persons condition and getting used to the changes caused by it
Family involved in care	Members of family help in care of condition and maintenance of health
Impact on family	Factors that have an impact of family life or members of family
Support from family	Family providing emotional/physical/care support to the person

IMPACTS OF CONDITION	
Finances	Having condition e.g. physical/emotional symptoms or side effects affecting flow of money
Leisure activities	Having condition e.g. physical/emotional symptoms or side effects affecting leisure activities
Loved ones	Having condition e.g. physical/emotional symptoms or side effects affecting loved ones and their life
Mental health	Having condition e.g. physical/emotional symptoms or side effects affecting the persons' mental health state
Physical health Condition inhibiting PA Deformity Fatigue Secondary effects	Having condition e.g. physical/emotional symptoms or side effects affecting the persons' physical health state e.g. restricting or affecting physical activity e.g. walking, driving etc Arthritis causing deformity of bones and joints Conditions causing the person to be extremely tired/exhausted, mental or physical exertion Condition causes other health problems/conditions
Work and employment	Condition affects the person's employment, e.g. they find work difficult, lose their job, difficult to find a job
Loss of Confidence	The person loses confidence in self/abilities as a result of condition
Loss of independence	

KNOWLEDGE	
Contradictions or reframing of story	During the interview, the person tells a story but later re-frames the it with different attitudes/emotions/perspective – changes his/her perspective or story
Information from others	Knowledge gathered from other people, what others have told them about their condition/symptoms
Internet	The person has gathered information/knowledge about their condition from the internet
Lay conceptions and beliefs	Thoughts/perceptions that a person has about their condition that is often not based on facts, only observations

	and beliefs
Own research	The person has gathered information/knowledge by researching for it
Previous knowledge and understanding	Beliefs/thoughts/perceptions of the condition has changed as new information has been gathered
Reflection and learning	The person reflects of their past (e.g. own behaviour) and learns from it

LIVING WITH CONDITION	
Attitude	The general way the person feels and thinks about their life/condition
Diet	Change in diet either required to maintain condition or experimental alternative treatment
Emotions	Range of emotions experiences by the person
Exercise	Levels and types of exercise that the person participates in (can also be part of alternative treatment methods)
Factors affecting condition	A number of things that affect the course of the condition e.g. weather, time of day, cold water etc.
Help seeking behaviour	The way that the person seeks medical help (e.g. waiting time) in relation to course of disease e.g. when symptoms get worse
Private about condition	The person chooses not to tell others or talk about condition in front of other people
Thoughts about future	Thoughts, predictions and feeling about the future that the condition may bring
Time	Used when the person describes evens in time e.g. that was 2 years ago, in 2004
Unpredictable condition	When the condition can't be controlled and outcomes may be surprising to the person or health professionals

PAIN	
Pain	Pain caused by condition
Pain relief	Ways to relief pain, often by use of surgery/medication from health professionals but can also be alternative treatments

SUPPORT	
Family and friends	Family and friends proving physical and emotional support to the person
Local council	Support from local council e.g. disabled parking spot
Other patients	Other patients sharing knowledge and proving emotional support
Social care	Support from social care e.g. someone to help with cleaning the house

Support groups	Support groups offering help/guidance/knowledge/advice and emotional support to the person
Work	Gaining support from employers and fellow employees

TREATMENT	
Alternative treatments	The person trying alternative medicine/treatments e.g. homeopathy
Cost of treatment or medication	The high cost of certain treatments not provided by the NHS and how this is justified/dealt with by the person
Medication Controlling or reducing medication Medication Medication side effects Worry about medication	 The person changing their medication intake (quantity) without consulting a health professional Medication used to reduce/maintain condition Side effects (physical and emotional) experiences by taking certain medications The person expressing worries and fears about taking certain medication
NHS vs Private	Care received in the NHS compared to care received by private organisations, in terms of benefits and outcomes
Related treatments	Treatments not directly related to healing of condition, but given by health professionals to maintain health or levitate discomfort caused by condition e.g. physiotherapy
Surgery	Surgery required to correct damage caused by condition

PATIENT CENTRED CARE?	
Communication	Between the person and health professional e.g. how information was presented to the person, but also between HPs
Competence of health professionals	Technical ability of health professionals to diagnose the person's condition, maintain their health with treatment/medication and in general have positive health outcomes
Empathy & Compassion	Shown by health professionals in a number of ways, e.g. in general, actually caring about the person and their outcomes
Information & Education	The health professional proving information to the person and at the same time educating them about their condition and treatments available
Patient Involvement Choice and control Involvement in care	 The person given choice over condition or treatments available The person being encouraged/given a chance to be involved in decisions made about their condition/treatment
Relationship with health	

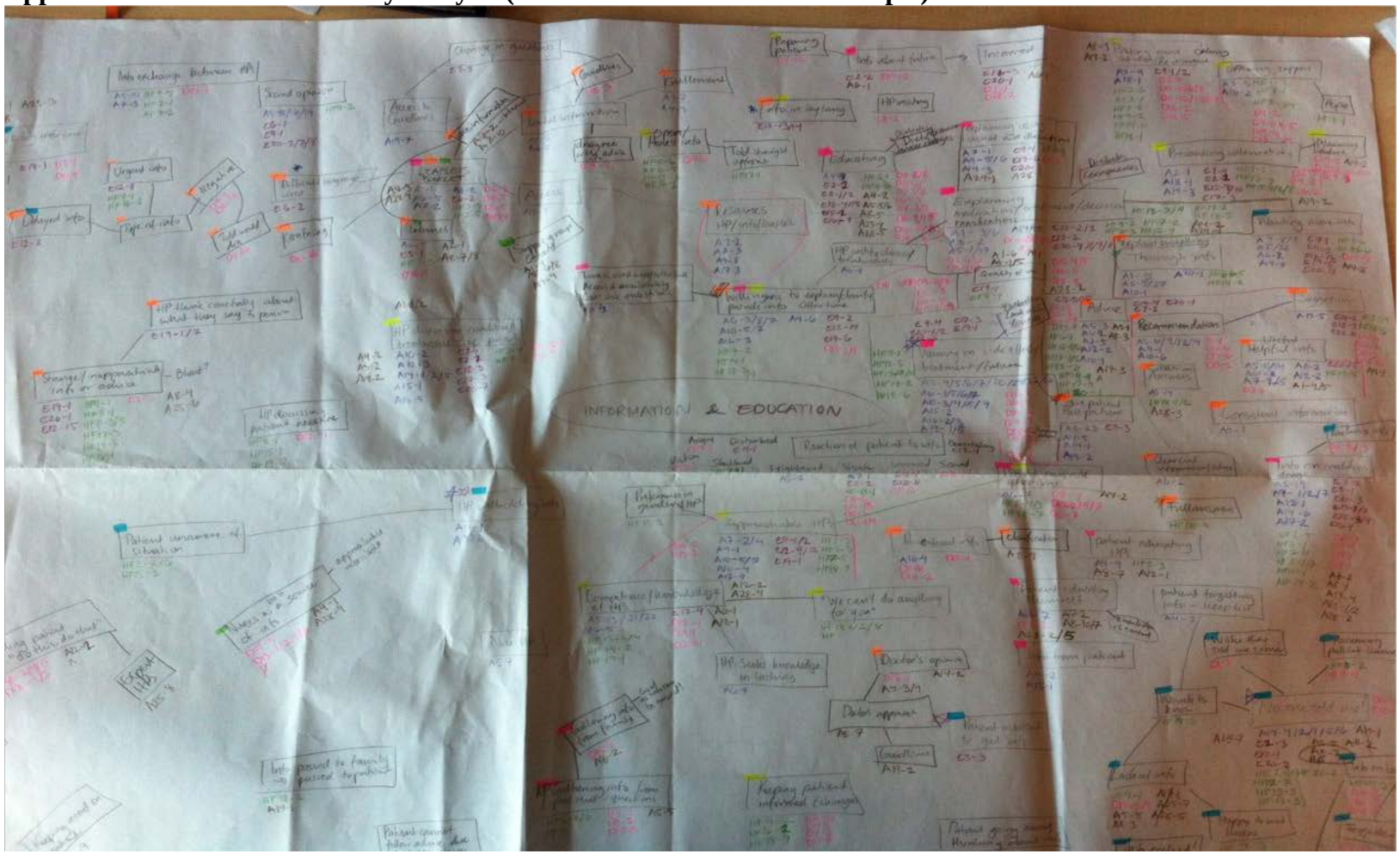
professionals Disagreement Doctor remembering personal history Trust Belief Risk	Between the person and their health professional, often in relation to treatment of condition Health professional making an effort to remember personal history e.g. previous treatments. Personal preferences etc. How the person trusts and has belief in the HP abilities and takes a risk by trusting their judgement
Respect & Dignity & Privacy	
Responsiveness to individual needs	How health professionals consider and respond to personal preferences/needs of the individual
Support from health professionals	Emotional/physical Support received from health professionals e.g. easing worries and fears about a treatment
Access & Availability	A&A given to primary and secondary health care e.g. referrals, investigations etc.
Environment	The environment in which care is provided, e.g. friendliness or staff, cleanliness of ward/office etc.
Consistency & Continuity	C&C provided in the care process e.g. seeing the same HPs, smooth transition of care etc.
Monitoring health	Health f the person being monitored on a regular basis so that action can be taken if something is discovered
Effectiveness	Effectiveness of the care provided in improving the problem or the person's health
Expectations	Expectations of the person of their care e.g. outcomes of treatment in improving symptoms

Appendix 4: Analytic memo for secondary analysis (rheumatoid arthritis example)

Code	Description
Diagnosis	Manly involves early signs of illness that were discovered by the person and reported to health professionals. Most interactions here are with GP and later referrals to specialists. This topic also highlights the process of diagnosis and early misdiagnosis by health professionals. This domain is greatly related patient-centred care, Time and Access and Availability.
Knowledge	This domain covers past and present knowledge as well as the process of gathering new information, whether by own means or through interaction with others. Lay conceptions refer to the person's ideas and beliefs about the condition such as origin and influential factors in relapse and healing. Contradictions or reframing of story stems from the theory that people present public and personal accounts when presenting their stories.
Impact of condition	These are the areas greatly affected by the condition. Physical health dominates this domain with many accounts of limited physical ability which can in turn affect other areas such as work, finances etc. Deformity and Fatigue may be limited to RA.
Living with condition	A number of issues that are dealt with by people with LTCs. Great emphasis on Diet, Exercise and Looking after own health but also covers a range of Emotions that are experienced during the course of the condition. Loss of independence is greatly related to Physical health and ability and to feeling of guilt over dependence on others. Health seeking behaviour is the process of taking responsibility for monitoring own health and seeking help and advice when necessary. This is an important area in chronic conditions as patients are given the choice and responsibility for their condition. Time refers to perceptions of time that has passed and reflection on the past.
Coping	Coping with the condition is presented in many forms and all sub-domains are interlinked. Loss or limited physical ability often leads to Adaptation of oneself to the environment and Use of Aid covers a range of products and equipment available to people with RA. Seeking normality is an interesting concept and often involves activities that provide control e.g. driving. But this can also refer to e.g. hiding disease from others (denial) in order to appear normal.
Pain	There are a great number of accounts of pain caused by condition and measures taken (medication, surgery, alternative therapies and treatment) to relieve pain. Often pain is the driving factor for Help seeking behaviour, agreeing to medication and limited physical activity. Not sure yet if this is specific to RA.
Support	Support is mostly provided by close family and sometimes friends. However, other patients, local council (e.g. help with cleaning, parking permit) and support groups do provide some support – although limited and does not apply to everyone.
Family	A separate domain as it is frequently covered. Interestingly, there are both positive and negative aspects of this impact. For instance, although there is often a great impact on family and young children,

	their adaptation and involvement in care provides them with knowledge and understanding as well as empathy and compassion for others. Family also provide QoL for the person and aid in coping with condition.
Treatment	This topic covers all medical, surgical and alternative treatments that the patient has experienced.
Patient-centred care?	Several sub-domains have been added to this domain. Communication is a separate sub-domain as it covers lack of communication and how information is presented to the patient. However, communication is not limited to the health professionals and patient, but also between health professionals about the patient. Information and Education are kept as one sub-domain as when you provide information, you also educate the person. Patients take away great knowledge from information provided by health professionals. Patient involvement is divided into Involvement in care and Choice and Control as often patients are informed and therefore involved in their care but they are not always presented with a choice. Responsiveness to individual needs is a grey area and overlaps with many other domains. For instance, it can be about referring a patient to a specialist for a specific need, a nurse being mindful of painful joints during therapy or it can also involve medication, e.g. changing medication when needed and not working well. Empathy and compassion involves showing interest in the patient's health and is very closely related to Support from health professionals. It is a more overall 'package' of care and caring about what happens to the patient. Privacy has been added to cover this need, both in relation to personal care and communication of important information by health professionals. Access and Availability of care dominates this domain as it covers referrals, access to hospitals and availability of care or treatment. This is often related to time (waiting) or denied access to special treatment and is closely related to domains of patient centred care such as Responsiveness to individual needs and Relationship with health professionals. Environment refers to hospital settings e.g. in-patient wards, waiting rooms, parking etc. The two sub-domains are closely related. Monitoring health is important in LTC, however, patients are often given the responsibility for their own health and are informed to seek help when needed. Consistency and continuity, when in relation to LTCs, is a very patient-centred domain as it covers relationship and support from health professionals and being in the care of the same specialist/health professional. Outcomes of treatment are often described by the person as either effective or ineffective. This is guarded by the person's expectations and [realistic] information from health professionals. Although patients appear to have realistic expectations in relation to the benefit of a treatment, they do expect a high level of competency from their health professionals.

Appendix 5: OSOP for secondary analysis (Information & Education example)



Appendix 6: Questionnaire v0.1

NAME OF QUESTIONNAIRE

Version 0.1, 01 Jan 2013

COMPLETING THIS QUESTIONNAIRE

The purpose of this questionnaire is for you to provide us with feedback about the care that you received for your long-term condition in the last 12 months.

Please tick **ONE** of the boxes to indicate your answer to each question.
If you make a mistake, simply cross out and put a tick in the correct box.

Please return this questionnaire in the envelope provided.
You do not have to use a stamp - the postage is already paid.

Thank you.

Section 1

The following questions are about *your views and experiences* of healthcare in relation to your long-term condition

1. Thinking about how different staff involved in your care communicated and updated each other about your treatment…

a. Did you receive **conflicting information** from different health professionals?
[ ] Yes, always
[ ] Yes, most of the time
[ ] Yes, some of the time
[ ] No, never
[ ] Don't know

b. Was there ever a **delay in your care** because of lack of communication between different health professionals?
[ ] Yes, always
[ ] Yes, most of the time
[ ] Yes, some of the time
[ ] No, never
[ ] Don't know

c. Did you feel that different health professionals kept each other informed of your medical history?
[ ] Yes, always
[ ] Yes, most of the time
[ ] Yes, some of the time
[ ] No, never
[ ] Don't know

2. Were you given follow-up appointments when you felt you needed them?
[ ] Yes, always
[ ] Yes, most of the time
[ ] Yes, some of the time
[ ] No, never
[ ] Don't know

3. Were you offered different ways of **contacting staff** outside of standard appointment times and services? (e.g. email or telephone number)
[ ] Yes
[ ] If yes, then please state how …….
[ ] No
[ ] No, but I would have liked to
[ ] No, and I didn't need it

4. If you did contact staff outside of standard appointment times, **how helpful were they** in…

a. Answering your questions?
[ ] Extremely helpful
[ ] Very helpful
[ ] Helpful
[ ] A little helpful
[ ] Not at all helpful
[ ] Don't know

b. Relieving your worries and fears?
[ ] Extremely helpful
[ ] Very helpful
[ ] Helpful
[ ] A little helpful
[ ] Not at all helpful
[ ] Don't know

c. Helping you manage your condition?
[ ] Extremely helpful
[ ] Very helpful
[ ] Helpful
[ ] A little helpful
[ ] Not at all helpful
[ ] Don't know

5. How **useful was the information** you received in helping you manage your condition?
[ ] Extremely helpful
[ ] Very helpful
[ ] Helpful
[ ] A little helpful
[ ] Not at all helpful
[ ] Don't know

6. How **helpful were health professionals in helping** you limit the impact of your condition on your life?
[ ] Extremely helpful
[ ] Very helpful
[ ] Helpful
[ ] A little helpful
[ ] Not at all helpful
[ ] Don't know

7. If there were any **changes to your treatment**, were you…

a. Involved in the discussion?
[ ] Yes, always
[ ] Yes, most of the time
[ ] Yes, some of the time
[ ] No, never
[ ] Don't know

b. Understand why these changes were happening?
[ ] Yes, always
[ ] Yes, most of the time
[ ] Yes, some of the time
[ ] No, never
[ ] Don't know

8. Did you get the information you wanted about the future of your condition? (e.g. side effects and secondary health issues)
[ ] Yes, always
[ ] Yes, most of the time
[ ] Yes, some of the time
[ ] No, never
[ ] Don't know

9. Were you given the opportunities you wanted to discuss how your condition may change over time? (e.g. side effects and secondary health issues)
[ ] Yes, always
[ ] Yes, most of the time
[ ] Yes, some of the time
[ ] No, never
[ ] Don't know

10. If you developed any **new symptoms or problems**, did the staff involved in your care…

a. Trust your judgement that something was wrong?
[ ] Yes, always
[ ] Yes, most of the time
[ ] Yes, some of the time
[ ] No, never
[ ] Don't know

b. Get you the right treatment quickly?
[ ] Yes, always
[ ] Yes, most of the time
[ ] Yes, some of the time
[ ] No, never
[ ] Don't know

11. Were you able to **talk with staff about personal issues that were important to you?** (e.g. how the condition affects your family and social life)
[ ] Yes, always
[ ] Yes, most of the time
[ ] Yes, some of the time
[ ] No, never
[ ] Don't know

12. Were you able to **discuss medication and treatment** options with staff? (e.g. changes, dosage)
[ ] Yes, always
[ ] Yes, most of the time
[ ] Yes, some of the time
[ ] No, never
[ ] Don't know

13. Were the advice and treatment you were given right for you?
[ ] Yes, always
[ ] Yes, most of the time
[ ] Yes, some of the time
[ ] No, never
[ ] Don't know

14. Were you able to discuss how you can adapt treatment to suit your personal situation?
[ ] Yes, always
[ ] Yes, most of the time
[ ] Yes, some of the time
[ ] No, never
[ ] Don't know

15. If you take lots of different medication for your condition(s), do you get enough practical help on how to take them?
[ ] Yes, always
[ ] Yes, most of the time
[ ] Yes, some of the time
[ ] No, never
[ ] Don't know

16. If you received new medication or treatment in the last 12 months, how **helpful were the instructions** you were given on how it should be used or taken?
[ ] Extremely helpful
[ ] Very helpful
[ ] Helpful
[ ] A little helpful
[ ] Not at all helpful
[ ] Don't know

17. Thinking about your appointments with health professionals…

a. How important was it for you to see the same person, rather than a different health professional(s)?
[ ] Very important
[ ] Important
[ ] I would prefer to see the same person
[ ] Not important
[ ] Don't know

b. Were you given the **option** of seeing the same health professional(s)?
[ ] Yes, always
[ ] Yes, most of the time
[ ] Yes, some of the time
[ ] No, never
[ ] Don't know

Section 2

The following questions are about *you and your long-term condition(s).*

1. How old are you in years?

_____

2. Are you male or female?
[ ] Male
[ ] Female

3. Select the highest level of education you have completed?
[ ] No formal education
[ ] Primary school
[ ] Secondary school
[ ] Third level (degree or higher)
[ ] Don't know
[ ] Other _____

4. To which of these groups do consider you belong?
[ ] WHITE: of British origin
[ ] WHITE: of other or origin
[ ] ASIAN: of Indian origin
[ ] ASIAN: of Bangladeshi origin
[ ] ASIAN: of Pakistani origin
[ ] ASIAN: of Chinese origin
[ ] ASIAN: of other origin
[ ] BLACK: of African origin
[ ] BLACK: of Caribbean origin
[ ] BLACK: of other origin
[ ] Don't know
[ ] Other _____

5. What is your principle economic status?
[ ] At work
[ ] Unemployed
[ ] Student
[ ] Retired (at retirement age)
[ ] Retired (due to ill health)
[ ] On home duties (e.g. housework, looking after children or other persons)

6. To which group do you belong?
[ ] I think I might have this condition
[ ] I care for someone who I think may have this condition
[ ] I have been diagnosed with this condition
[ ] I care for someone who has been diagnosed with this condition
[ ] Other _____

Thank you for completing this questionnaire. Your contribution to our survey is extremely valued.

Appendix 7: Questionnaire v1.0

Experience of care in long-term conditions

Version 1, 01 Feb 2013

COMPLETING THIS QUESTIONNAIRE

The purpose of this questionnaire is for you to provide us with feedback about the care that you received for your long-term condition in the last 12 months.

Please tick **ONE** of the boxes to indicate your answer to each question.
If you make a mistake, simply cross out and put a tick in the correct box.

Please return this questionnaire in the envelope provided.
You do not have to use a stamp - the postage is already paid.

Thank you for taking the time to complete this.

Section 1
The following questions are about *your views and experiences* of healthcare in relation to your long-term condition(s)

1. Thinking about how different staff involved in your care communicated and updated each other about your treatment…

a. Did you receive conflicting information from different health professionals?
[ ] Yes, always
[ ] Yes, most of the time
[ ] Yes, some of the time
[ ] No, never
[ ] Don't know

b. Was there ever a delay in your care because of lack of communication between different health professionals?
[ ] Yes, always
[ ] Yes, most of the time
[ ] Yes, some of the time
[ ] No, never
[ ] Don't know

c. Did you feel that different health professionals kept each other informed of your medical history?
[ ] Yes, always
[ ] Yes, most of the time
[ ] Yes, some of the time
[ ] No, never
[ ] Don't know

2. Were you given follow-up appointments when you felt you needed them?
[ ] Yes, always
[ ] Yes, most of the time
[ ] Yes, some of the time
[ ] No, never
[ ] Don't know

3. Were you offered different ways of contacting staff in between standard appointment times and services? (e.g. email or telephone number)
[ ] Yes
[ ] If yes, please state how
……..
[ ] No
[ ] No, but I would have liked to
[ ] No, and I didn't need it

4. If you did contact staff outside of standard appointment times, how helpful were they in…

a. Answering your questions?
[ ] Extremely helpful
[ ] Very helpful
[ ] Helpful
[ ] A little helpful
[ ] Not at all helpful
[ ] Don’t know

b. Relieving your worries and fears?
[ ] Extremely helpful
[ ] Very helpful
[ ] Helpful
[ ] A little helpful
[ ] Not at all helpful
[ ] Don’t know

c. Helping you manage your condition(s)?
[ ] Extremely helpful
[ ] Very helpful
[ ] Helpful
[ ] A little helpful
[ ] Not at all helpful
[ ] Don’t know

5. How useful was the information you received in helping you manage your condition(s)?
[ ] Extremely helpful
[ ] Very helpful
[ ] Helpful
[ ] A little helpful
[ ] Not at all helpful
[ ] Don’t know

6. How helpful were health professionals in helping you limit the impact of your condition(s) on your life?
[ ] Extremely helpful
[ ] Very helpful
[ ] Helpful
[ ] A little helpful
[ ] Not at all helpful
[ ] Don’t know

7. If there were any changes to your treatment, were you…

a. Involved in the discussion?
[ ] Yes, always
[ ] Yes, most of the time
[ ] Yes, some of the time
[ ] No, never
[ ] Don't know

b. Understand why these changes were happening?
[ ] Yes, always
[ ] Yes, most of the time
[ ] Yes, some of the time
[ ] No, never
[ ] Don't know

8. Did you get the information you wanted about how your condition(s) may change over time?
[ ] Yes, always
[ ] Yes, most of the time
[ ] Yes, some of the time
[ ] No, never
[ ] Don't know/information not wanted

9. Were you given the opportunities you wanted to discuss how your condition(s) may change over time?
[ ] Yes, always
[ ] Yes, most of the time
[ ] Yes, some of the time
[ ] No, never
[ ] Don't know/I did not want to discuss this

10. If you developed any new symptoms or problems, did the staff involved in your care…

a. Trust your judgement that something was wrong?
[ ] Yes, always
[ ] Yes, most of the time
[ ] Yes, some of the time
[ ] No, never
[ ] Don't know

b. Get you the right treatment quickly?
[ ] Yes, always
[ ] Yes, most of the time
[ ] Yes, some of the time
[ ] No, never
[ ] Don't know

11. Were you able to talk with staff about personal issues that were important to you? (e.g. how the condition(s) affects your family and social life)
[ ] Yes, always
[ ] Yes, most of the time
[ ] Yes, some of the time
[ ] No, never
[ ] Don’t know

12. Were you able to discuss medication and treatment options with staff? (e.g. changes, dosage)
[ ] Yes, always
[ ] Yes, most of the time
[ ] Yes, some of the time
[ ] No, never
[ ] Don’t know

13. Were the advice and treatment you were given right for you?
[ ] Yes, always
[ ] Yes, most of the time
[ ] Yes, some of the time
[ ] No, never
[ ] Don’t know

14. Were you able to discuss how you can adapt treatment to suit your personal situation?
[ ] Yes, always
[ ] Yes, most of the time
[ ] Yes, some of the time
[ ] No, never
[ ] Don’t know

15. If you take lots of different medication for your condition(s), do you get enough practical help on how to take them?
[ ] Yes, always
[ ] Yes, most of the time
[ ] Yes, some of the time
[ ] No, never
[ ] Don’t know

16. If you received new medication or treatment, how helpful were the instructions you were given on how it should be used or taken?
[ ] Extremely helpful
[ ] Very helpful
[ ] Helpful
[ ] A little helpful
[ ] Not at all helpful
[ ] Don’t know

17. Thinking about your appointments with health professionals…

a. How important was it for you to see the same person, rather than a different health professional(s)?
[ ] Very important
[ ] Important
[ ] I would prefer to see the same person
[ ] Not important
[ ] Don't know

b. Were you given the option of seeing the same health professional(s)?
[ ] Yes, always
[ ] Yes, most of the time
[ ] Yes, some of the time
[ ] No, never
[ ] Don't know

18. In the last 12 months, have you had a full review of your condition and treatment?
[ ] Yes
[ ] No
[ ] Don't know

19. If you did have a full review, how helpful was this to you?
[ ] Extremely helpful
[ ] Very helpful
[ ] Helpful
[ ] A little helpful
[ ] Not at all helpful
[ ] Don't know

20. Did you get to see a specialist nurse for your condition?
[ ] Yes
[ ] Yes, and I value this
[ ] No
[ ] No, but I would like to have one
[ ] No, I don't need this

21. Any other comments of experiences you want to share?

_____

Section 2
The following questions are about *you and your long-term condition(s)*.

1. How old are you in years?
_____

2. Are you male or female?
[ ] Male [ ] Female

3. Select the highest level of education you have completed?
[ ] Secondary school
[ ] Third level (degree or higher)
[ ] Don't know
[ ] Other _____

4. What is your working status?
[ ] At work
[ ] Unemployed
[ ] Student
[ ] Retired
[ ] Not working due to ill health
[ ] Not working other reasons (e.g. housework, looking after children or other persons)

5. To which of these groups do consider you belong?
[ ] WHITE: of British origin
[ ] WHITE: of other origin
[ ] ASIAN: of Indian origin
[ ] ASIAN: of Bangladeshi origin
[ ] ASIAN: of Pakistani origin
[ ] ASIAN: of Chinese origin
[ ] ASIAN: of other origin
[ ] BLACK: of African origin
[ ] BLACK: of Caribbean origin
[ ] BLACK: of other origin
[ ] Don't know
[ ] Other _____

Thank you for completing this questionnaire. Your contribution to our survey is extremely valued.

Appendix 8: Recruitment advert

School for Primary Care Research

Increasing the evidence base for primary care practice

What do people with long term conditions think is important about their health care?

UNIVERSITY OF OXFORD

Do you have a long term condition?
Would you be interested in taking part in our research?

People with long-term conditions may have distinctive views and experiences about the way health care is provided. Our research explores whether these views and experiences can be captured in a newly developed questionnaire.

Your involvement

We are now looking to interview people who have one or more long-term conditions. Taking part in this research would involve being interviewed and asked to provide some feedback about our questionnaire. For instance, we are interested in identifying questions which people may find difficult to answer. We would also want to make sure that we have accurately captured aspects of care that are important to people with long-term conditions. The information you provide may help us improve our questions and better understand the experiences of healthcare that are important to people with long-term conditions.

Can the work be done from home?

Yes. We can interview you by telephone or by Skype. If you prefer, we can do a face to face interview at your home or in Oxford.

Thank you token and expenses

A token will be given of £20. All telephone calls will be made by the research team. If travel is required then expenses will be covered.

Contact

For more information on taking part, please contact Researcher and PhD student Monica Hadi via email: monica.hadi@phc.ox.ac.uk or phone: 01865 849955/07830 962978.

The National Institute for Health Research School for Primary Care Research is a partnership between the Universities of Birmingham, Bristol, Keele, Manchester, Nottingham, Oxford, Southampton and UCL.

This poster summarises independent research funded by the National Institute for Health Research. The views expressed are those of the author(s) and not necessarily those of the NHS, the NIHR or the Department of Health.

NHS National Institute for Health Research

Appendix 9: Information sheet



'Examining key experiences of health care delivery that matter to people with long-term conditions'

INFORMATION ABOUT THE RESEARCH

What is the purpose of the study?

Patient with long-term conditions may have distinctive views and experiences about the way health care is provided, which are perhaps different to patients with acute or curable conditions. The aim of this research is to examine whether these views and experiences can be accessed via a questionnaire.

We have developed a series of questions following in-depth analysis of interviews with people with several different long-term conditions. We would like to find out whether the questions are both easy to understand and accurately capture aspects of care that are important to people with long-term conditions.

Why have I been asked to take part in the study?

You have been identified by the researcher, or by someone known to the researcher, as someone who may have a diagnosis of a particular long-term condition.

Am I eligible to take part in this study?

We are looking for people aged 18 or over who have a current diagnosis of a long-term condition. You must also be able to answer a questionnaire independently.

What will taking part in the interview involve?

We will ask you to take some time to complete a set of questions. The researcher will discuss your answers with you to see how you arrived at your answer. By doing this we can identify questions which people may find difficult to answer or questions which may be unclearly worded. We can use your opinions to improve our questions.

You can choose where to be interviewed (for example, this may be in your own home or in the Department of Primary Care Health Sciences, University of Oxford) at a time that suits you. Alternatively, the interview can also be conducted over telephone or on the internet, using Skype. Again, the researcher would contact you and arrange a time that suits you. The interview will be audio recorded.

Taking part in this study will take about 40-50 minutes your time. The interview will be recorded to save the researcher time writing notes; however, all information you give will remain strictly confidential and will only be seen by members of the research team.

What are the possible disadvantages or risks of taking part?
Given the nature of this research, it is unlikely that there will be any harms or risks to you by taking part in this study. You can decide not to take part at any point during the study and you can choose not to discuss your responses to the questions if you feel that it may make you uncomfortable. If you choose to withdraw, then your information and any contributions would be destroyed.

What are the possible benefits of taking part?
The information you provide may help us better understand the experiences of care that are important to people with long-term conditions.

We offer £20 to those taking part in this research and will reimburse any travel expenses you may incur.

What will happen to the results of the study?
The results of this study will be used to refine the questions we have developed. These questions will be used to evaluate the quality of care that people with long-term conditions receive. Findings from the study will be written up as a journal article and presented at conferences.

This study will also contribute to doctoral research.

Who is organising and funding the research?
This research will be undertaken by the Departments of Primary Care Health Sciences, University of Oxford, in collaboration with the National School of Primary Care Research (NSPCR).

Questions or help?
Please contact Monica Hadi (doctoral student) by telephone on 01865 849955 or by email monica.hadi@hmc.ox.ac.uk

Appendix 10: Consent form



CONSENT FORM

'Examining key experiences of health care delivery that matter to people with long-term conditions'

Investigators: Monica Hadi (DPhil student), Dr Louise Locock and Professor Ray Fitzpatrick

Please indicate that you understand the following by placing a tick [✓] in each box:

I understand my participation is entirely voluntary	
I understand I can refuse to answer a question at any time	
I understand I am free to withdraw at any time, without giving any reason	
I understand the interview will be audio recorded	
The results of the study will only be presented in anonymous form	
If any direct quotes from the interview are used in reports, these will be anonymised	

Please sign this form to indicate that you are willing to take part in this study:

Interviewee: _____

Researcher:_____

Date: _____

Appendix 11: Topic guide

Topic guide for cognitive interviews with people with long-term conditions	**Introduction** Researcher explains purpose of interview and how interview will be conducted Assure confidentiality Allow interviewee to ask additional questions **General feedback** How relevant was the overall content in relation to your condition? Were there topics or aspects that were missing? Or not important to you? Length Presentation Were instructions clear? any concerns? repetitive? Would you complete it if it were sent to you by post? Or given in hospital/GP surgery? **Item specific** Does this question make sense to you? How did you arrived at the answer? Was this difficult or easy to answer? Do you have any suggestions for re-wording? How did you find the response options? Do the options provided make sense to you? How would you make them clearer or easier to understand?

Topic guide for cognitive interviews with health professionals	**Introduction** Researcher explains purpose of interview and how interview will be conducted Assure confidentiality Allow interviewee to ask additional questions **General feedback** General impressions Relevance to people with long-term conditions Were there topics or aspects that were missing? Or not important? Length Presentation Were instructions clear? Any concerns? Repetitive? Would you ask your patients to complete this questionnaire? **Item specific** Does this question make sense to you? Difficult/Easy understanding Do you have any suggestions for re-wording? What do you think of the response options? Do the options provided make sense to you? How would you make them clearer or easier to understand?

Appendix 12: Questionnaire v2.0

Experience of care in long-term conditions

Version 2, 01 May 2013

COMPLETING THIS QUESTIONNAIRE

The purpose of this questionnaire is for you to provide us with feedback about the care that you received for your long-term condition in the last 12 months.

Please tick **ONE** of the boxes to indicate your answer to each question.
If you make a mistake, simply cross out and put a tick in the correct box.

Please return this questionnaire in the envelope provided.
You do not have to use a stamp - the postage is already paid.

Thank you for taking the time to complete this.

Section 1

The following questions are about *your views and experiences* of healthcare in relation to your long-term condition(s)

1. In the last 12 months, how many times did you see any of the following health professionals for your condition(s)…

a. General Practitioner
[ ] Not at all
[ ] 1-2 times
[ ] 3 or more
[ ] Don't know
[ ] N/A

b. Hospital doctor
[ ] Not at all
[ ] 1-2 times
[ ] 3 or more
[ ] Don't know
[ ] N/A

c. Practice or specialist nurse
[ ] Not at all
[ ] 1-2 times
[ ] 3 or more
[ ] Don't know
[ ] N/A

d. Other health professional
[ ] Not at all
[ ] 1-2 times
[ ] 3 or more
[ ] Don't know
[ ] N/A

2. Thinking about your appointments with health professionals…

a. How important was it for you to see the same person, rather than a different health professional(s)?
[ ] Very important
[ ] Important
[ ] I would prefer to see the same person
[ ] Not important
[ ] Don't know
[ ] N/A

b. Were you given the option of seeing the same health professional(s)?
[ ] Yes, always
[ ] Yes, most of the time
[ ] Yes, some of the time
[ ] No, never
[ ] Don't know
[ ] N/A

3. Were you given follow-up appointments when you requested them?
[ ] Yes, always
[ ] Yes, most of the time
[ ] Yes, some of the time
[ ] No, never
[ ] Don't know
[ ] N/A

4. Did you get to see a specialist nurse for your condition?
[ ] Yes
[ ] Yes, and I value this
[ ] No
[ ] No, but I would like to have seen one
[ ] No, I don't need this
[ ] N/A

5. In the last 12 months, do you feel that you have had a full review of your condition and treatment?
[ ] Yes
[ ] No
[ ] Don't know
[ ] N/A

6. If you did have a full review, how helpful was this to you?
[ ] Extremely helpful
[ ] Very helpful
[ ] Helpful
[ ] Not at all helpful
[ ] Don't know
[ ] N/A

7. Were you offered different ways of contacting health professionals in between your usual appointments? (e.g. email or telephone number)
[ ] Yes
If yes, please state how
……..
[ ] No
[ ] No, but I would have liked to
[ ] No, and I didn't need it
[ ] N/A

8. If you did contact staff outside of standard appointments, how helpful were they in…

a. Answering your questions?
[ ] Extremely helpful
[ ] Very helpful
[ ] Helpful
[ ] Not at all helpful
[ ] Don't know
[ ] N/A

b. Helping you manage your condition(s)?
[ ] Extremely helpful
[ ] Very helpful
[ ] Helpful
[ ] Not at all helpful
[ ] Don't know
[ ] N/A

c. Relieving your worries and fears?
[ ] Extremely helpful
[ ] Very helpful
[ ] Helpful
[ ] Not at all helpful
[ ] Don't know
[ ] N/A

9. How useful was the information you received in helping you manage your condition(s)?
[ ] Extremely useful
[ ] Very useful
[ ] Useful
[ ] Not at all useful
[ ] Don't know
[ ] N/A

10. How useful were health professionals in helping you limit the impact of your condition(s) on your life?
[ ] Extremely useful
[ ] Very useful
[ ] Useful
[ ] Not at all useful
[ ] Don't know
[ ] N/A

11. Did you get the information you felt you needed about how your condition(s) may change over time?
[ ] Yes, always
[ ] Yes, most of the time
[ ] Yes, some of the time
[ ] No, never
[ ] Don't know/information not wanted
[ ] N/A

12. Were you given the opportunities you felt you needed to discuss how your condition(s) may change over time?
[ ] Yes, always
[ ] Yes, most of the time
[ ] Yes, some of the time
[ ] No, never
[ ] Don't know/I did not want to discuss this
[ ] N/A

13. Did you feel able to talk with health professionals about personal issues that were important to you? (e.g. how the condition(s) affects your family and social life)
[ ] Yes, always
[ ] Yes, most of the time
[ ] Yes, some of the time
[ ] No, never
[ ] Don't know/I did not wish to discuss this
[ ] N/A

14. Did you feel able to discuss medication and treatment options with health professionals? (e.g. changes, dosage)
[ ] Yes, always
[ ] Yes, most of the time
[ ] Yes, some of the time
[ ] No, never
[ ] Don't know
[ ] N/A

15. Did you feel that the advice and treatment you were given were right for you?
[ ] Yes, always
[ ] Yes, most of the time
[ ] Yes, some of the time
[ ] No, never
[ ] Don’t know
[ ] N/A

16. Were you given the opportunity to discuss how you can adapt treatment to suit your personal situation?
[ ] Yes, always
[ ] Yes, most of the time
[ ] Yes, some of the time
[ ] No, never
[ ] Don’t know
[ ] N/A

17. Did you get enough practical advice on how to take your medication(s)?
[ ] Yes, always
[ ] Yes, most of the time
[ ] Yes, some of the time
[ ] No, never
[ ] Don’t know
[ ] N/A

18. If you take more than one type of medication, did you get enough advice on how to manage them?
[ ] Yes, always
[ ] Yes, most of the time
[ ] Yes, some of the time
[ ] No, never
[ ] Don’t know
[ ] N/A

19. If you received new medication or treatment, how helpful was the advice you were given on how it should be used or taken?
[ ] Extremely helpful
[ ] Very helpful
[ ] Helpful
[ ] Not at all helpful
[ ] Don’t know
[ ] N/A

20. Thinking about how different health professionals involved in your care communicated and updated each other about your treatment…

a. Did you receive conflicting information from different health professionals?
[ ] Yes, always
[ ] Yes, most of the time
[ ] Yes, some of the time
[ ] No, never
[ ] Don't know
[ ] N/A

b. Was there ever a delay in your care because of lack of communication between different health professionals?
[ ] Yes, always
[ ] Yes, most of the time
[ ] Yes, some of the time
[ ] No, never
[ ] Don't know
[ ] N/A

c. Did you feel that different health professionals kept each other informed of your medical history?
[ ] Yes, always
[ ] Yes, most of the time
[ ] Yes, some of the time
[ ] No, never
[ ] Don't know
[ ] N/A

21. If you developed any new symptoms or problems, did the health professionals involved in your care…

a. Trust your judgement that something was wrong?
[ ] Yes, always
[ ] Yes, most of the time
[ ] Yes, some of the time
[ ] No, never
[ ] Don't know
[ ] N/A

b. Get you the right treatment quickly?
[ ] Yes, always
[ ] Yes, most of the time
[ ] Yes, some of the time
[ ] No, never
[ ] Don't know
[ ] N/A

22. If there were any changes to your treatment…

a. Were you involved in the discussion?
[ ] Yes, always
[ ] Yes, most of the time
[ ] Yes, some of the time
[ ] No, never
[ ] Don't know
[ ] N/A

b. Did understand why these changes were happening?
[ ] Yes, always
[ ] Yes, most of the time
[ ] Yes, some of the time
[ ] No, never
[ ] Don't know
[ ] N/A

23. Any other comments or experiences you want to share?

_____

Section 2

The following questions are about *you and your long-term condition(s)*.

1. How old are you in years?

_____

2. Are you male or female?

[ ] Male [ ] Female

3. Please list any long term conditions you have

_____

4. Select the highest level of education you have completed?

[ ] Secondary school
[ ] Third level (degree or higher)
[ ] Don't know
[ ] Other _____

5. What is your working status?

[ ] Employed
[ ] Unemployed
[ ] Student
[ ] Retired
[ ] Not working due to ill health
[ ] Not working other reasons (e.g. housework, looking after children or other persons)

6. To which of these groups do consider you belong?

[ ] WHITE: of British origin
[ ] WHITE: of other origin
[ ] ASIAN: of Indian origin
[ ] ASIAN: of Bangladeshi origin
[ ] ASIAN: of Pakistani origin
[ ] ASIAN: of Chinese origin
[ ] ASIAN: of other origin
[ ] BLACK: of African origin
[ ] BLACK: of Caribbean origin
[ ] BLACK: of other origin
[ ] MIXED RACE
[ ] Don't know
[ ] Other _____

Thank you for completing this questionnaire. Your contribution to our survey is extremely valued.

Appendix 13: Questionnaire v3.0



Experience of Care in Long-Term Conditions

Version 3, 01 Jun 2013

COMPLETING THIS QUESTIONNAIRE

The purpose of this questionnaire is for you to provide us with feedback about the care you received for your long-term condition(s) in the last 12 months.

For each question, please tick **ONE** of the boxes to indicate your answer to each question.
If you make a mistake, simply cross it and put a tick in the correct box. If you do not wish to answer a question, then leave it blank.

Please return this questionnaire in the envelope provided.
You do not have to use a stamp - the postage is already paid for.

Thank you for taking the time to complete this questionnaire.

SECTION 1
The following questions are about *your long-term condition(s)*

1. Please list the long-term condition(s) you have:

2. In the last 12 months…

a. How often did your long-term condition(s) affect you emotionally?

- ☐ Very often
- ☐ Often
- ☐ Sometimes
- ☐ Rarely
- ☐ Never
- ☐ Don't know

b. How often did your long-term condition(s) affect your daily activities?

- ☐ Very often
- ☐ Often
- ☐ Sometimes
- ☐ Rarely
- ☐ Never
- ☐ Don't know

SECTION 2

The following questions are about *your views and experiences of healthcare* in relation to your long-term condition(s)

1. In the last 12 months, how many times did you see any of the following health professionals for your condition(s)...

a. General Practitioner (GP)

- ☐ 1-2 times
- ☐ 3 or more times
- ☐ Not at all, I didn't need an appointment
- ☐ Not at all, I wasn't offered an appointment
- ☐ Don't know

b. Hospital Doctor (e.g. specialist)

- ☐ 1-2 times
- ☐ 3 or more times
- ☐ Not at all, I didn't need an appointment
- ☐ Not at all, I wasn't offered an appointment
- ☐ Don't know

c. Practice nurse or specialist nurse

- ☐ 1-2 times
- ☐ 3 or more times
- ☐ Not at all, I didn't need an appointment
- ☐ Not at all, I wasn't offered an appointment
- ☐ Don't know

d. Other Health Professional (e.g. Dietician, Physiotherapist)

- ☐ 1-2 times
- ☐ 3 or more times
- ☐ Not at all, I didn't need an appointment
- ☐ Not at all, I wasn't offered an appointment
- ☐ Don't know

SECTION 2

The following questions are about *your views and experiences of healthcare* in relation to your long-term condition(s)

2. Thinking about your appointments with health professionals in the last 12 months…

a. How important is it for you to see the same person, rather than a different health professional(s)?

- ☐ Very important
- ☐ Important
- ☐ Not very important
- ☐ Not important at all
- ☐ Don't know
- ☐ I didn't see anyone in the last 12 months

b. Were you given the option of seeing the same health professional(s)?

- ☐ Yes, always
- ☐ Yes, most of the time
- ☐ Yes, some of the time
- ☐ No, never
- ☐ Don't know
- ☐ I didn't see anyone in the last 12 months

c. Were you given appointments when you requested them?

- ☐ Yes, always
- ☐ Yes, most of the time
- ☐ Yes, some of the time
- ☐ No, never
- ☐ Don't know
- ☐ I didn't request appointments in the last 12 months

d. Did you get to see a specialist nurse for your condition?

- ☐ Yes
- ☐ Yes, and I value this
- ☐ No, I did not need to see one
- ☐ No, but I would like to have seen one
- ☐ I didn't see a specialist nurse in the last 12 months

SECTION 2

The following questions are about *your views and experiences of healthcare* in relation to your long-term condition(s)

3. In the last 12 months…

a. Did you have a full annual review of your condition and treatment?

- ☐ Yes
- ☐ No, I wasn't offered one
- ☐ No, I didn't need one
- ☐ Don't know

b. If you did have a full annual review, how helpful was this to you?

- ☐ Very helpful
- ☐ Helpful
- ☐ Not very helpful
- ☐ Not at all helpful
- ☐ Don't know
- ☐ I didn't have a review

c. If you didn't have a full annual review, did you feel that you received any kind of review for your condition and treatment?

- ☐ Yes
- ☐ No, I wasn't offered one
- ☐ No, I didn't need it
- ☐ Don't know

SECTION 2

The following questions are about *your views and experiences of healthcare* in relation to your long-term condition(s)

4. In the last 12 months, were you offered different ways of contacting health professionals in between your usual appointments to discuss your condition? *(e.g. via email or telephone for reasons other than booking appointments or ordering medication)*

- ☐ Yes
  If yes, please state how
  _____
- ☐ Yes, but I didn't need or want it
- ☐ No, but I would have liked to
- ☐ No, I didn't need it
- ☐ Don't know/Not sure

5. If you did contact health professionals in between your usual appointments, how helpful were they in…

a. Answering your questions?

- ☐ Very helpful
- ☐ Helpful
- ☐ Not very helpful
- ☐ Not at all helpful
- ☐ Don't know
- ☐ I didn't contact anyone

b. Helping you manage your condition(s)?

- ☐ Very helpful
- ☐ Helpful
- ☐ Not very helpful
- ☐ Not at all helpful
- ☐ Don't know
- ☐ I didn't contact anyone

c. Addressing your worries and fears?

- ☐ Very helpful
- ☐ Helpful
- ☐ Not very helpful
- ☐ Not at all helpful
- ☐ Don't know
- ☐ I didn't contact anyone

SECTION 2

The following questions are about *your views and experiences of healthcare* in relation to your long-term condition(s)

6. Thinking about your appointments with health professionals in the last 12 months…

a. How useful was the information you received in helping you manage your condition(s)?

- ☐ Very useful
- ☐ Useful
- ☐ Not very useful
- ☐ Not at all useful
- ☐ Don't know
- ☐ I didn't receive any information in the last 12 months

b. Did you get the information you felt you needed about how your condition(s) may change over time?

- ☐ Yes, always
- ☐ Yes, most of the time
- ☐ Yes, some of the time
- ☐ No, never
- ☐ I did not want or need this information
- ☐ Don't know
- ☐ I didn't receive any information in the last 12 months

c. Were you given the opportunities you felt you needed to discuss how your condition(s) may change over time?

- ☐ Yes, always
- ☐ Yes, most of the time
- ☐ Yes, some of the time
- ☐ No, never
- ☐ I didn't want or need to discuss this
- ☐ Don't know
- ☐ I didn't see anyone in the last 12 months

d. Did you feel that the information and advice you were given was right for you?

- ☐ Yes, always
- ☐ Yes, most of the time
- ☐ Yes, some of the time
- ☐ No, never
- ☐ Don't know
- ☐ I didn't receive any advice in the last 12 months

SECTION 2

The following questions are about *your views and experiences of healthcare* in relation to your long-term condition(s)

7. Thinking about your appointments with health professionals in the last 12 months…

a. Did you feel that health professionals listened to what you had to say?

- ☐ Yes, always
- ☐ Yes, most of the time
- ☐ Yes, some of the time
- ☐ No, never
- ☐ Don't know
- ☐ I didn't see anyone in the last 12 months

b. Did you feel able to talk with health professionals about personal issues that were important to you? *(e.g. how the condition(s) affects your family and social life)*

- ☐ Yes, always
- ☐ Yes, most of the time
- ☐ Yes, some of the time
- ☐ No, never
- ☐ I did not wish to discuss this
- ☐ Don't know
- ☐ I didn't see anyone in the last 12 months

c. How useful were health professionals in helping you limit the impact of your condition(s) on your life?

- ☐ Very useful
- ☐ Useful
- ☐ Not very useful
- ☐ Not at all useful
- ☐ Don't know
- ☐ I didn't see anyone in the last 12 months

SECTION 2

The following questions are about *your views and experiences of healthcare* in relation to your long-term condition(s)

8. Thinking about the health care you received in the last 12 months…

a. Did you feel able to discuss medication and treatment options with health professionals? *(e.g. changes in medication or dosage)*

- ☐ Yes, always
- ☐ Yes, most of the time
- ☐ Yes, some of the time
- ☐ No, never
- ☐ Don't know
- ☐ I didn't see anyone in the last 12 months

b. Were you given the opportunity to discuss how you can adapt treatment to suit your personal situation? *(e.g. changes in medication or dosage)*

- ☐ Yes, always
- ☐ Yes, most of the time
- ☐ Yes, some of the time
- ☐ No, never
- ☐ Don't know
- ☐ I didn't see anyone in the last 12 months

c. Did you feel that the treatment you were given was right for you?

- ☐ Yes, always
- ☐ Yes, most of the time
- ☐ Yes, some of the time
- ☐ No, never
- ☐ Don't know
- ☐ I didn't receive any treatment in the last 12 months

d. Did you ask for a second opinion about your condition or treatment?

- ☐ Yes
- ☐ No, I did not need this
- ☐ No, but I would have liked to

SECTION 2

The following questions are about *your views and experiences of healthcare* in relation to your long-term condition(s)

9. Thinking about your medication in the last 12 months…

a. Did you get enough practical advice on how to take your medication? *(e.g. from GP, nurse, pharmacist)*

- ☐ Yes, always
- ☐ Yes, most of the time
- ☐ Yes, some of the time
- ☐ No, never
- ☐ Don't know
- ☐ N/A

b. If you take more than one type of medication, did you get enough advice on how to manage them?

- ☐ Yes, always
- ☐ Yes, most of the time
- ☐ Yes, some of the time
- ☐ No, never
- ☐ Don't know
- ☐ N/A

c. If you received new medication or treatment, how helpful was the advice you were given on how it should be used or taken?

- ☐ Very helpful
- ☐ Helpful
- ☐ Not very helpful
- ☐ Not at all helpful
- ☐ Don't know
- ☐ N/A

SECTION 2

The following questions are about *your views and experiences of healthcare* in relation to your long-term condition(s)

10. If there were any changes to your treatment in the last 12 months…

a. Were you involved in the discussion?

- ☐ Yes, always
- ☐ Yes, most of the time
- ☐ Yes, some of the time
- ☐ No, never
- ☐ Don't know
- ☐ There were no changes in my treatment in the last 12 months

b. Did you understand why these changes were happening?

- ☐ Yes, always
- ☐ Yes, most of the time
- ☐ Yes, some of the time
- ☐ No, never
- ☐ Don't know
- ☐ There were no changes in my treatment in the last 12 months

SECTION 2

The following questions are about *your views and experiences of healthcare* in relation to your long-term condition(s)

11. If you developed any new symptoms or problems in the last 12 months…

a. Did health professionals take your concerns seriously?

- ☐ Yes, always
- ☐ Yes, most of the time
- ☐ Yes, some of the time
- ☐ No, never
- ☐ Don't know
- ☐ I did not develop any new symptoms in the last 12 months

b. Did you feel you received the right investigation(s)?

- ☐ Yes, always
- ☐ Yes, most of the time
- ☐ Yes, some of the time
- ☐ No, never
- ☐ Don't know
- ☐ This wasn't possible in my case
- ☐ I did not develop any new symptoms in the last 12 months

c. Did you feel you received the right treatment(s)?

- ☐ Yes, always
- ☐ Yes, most of the time
- ☐ Yes, some of the time
- ☐ No, never
- ☐ Don't know
- ☐ This wasn't possible in my case
- ☐ I did not develop any new symptoms in the last 12 months

SECTION 2

The following questions are about *your views and experiences of healthcare* in relation to your long-term condition(s)

12. Thinking about how different health professionals involved in your care communicated and updated each other about your treatment…

a. Did you receive conflicting information from different health professionals?

- ☐ Yes, always
- ☐ Yes, most of the time
- ☐ Yes, some of the time
- ☐ No, never
- ☐ Don't know
- ☐ I didn't see anyone in the last 12 months

b. Was there ever a delay in your care because of lack of communication between different health professionals?

- ☐ Yes, always
- ☐ Yes, most of the time
- ☐ Yes, some of the time
- ☐ No, never
- ☐ Don't know
- ☐ I didn't see anyone in the last 12 months

c. Did you feel that different health professionals kept each other informed of your medical history?

- ☐ Yes, always
- ☐ Yes, most of the time
- ☐ Yes, some of the time
- ☐ No, never
- ☐ Don't know
- ☐ I didn't see anyone in the last 12 months

SECTION 2

The following questions are about *your views and experiences of healthcare* in relation to your long-term condition(s)

13. Overall, how has your health care changed over the last 12 months, compared to the care you received in the past?

- ☐ My care has improved
- ☐ My care has remained the same
- ☐ My care has got worse
- ☐ Don't know
- ☐ N/A

14. Please use this space for other comments or experiences you wish to share…

1. Date of Birth

2. Sex

- ☐ Male
- ☐ Female

3. Working Status

- ☐ Employed
- ☐ Unemployed
- ☐ Student
- ☐ Retired
- ☐ Not working due to ill health
- ☐ Not working other reasons

4. Ethnicity

- ☐ WHITE: of British origin
- ☐ WHITE: of Irish origin
- ☐ WHITE: of other origin
- ☐ ASIAN: of Indian origin
- ☐ ASIAN: of Bangladeshi origin
- ☐ ASIAN: of Pakistani origin
- ☐ ASIAN: of Chinese origin
- ☐ ASIAN: of other origin
- ☐ BLACK: of African origin
- ☐ BLACK: of Caribbean origin
- ☐ BLACK: of other origin
- ☐ Mixed Race
- ☐ Don't know
- ☐ Other, Please state _____
- ☐ I do not wish to disclose my ethnic origin

Thank you for completing this questionnaire. Your contribution to our survey is extremely valued

Appendix 14: Summary table (interviews 1-10 example)

	Q1. Thinking about how different staff involved in your cared communicated and updated each other about your treatment…	Q2. Were you given follow-up appointments when you felt you needed them?	Q3. Were you offered different ways of contacting staff in between standard appointment times and services?
P1	Take out' involved in your care not care' – not necessary b) Grammar mistake – "a" lack of info, what do we mean by "delay"	Good	'Were you offered' indicated that it has happened in last 12 months, but knowledge may be there from previous Maybe – 'in the last 12 months, did you contact' And RO – 'No, I was not offered this' RO – have 2 "yes" not necessary
P2	a) Strong start question, perhaps start with another question c) Possibly not 100% sure if there has been a lack of communication	Good question	Different interpretation "in between" could mean out of hours but also in hours such as different ways of contacting staff in hours
P3	Good	Good	'Services' – vague, could range from operation to NH direct RO – if yes, state how, No, just need latter two
P4	Good	Good	Good
P5	HPs – who do you mean? Conflicting is a good term Possibly give people examples e.g. do you mean notes shared?	Good	Staff or HPs? Is this about making appointments? Not clear
P6	Good	Good	Not clear about 'between standard appointment times'
P7	Good question	Good question	Wording – mixture of asking about medication and further appointments
P8	a) HPs – who do you mean? Registrar? Consultant> Specialist? (Give an example) c) Depends on interpretation, patient not always aware of what's going on		Do you mean to make appointments? Or specialist nurse contact?
P9	c) Patients can never know 100% if they were not informed	Re-word to 'when you requested them'	Good
P10	RO – N/A option The term 'medical history' doesn't cover the present	RO – 'No' is too negative	Wording – 'usual or scheduled appointments' RO – 'No, other reasons, please state how'

	Q4. If you did contact staff outside of standard appointment times, how helpful were they in…	Q5. How useful was the information you received in helping you manage your condition(s)?	Q6. How helpful were health professionals in helping you limit the impact of your condition(s)?	Q7. If there were any changes to your treatment, were you…
P1	Word "staff" needs to be clarified, do we mean health professionals?	RO – change useful to helpful	Uses 'Help' twice in one sentence –	RO – have N/A options
P2	Reword – "outside of standard appointment times" to perhaps "In between your regular appointments" RO – should include "non-applicable"	Information – what info? Suggestion – 'the info you received in appointments'	Uses 'Help' twice in one sentence – possibly change to useful	RO – have N/A options b) informed of why these changed were happening
P3	Helpful is a broad term RO – 'extremely helpful' what does this mean?	Too similar to question 4c	Broad question, conflicting experiences Limit impact –HP might help but this may not always have positive outcome	Good
P4	Good	Good	Good	Good
P5	Good	Good	Really good question	Good
P6	Good	Good	Good	Good
P7	'push appointment forward' has not been captured, GP surgery don't always have the time	Difficult question, people have lots of things wrong with them	Difficult question, not just HPs but down to the person, it's a partnership. Expert patient – "how well do you get along with HPs and get what you need"	Good
P8	RO – 'a little helpful' and 'helpful' are too similar – what is the difference? b) Only relevant when you're first diagnosed. Expert patient knows their condition better	Possibly vague, information can mean different things e.g. information leaflet, support groups etc.	Vague question, people can interpret 'helpful' differently	Good important question
P9	RO – N/A	Easy good question	Good order from Q5	Instead of 'and were you involved' ask 'and did you understand' RO – for patients that were involved but did not understand why these changes were happening
P10	Change 'how helpful were they in reassuring you' RO – N/A	Good	Good	RO – N/A or 'there were no changes in my treatment'

	Q8. Did you get the information you wanted about how your condition(s) may change over time?	Q9. Were you given the opportunities you wanted to discuss how your condition(s) may change over time?	Q10. If you developed any new symptoms or problems, did the staff involved in your care…	Q11. Were you able to talk with staff about personal issues that were important to you?
P1	Good	RO – 'info not needed'	Good	Good
P2	Not obvious that it's asking about future. Some conditions e.g. asthma don't change much over future Re-word – maybe mention the word 'future'	Same as Q8 RO – 'info not needed' Over time – do you mean months or years?	Good	Good
P3	Broad and vague RO – worth separating the last two	Good	Staff – be consistent and change to HPs	Good
P4	RO – info not wanted (depends on condition)	Good	Difference between staff e.g. nurses or doctors, maybe say HPs	Good
P5	Good	Good	RO – N/A option if no new symptoms developed	Good
P6	Good	Good	Good	Good
P7	Good	Good	Good question	Personal question – some people find it hard to discuss personal issues with HPs RO – should reflect this e.g. I did not want to discuss this
P8	RO – 'information not wanted' is good	Good	b) maybe 'resolve problem quickly or efficiently' not always about treatment, might only need re-assurance	Good examples. RO – maybe 'I do not wish to answer'
P9	Patients may not know what they want, Change to 'info you felt you needed' RO – N/A	Same as Q8	Makes sense, good question	Change to 'did you feel able to talk' or 'did HPs encourage you/make you feel comfortable'
P10	Split into 2 Qs 1- side effects of treatment 2 – how the conditions will evolve RO – Don't know and info not wanted should be seperated	Same as Q8	Split into 2 Qs 1 get them the right treatment 2 get them the treatment quickly	Good

	Q12. Were you able to discuss medication and treatment options with staff?	Q13. Were the advice and treatment you were given right for you?	Q14. Were you able to discuss how you can adapt treatment to suit your personal situation?	Q15. If you take lots of different medication for your condition(s), do you get enough practical help on how to take them?
P1	Good	Good	Good	Good
P2	Too similar to Q7	Treatment is trial and error, maybe something about can go back and discuss if treatment is not working	Good	a) RO – 'prefer' maybe change to 'would like to'
P3	Good	Treatment being right or successful? Right for you depends of lifestyle of the individual	Good	Wording suggests multiple medication, but this may only apply to one type of meds e.g. injection Confusing question – potentially need one more question Practical help is hands on and doesn't apply to pills
P4	Good	Treatment is often trial and error	Can vary depending on condition	Practical helps – implies a hands on thing
P5	Good	Good	Good	RO – N/A should be available
P6	Good	Good	Good	Good question, very important
P7	Good, clear question. Some people don't know their treatment options e.g. elderly and new drugs available	Vague question, "right for you" – nothing to judge it against, is it doing you any good? What is 'right'? is it just keeping you alive? QoL?	Vague question 'Personal situation' – perhaps change to personal preferences	Clear and relevant question
P8	Clear, relevant question and examples.	'Right for you' is vague, not clear (is this about effect on QoL? Or info pitched at right level?) – Perhaps break into 2 questions Advice and treatment - different things example – Advice given at right level of understanding? Example – Any side effects to your treatment that affected QoL?	Treatment? Is this about medical treatment or mobility? Tablet taking? This may not apply to every LTC	Clear question
P9	Be consistent, change wording to same as Q11	Change to 'did you feel'	'were you given the opportunity to discuss'	RO – N/A
P10	Same as Q11	'did you feel the advice and …'	''discuss ways in which you can adapt'	RO – N/A

	Q16. If you received new medication or treatment, how helpful were the instructions you were given on how it should be taken or used?	Q17. Thinking about your appointments with health professionals…	Q18. In the last 12 months, have you had a full review of your condition and treatment?	Q19. If you did have a full review, how helpful was this to you?
P1		Good	Full review – what do you mean?	RO – should have N/A
P2	Good	Good	Full review – what do you mean? Don't think I have this	RO – should have N/A
P3	Same as 15	Good	Full review – confusing, might not be clear is chat or testing?	Good
P4	Good	Good	Good	RO – should have N/A
P5	RO – N/A	a) RO – too drawn to 3rd option, perhaps be better balanced	Good	RO – N/A
P6	Good	Good	Good	Good
P7	Clear and relevant question	Very relevant, easy to answer	Not a lot of people know about this	Good
P8	Instructions – Do you mean from label or doctor? Re-word – How helpful were the instructions given to you by health professionals	Relevant and made sense. a) Good point, makes a difference	Full review – HP looking through the last year and suggests medication, round it all together	Good follow on question
P9	'When issued with new medication' RO – N/A	a) RO – 'I would prefer where possible'	Good but may not be clear to all patients	Good
P10	RO – N/A	Good	Good	RO – N/A Maybe make this part of Q18

	Q20. Did you get to see a specialist nurse for your condition?	Q21. Any other comments	General feedback	Missing
P1	Good	Good to have this space	Section 2 – clear Instructions – clear, some typo Length – good and brief, 10 min	None
P2	Typo – 'or'	Good space	Questionnaire ends on strange question, better to finish on full review Good that response options are similar throughout Instructions – clear Length – fine, 10-15min	None
P3	Potential RO – Yes, but I don't need this	Good, value having this space	Section 2 – third level degree? Introduction – 'in the last 12 months' Instructions – clear Length – Good, 10-15min	None
P4	Good	Value having this but not everyone wants to share	Presentation – make questionnaire look more inviting Length – good, covers a lot in a short period, 15min AOC – good as many different conditions can be covered Instructions – clear	None
P5	Good	Good	Length – good, 10 min or less Presentation – break up layout so it looks like less questions on one page, bigger text	Getting second opinions which involves the patient loosing confidence and trust and making a decision themselves
P6	Good	Good	Length – 10-15min Easy to understand and relate to	Perhaps patient seeking herbal/alternative treatment
P7	Good	Good	Comprehensive questionnaire Instructions – easy to understand Length – fine, difficult to cut down, 10-15min AOC – Very relevant to people with RA	Maybe include a question about being 'Listened to' lots of EPP participants have reported that health professionals don't seem to listen properly and look at the computer rather than at them. Question 6 maybe should be 'How helpful were the health care professionals in helping you manage your condition better by suggesting exercise on prescription, physiotherapy, EPP course, dietician, support groups etc.'
P8	Good question	Value having this	Section 2 – clear Instructions – clear	None

			Length – good and brief, 10 min to complete AOC – not too invasive on personal life	
P9	RO – 'No, but I would like to have seen one'	Good option, always something that is missed or needs to be stated.	Good RO options, like the tick question options Length – good, 10 min Relevance – good covers a range of LTCs	None
P10	Also ask about other HPs	Good	Section 2 – Dob instead of years Transgender option? Education confusing Not working for 'other reasons', some of it is work, just call it other Not use capitals Overall - Relevant content, A bit too long, but you need all questions Length – 10-15min Instructions – clear Presentation, more inviting, put questions into boxes, larger print	How condition is affecting sexual health/life (sort of covered in Q11)

Appendix 15: Questionnaire v4.0

Your Experience of Care in Long-Term Conditions

Version 4, 01 Aug 2013

COMPLETING THIS QUESTIONNAIRE

The purpose of this questionnaire is for you to provide us with feedback about the care you received for your long-term condition(s) in the last 12 months.

For each question, please tick **ONE** of the boxes to indicate your answer to each question.
If you make a mistake, simply cross it and put a tick in the correct box. If you do not wish to answer a question, then leave it blank.

Please return this questionnaire in the envelope provided.
You do not have to use a stamp - the postage is already paid for.

Thank you for taking the time to complete this questionnaire.



SECTION 1

The following questions are *about your long-term condition(s)*

1. Please list the long-term condition(s) you have:

2. In the last 12 months…

a. How often did your long-term condition(s) affect your everyday activities?

☐ All the time
☐ Often
☐ Sometimes
☐ Rarely
☐ Never
☐ Don't know

b. How often did your long-term condition(s) affect you emotionally? (e.g. feeling depressed or anxious)

☐ All the time
☐ Often
☐ Sometimes
☐ Rarely
☐ Never
☐ Don't know

SECTION 2

The following questions are about *your views and experiences of healthcare* in relation to your long-term condition(s)

1. In the last 12 months, how many times were you in contact with any of the following health professionals for your condition(s)…

a. General Practitioner (GP)

☐ 1-2 times
☐ 3 or more times
☐ Not at all, I did not need an appointment
☐ Not at all, I was not offered an appointment
☐ Don't know

b. Hospital Doctor (e.g. specialist)

☐ 1-2 times
☐ 3 or more times
☐ Not at all, I did not need an appointment
☐ Not at all, I was not offered an appointment
☐ Don't know

c. Practice Nurse or Specialist Nurse

☐ 1-2 times
☐ 3 or more times
☐ Not at all, I did not need an appointment
☐ Not at all, I was not offered an appointment
☐ Don't know

d. Other Health Professional (e.g. Dietitian, Physiotherapist)

☐ 1-2 times
☐ 3 or more times
☐ Not at all, I did not need an appointment
☐ Not at all, I was not offered an appointment
☐ Don't know

SECTION 2

2. Thinking about your appointments with health professionals in the last 12 months…

a. Were you given the option of seeing the same health professional(s)?

☐ Yes, always
☐ Yes, most of the time
☐ Yes, some of the time
☐ No, never
☐ Don't know
☐ I did not see anyone in the last 12 months

b. How important is it for you to see the same person, rather than a different health professional(s)?

☐ Very important
☐ Important
☐ Not very important
☐ Not important at all
☐ Don't know
☐ I did not see anyone in the last 12 months

c. Were you given appointments when you requested them? (e.g. with GP, nurse or other health professioanls)

☐ Yes, always
☐ Yes, most of the time
☐ Yes, some of the time
☐ No, never
☐ Don't know
☐ I did not request appointments in the last 12 months

d. Did you get to see a specialist nurse for your condition?

☐ Yes
☐ Yes, and I value this
☐ No, I did not need to see one
☐ No, but I would like to have seen one
☐ I did not see a specialist nurse in the last 12 months

SECTION 2

3. In the last 12 months…

a. Did you have a full annual review of your condition and treatment?

☐ Yes
☐ No, I was not offered one
☐ No, I did not need one
☐ Don't know

b. If you did have a full annual review, how helpful was this to you?

☐ Very helpful
☐ Helpful
☐ Not very helpful
☐ Not at all helpful
☐ Don't know
☐ I did not have a review

c. If you did not have a full annual review, did you feel that you received any kind of review for your condition and treatment?

☐ Yes
☐ No, I was not offered one
☐ No, I did not need it
☐ Don't know

SECTION 2

4. In the last 12 months, were you offered different ways of contacting health professionals in between your usual appointments to discuss your condition(s)? ***(e.g. via email or telephone)***

- ☐ Yes
  If yes, please state how _____
- ☐ Yes, but I did not need or want it
- ☐ No, but I would have liked to
- ☐ No, I did not need it
- ☐ Don't know/Not sure

5. If you did contact health professionals in between your usual appointments, how helpful were they in…

a. Answering your questions?

- ☐ Very helpful
- ☐ Helpful
- ☐ Not very helpful
- ☐ Not at all helpful
- ☐ Don't know
- ☐ I did not contact anyone

b. Helping you manage your condition(s)?

- ☐ Very helpful
- ☐ Helpful
- ☐ Not very helpful
- ☐ Not at all helpful
- ☐ Don't know
- ☐ I did not contact anyone

c. Addressing your worries and fears?

- ☐ Very helpful
- ☐ Helpful
- ☐ Not very helpful
- ☐ Not at all helpful
- ☐ Don't know
- ☐ I did not contact anyone

SECTION 2

6. Thinking about your appointments with health professionals in the last 12 months…

a. How useful was the information you received in helping you manage your condition(s)?

☐ Very useful
☐ Useful
☐ Not very useful
☐ Not at all useful
☐ Don't know
☐ I did not receive any information in the last 12 months

b. Did you get the information you felt you needed about how your condition(s) may change over time?

☐ Yes, always
☐ Yes, most of the time
☐ Yes, some of the time
☐ No, never
☐ I did not want or need this information
☐ Don't know
☐ I did not receive any information in the last 12 months

c. Were you given the opportunities you felt you needed to discuss how your condition(s) may change over time?

☐ Yes, always
☐ Yes, most of the time
☐ Yes, some of the time
☐ No, never
☐ I did not want or need to discuss this
☐ Don't know
☐ I did not see anyone in the last 12 months

d. Did you feel that the information you were given was right for you?

☐ Yes, always
☐ Yes, most of the time
☐ Yes, some of the time
☐ No, never
☐ Don't know
☐ I did not receive any advice in the last 12 months

SECTION 2

7. Thinking about your appointments with health professionals in the last 12 months…

a. Did you feel that health professionals listened to what you had to say?

☐ Yes, always
☐ Yes, most of the time
☐ Yes, some of the time
☐ No, never
☐ Don't know
☐ I did not see anyone in the last 12 months

b. Did you feel able to talk with health professionals about personal issues that were important to you? ***(e.g. how the condition(s) affects your family and social life)***

☐ Yes, always
☐ Yes, most of the time
☐ Yes, some of the time
☐ No, never
☐ I did not wish to discuss this
☐ Don't know
☐ I did not see anyone in the last 12 months

c. How useful were health professionals in helping you limit the impact of your condition(s) on your life?

☐ Very useful
☐ Useful
☐ Not very useful
☐ Not at all useful
☐ Don't know
☐ I did not see anyone in the last 12 months

SECTION 2

8. Thinking about the health care you received in the last 12 months…

a. Did you feel able to discuss medication and treatment options with health professionals? ***(e.g. changes in medication or dosage)***

☐ Yes, always
☐ Yes, most of the time
☐ Yes, some of the time
☐ No, never
☐ Don't know
☐ I did not see anyone in the last 12 months

b. Were you given the opportunity to discuss how you could adapt treatment to suit your personal situation? ***(e.g. changes in medication or dosage)***

☐ Yes, always
☐ Yes, most of the time
☐ Yes, some of the time
☐ No, never
☐ Don't know
☐ I did not see anyone in the last 12 months

c. Did you feel that the treatment you were given was right for you?

☐ Yes, always
☐ Yes, most of the time
☐ Yes, some of the time
☐ No, never
☐ Don't know
☐ I did not receive any treatment in the last 12 months

d. Did you ask for a second opinion about your condition or treatment?

☐ Yes
☐ No, I did not need this
☐ No, but I would have liked to

SECTION 2

9. Thinking about your medication in the last 12 months…

a. Did you get enough practical advice on how to take your medication? ***(e.g. from GP, nurse, pharmacist)***

- ☐ Yes, always
- ☐ Yes, most of the time
- ☐ Yes, some of the time
- ☐ No, never
- ☐ Don't know
- ☐ I did not take any medication in the last 12 months

b. If you take more than one type of medication, did you get enough advice on how to manage them?

- ☐ Yes, always
- ☐ Yes, most of the time
- ☐ Yes, some of the time
- ☐ No, never
- ☐ Don't know
- ☐ I did not take more than one type of medication in the last 12 months

c. If you received new medication or treatment, how helpful was the advice you were given on how it should be used or taken?

- ☐ Very helpful
- ☐ Helpful
- ☐ Not very helpful
- ☐ Not at all helpful
- ☐ Don't know
- ☐ I did not receive any new medication in the last 12 months

SECTION 2

10. If there were any changes to your treatment in the last 12 months…

a. Were you involved in the discussion?

☐ Yes, always
☐ Yes, most of the time
☐ Yes, some of the time
☐ No, never
☐ Don't know
☐ There were no changes in my treatment in the last 12 months

b. Did you understand why these changes were happening?

☐ Yes, always
☐ Yes, most of the time
☐ Yes, some of the time
☐ No, never
☐ Don't know
☐ There were no changes in my treatment in the last 12 months

SECTION 2

11. If you developed any new symptoms or problems in the last 12 months…

a. Did health professionals take your concerns seriously?

☐ Yes, always
☐ Yes, most of the time
☐ Yes, some of the time
☐ No, never
☐ Don't know
☐ I did not develop any new symptoms in the last 12 months

b. Did you feel you received the right investigation(s) and test(s)?

☐ Yes, always
☐ Yes, most of the time
☐ Yes, some of the time
☐ No, never
☐ Don't know
☐ N/A
☐ I did not develop any new symptoms in the last 12 months

c. Did you feel you received the right treatment(s)?

☐ Yes, always
☐ Yes, most of the time
☐ Yes, some of the time
☐ No, never
☐ Don't know
☐ N/A
☐ I did not develop any new symptoms in the last 12 months

SECTION 2

12. Thinking about how different health professionals involved in your care communicated and updated each other about your treatment…

a. Did you receive conflicting information from different health professionals?

☐ Yes, always
☐ Yes, most of the time
☐ Yes, some of the time
☐ No, never
☐ Don't know
☐ I did not see anyone in the last 12 months

b. Was there ever a delay in your care because of lack of communication between different health professionals?

☐ Yes, always
☐ Yes, most of the time
☐ Yes, some of the time
☐ No, never
☐ Don't know
☐ I did not see anyone in the last 12 months

c. Did you feel that different health professionals kept each other informed of your medical history?

☐ Yes, always
☐ Yes, most of the time
☐ Yes, some of the time
☐ No, never
☐ Don't know
☐ I did not see anyone in the last 12 months

SECTION 2

13. Overall, how has your health care changed over the last 12 months, compared to the care you received in the past?

- ☐ My care has improved
- ☐ My care has remained the same
- ☐ My care has got worse
- ☐ Don't know
- ☐ N/A

14. Please use this space for other comments or experiences you wish to share…

SECTION 2

The following questions are about you

1. Date of Birth

2. Sex

- ☐ Male
- ☐ Female

3. Working Status

- ☐ Employed
- ☐ Unemployed
- ☐ Student
- ☐ Retired
- ☐ Not working due to ill health
- ☐ Not working other reasons

4. Education

What age did you leave school? _____

Did you/do you go to University? _____

5. Ethnicity

- ☐ WHITE: of British origin
- ☐ WHITE: of Irish origin
- ☐ WHITE: of other origin
- ☐ ASIAN: of Indian origin
- ☐ ASIAN: of Bangladeshi origin
- ☐ ASIAN: of Pakistani origin
- ☐ ASIAN: of Chinese origin
- ☐ ASIAN: of other origin
- ☐ BLACK: of African origin
- ☐ BLACK: of Caribbean origin
- ☐ BLACK: of other origin
- ☐ Mixed Race
- ☐ Don't know
- ☐ Other

  Please state _____
- ☐ I do not wish to disclose my ethnic origin

Thank you for completing this questionnaire. Your contribution to our survey is extremely valued