Coordination of Primary Health Care

A thesis submitted to the University of Manchester for the degree of Doctor of Philosophy (PhD) in the Faculty of Medical and Human Sciences

2014

Rachel Christine Foskett-Tharby

School of Medicine

List of contents

Word count = 67,404

List of Appendices

List of tables

List of figures

Abstract

Background

Improving coordination of care is a major challenge for health systems internationally. Tools are required to evaluate alternative approaches to improve coordination from the patient perspective. This study aimed to develop and validate a new measure of coordination for use in a primary care setting.

Methods

Four methods were used. Firstly, a concept analysis was undertaken to identify the essential attributes of coordination drawing upon literature from health and organisational studies and to establish its boundaries with related concepts such as continuity of care, integration and patient centred care. Secondly, existing measures of coordination were reviewed to assess the extent to which item content reflected the definition arising from the concept analysis and to appraise psychometric properties. Thirdly, a new instrument, the Care Coordination Questionnaire (CCQ), was developed utilising items from existing questionnaires and others developed following focus groups with 30 patients. Ten cognitive interviews were used to evaluate the items generated. Finally, the CCQ was administered in a cross sectional survey to 980 patients. Item and model analyses were performed. Test-retest reliability was evaluated through a second administration of the CCQ after two weeks. Concurrent validity was evaluated through correlation with the Client Perceptions of Coordination Questionnaire (CPCQ). Construct validity was evaluated through correlation with responses to a global coordination item and a satisfaction scale and the testing of two a prior hypotheses: i) coordination scores would decrease with increasing numbers of providers and ii) coordination scores would decrease with increasing numbers of long-term conditions.

Results

The concept analysis suggested that coordination should be considered as a process for the organisation of patient care characterised by: purposeful activity, information exchange, knowledge of roles and responsibilities, and responsiveness to change. The systematic review identified 5 existing measures of coordination and a further 10

measures which incorporated a coordination subscale. Only one demonstrated conceptual coverage but had poor psychometric properties. A new instrument was therefore developed and tested as described above. 299 completed surveys were returned. Respondents were predominantly elderly and of white ethnicity; approximately half were female. Five items were deleted following item analyses. Model analysis suggested a four factor two-level model of coordination comprising of 18 items. This correlated well with the CPCQ, the global coordination item and satisfaction scale. The *a priori* hypotheses were upheld. Retest reliability was acceptable at the patient group level.

Conclusions

The CCQ has demonstrated good psychometric characteristics in terms of item responses, reliability and construct validity. Further exploration of these properties is required in a larger, more diverse sample before it can be recommended for widespread use, but it shows potential utility in the evaluation of different approaches to coordinating care.

Declaration

No portion of the work referred to in the thesis has been submitted in support of an application for another degree or qualification of this or any other university or other institute of learning.

Copyright Statement

The author of this thesis (including any appendices and/or schedules to this thesis) owns certain copyright or related rights in it (the "Copyright") and s/he has given The University of Manchester certain rights to use such Copyright, including for administrative purposes.

Copies of this thesis, either in full or in extracts and whether in hard or electronic copy, may be made **only** in accordance with the Copyright, Designs and Patents Act 1988 (as amended) and regulations issued under it or, where appropriate, in accordance with licensing agreements which the University has from time to time. This page must form part of any such copies made.

The ownership of certain Copyright, patents, design, trade marks and other intellectual property (the "Intellectual Property") and any reproductions of copyright works in the thesis, for example graphs and tables ("Reproductions"), which may be in described in this thesis, may not be owned by the author and may be owned by third parties. Such Intellectual Property and Reproductions cannot and must not be made available for use without the prior written permission of the owner(s) of the relevant Intellectual Property and/or Reproductions.

Further information on the conditions under which disclosure, publication and commercialisation of this thesis, the Copyright and any Intellectual Property and/or Reproductions described in it may take place is available in the University IP Policy (see http://documents.manchester.ac.uk/DocuInfo.aspx?DocID=487) , in any relevant Thesis restriction declarations deposited in the University Library, The University Library's regulations (see http://www.manchester.ac.uk/library/aboutus/regulations) and in The University's policy on presentation of Theses.

Dedication

This thesis is dedicated to two people who have had a significant impact upon the course of this work. Firstly, it is dedicated to my friend and colleague, the late Professor Helen Lester. Helen gave me the confidence to believe that completing this work was possible, encouraged me to apply and provided support when things got tough. Sadly, Helen isn’t here to see the completed work. Secondly, it is dedicated to my son Maximilian, whose unexpected arrival delayed completion.

Acknowledgements

I wish to express my gratitude to my supervisors Professor Bonnie Sibbald, Dr David Reeves and Dr Elaine Harkness for their unfailing support throughout my years of doctoral study. This has been invaluable in ensuring that I finally made it!

I also wish to express my gratitude to the Medical Research Council who supported my studentship and the NIHR School of Primary Care who provided funding for the administration of the survey.

Thanks are also due to the many friends I have made during my studies who have provided ongoing support, cups of tea and glasses of wine.

Finally, I wish to express my thanks to my husband, Peter. Without his support, I would never have started this study and certainly not completed it. Thank you for the endless supply of cups of tea, additional childcare and the time taken to complete final proofreading.

Chapter 1: Introduction

1.1: Introduction

Successful integration of health care is the holy grail of many health systems struggling to respond to an aging population with an increasing demand for health care. Achieving integration is anticipated to result in improvements in coordination along with delivering improved clinical outcomes, an enhanced patient experience and cost savings through the reduction of waste (NHS Institute, 2013). But the challenge of coordinating care is not new, having been written about for over a century, with different professional groups claiming it as a key responsibility (Stille et al., 2005, Knudson, 1968). This raises two questions: firstly, why is it so difficult to achieve and secondly, why is it of interest to policy makers now?

The first of these questions will be addressed throughout this thesis as I consider how coordination can be defined and subsequently measured and the challenges associated with this. The second will be considered in this opening chapter with a specific focus upon demographic changes and their impact upon the health needs of a population, workforce developments including role expansion and specialisation resulting in an increasing number of professionals involved in an individual's care, and the complex structure of health and social care systems. Running in parallel with these demographic and professional developments has been the emergence of philosophies such as patient centred care, with an explicit focus upon understanding and valuing the patient experience (Epstein et al., 2010). I will then consider how recent health policy developments in the National Health Service (NHS) in England have both driven and responded to these factors. The relevance of coordination to international health policy will also be considered.

1.2: Demographic change

In common with other countries the population of the UK is aging with the median age in England and Wales predicted to rise from 39.7 years in 2010 to 42.2 years by 2035 (Office for National Statistics, 2013c). The proportion of the population represented by the very old, those aged 90 years and over, whilst continuing to be a very small proportion of the total population (1%) has nevertheless increased by 26% between 2002 and 2011 (Office for National Statistics, 2013a). However, this increasing longevity has yet to be matched by increases in health life expectancy. Whilst the proportion of the population reporting a long-standing illness or disability has remained relatively constant since 1991 at around 32% the prevalence of both long-standing conditions and those which limit activities has increased with age (Office for National Statistics, 2013b). In 2011, 42% of people aged 45 to 64 years reported a long standing illness compared with 58% of those aged 65 to 74 years and 68% of those aged over 75 years. Similarly, the proportion of people reporting an illness which limited their activities rose with age from 25% in the 45 to 64 year age group to 47% in those aged 75 years and over (Office for National Statistics, 2013b).

There is also evidence to suggest that a number of people have more than one long-term condition (Department of Health, 2008c), with a reported doubling of the numbers of people with two or more chronic conditions to 23% between 1994 and 2003 (Hippisley-Cox and Pringle, 2007). In the latest General Lifestyle Survey in England and Wales the most frequently reported conditions were those affecting the musculoskeletal system, specifically arthritis, followed by cardiovascular conditions, endocrine conditions and respiratory problems (Office for National Statistics, 2013b).

Alongside this increase in co-occurring disease is a predicted rise in the prevalence of degenerative conditions (Mathers and Loncar, 2007) with an associated requirement for both health and social support. These patients are likely to need complex care packages delivered by a number of different providers with the potential for fragmentation and organisational breakdown (Allen et al., 2004).

Co-occurring disease, or multi-morbidity, presents new disease management challenges for both clinicians and patients. Within fee paying health systems, patients have been reported as prioritising the management of one condition over another on financial grounds with the prioritised condition usually being that which causes the most worry or fear of disability (Bayliss et al., 2003, Schoenberg et al., 2009). However, this may also be a practical strategy as the optimal management of one condition may be antagonistic, agonistic or neutral in its impact upon another, with an enhanced understanding of these interactions being necessary to improve clinical care (Valderas et al., 2009). Despite this, the focus of clinical quality improvement has been upon single disease management strategies with adherence to these supported and promoted by protocols, guidelines (Campbell and Roland, 2003) and, within primary care in the UK, financial incentives distributed through the Quality and Outcomes Framework (NHS Confederation, 2003). This single disease focus is of limited relevance to patients with multi-morbidity, as they require support to synthesize potentially conflicting advice into a manageable and acceptable approach to care (Stille et al., 2005, Starfield et al., 2003).

1.3: Workforce changes

When Florence Nightingale was writing about coordination in the 1800's the main focus of her work was about how a nurse ensured that care was given in her absence (Nightingale, 1898). Whilst this remains a present day concern in the delivery of coordinated care, the health care landscape has become more complicated due to both increasing numbers and increasingly more specialised staff and structural divisions between providers. At the turn of this century, the pre-existing professional boundaries between healthcare professionals were viewed as detrimental to meeting the changing needs of patients and the NHS Plan in England made a commitment to provide 'more staff working differently' (Department of Health, 2000). This aimed to create new opportunities for nurses, general practitioners (GPs) and allied health professionals to improve care through an orientation upon the needs of the patient unhampered by historical professional boundaries. Legal barriers which denied certain staff groups from undertaking specific activities, such as prescribing, were removed and GPs were encouraged to specialise in the care of particular patients through the creation of the GP with a special interest (GPwSI) role. This allows GPs to develop specialist knowledge in a clinical area, to take referrals from other GPs, offer diagnostic and treatment services and provide clinical leadership. One of the aims was to reduce reliance upon costly, secondary care referrals and to increase the amount of care delivered in the community (Department of Health, 2006).

The intervening years have seen an increase in the number of general practitioners and nursing staff in both traditional and new roles (Gemmel et al., 2009). Nurse practitioners are increasingly being used as first contact practitioners in primary care (Laurant et al., 2004, Horrocks et al., 2002), whilst there is also evidence to suggest that nurses are assuming increasing responsibility for the management of chronic disease (McDonald et al., 2009). There has also been the emergence of new roles for healthcare assistants, assistant practitioners and mental health workers (Harkness et al., 2005).

Whilst many of these changes have been positive they also introduce a potential for replication of the medical specialisation seen in secondary care and a subsequent loss of generalist skills. As a consequence of this, the number of professionals a patient is likely to encounter may increase due to no single person having the necessary skills, knowledge and resources to deliver the care that an individual may require. A situation that may be compounded for those with co-occurring conditions if care is systematically structured into the management of single conditions. This dispersion of care can lead to both fragmentation and perceptions of fragmentation.

1.4: Structural complexity of health care

Historically, within the NHS in England, health care has been structured so that it is free at the point of delivery with individuals registering with a GP practice that acts as the point of entry and 'gatekeeper' to specialised care. Health care is delineated from social care in terms of its provision, funding and eligibility criteria. However, patients with co-occurring disease and/or degenerative, limiting long-standing illnesses frequently have support needs which traverse these two entities and for whom the differentiation between health needs and social needs is spurious and potentially challenging to navigate. As noted by the patient organisation, National Voices, "care is care is care' for the person who needs it' (National Voices, 2012).

Whilst the division between health and social care is both longstanding and commonly cited, there is an increasing potential for care to be delivered by multiple provider organisations as a result of competitive tendering for health service provision open to any qualified provider (British Medical Association, 2013). This plurality of provision may further increase the burden of coordination through increased communication and information processing requirements for both providers and patients (Powell Davies et al., 2006).

1.5: The emergence of patient centred care

Patient centred care has emerged as a key philosophy in the planning and delivery of health services since the turn of the century when it was adopted by the Institute of Medicine (2001) as one of their core requirements for quality healthcare along with safety, effectiveness, timeliness of care, efficiency and being equitable. They defined patient centred care as care which is 'respectful of and responsive to individual patient preferences, needs and values, and ensuring that patient values guide all clinical decisions' (Institute of Medicine, 2001). Since publication this definition has been debated, researched in the context of different health conditions and settings resulting in other elements being suggested. This will be returned to in Chapter 3 where I give greater consideration to the boundaries and potential overlap between coordination of care and patient centred care. However, what was revolutionary in the adoption of this as a cornerstone of quality healthcare was the stress placed upon knowing patients as individuals whose views are sought, listened to, respected and honoured (Epstein and Street, 2011). In the context of medical care it has led to a recognition of the importance of supplementing medical facts with patient values when determining important outcomes (Sullivan, 2003). Active consideration of patient preferences also results in increased patient satisfaction (Michie et al., 2003).

Adopting a patient centred philosophy places an explicit value upon the patient's subjective experience of their care, from both a medical and organisational perspective. Whilst this does not have the same impact upon the requirement for coordination as the demographic changes described above it has contributed to the renewed interest in the topic from a health policy perspective as poor coordination results in patient dissatisfaction (McDonald et al., 2007).

1.6: Integration, coordination and health policy in the NHS

Within the NHS in England recent interest and recognition of the need to improve integration was highlighted in 2008 as part of the NHS Next Stage Review (Department of Health, 2008a). This acknowledged patient concerns regarding the fragmentation of care and their desire for seamless services. It also included a commitment to fund and pilot new approaches to integration within the NHS through the development and subsequent evaluation of 16 Integrated Care Organisations (ICOs). The resulting ICOs were diverse in terms of the populations they targeted and the mechanisms piloted to improve integration (Department of Health, 2009). However, many focused upon the management of single long term conditions with few taking a more holistic approach to individual care.

Evaluation of these identified improvements in the performance of staff led integration processes although this was not necessarily reflected in reported patient experiences, with patients reporting being less involved with their care, less likely to be listened to and finding it more difficult to see the professional of their choice. Some improvements were seen in patient reports of coordination activities with a significant increase in the use of care plans and better coordination of hospital discharge (RAND Europe and Ernst and Young, 2012). There may be a trade-off between simultaneously providing structured, coordinated care and some aspects of personalised care and patient choice. The pilots were also associated with increased rates of emergency admissions, although this was balanced by reductions in elective admissions and outpatient attendances. In terms of costs the authors concluded, in common with others (Ovretveit, 2011), that savings were not inevitable and were unlikely to be seen in the short term. Thus challenging some of the policy aspirations that integration and the resulting improved coordination necessarily leads to cost savings (NHS Institute, 2013).

This commitment to integration has been reiterated in Equity and Excellence: Liberating the NHS (Department of Health, 2010a), the work of the Future Forum (NHS Future Forum, 2012) and the subsequent Health and Social Care Act 2012. The legislative changes within the Act place an emphasis on working together, with integration being driven by clinical commissioning groups who are coterminous with local authorities. These groups have a duty to promote integrated working (Department of Health, 2012). This focus upon integration as a part of commissioning services is hoped to alleviate some of the concerns that a competition and market-based approach to healthcare actively prevents integration. The underpinning philosophy is for care to be integrated around the person rather than the system, with named coordinators for people with long-term or complex needs (Field, 2012).

To facilitate the realisation of the vision of integrated care a National Collaboration for Integrated Care and Support has been established in England. This body will oversee the provision of support to localities to enable them to develop or adopt models of commissioning and care delivery which support integrated care. The underpinning definition of integration which has been adopted is that developed by National Voices (National Voices, 2013), a coalition of health and social care charities in England. This defines a narrative for integrated care as:

'I can plan my care with people who work together to understand me and my carer(s), allow me control, and bring together services to achieve the outcomes important to me.'

This headline statement is supported by a series of 37 'I' statements to describe the individual experience of person-centred, coordinated care. Given some of the emerging findings from the integrated care pilots, being both person-centred and coordinated may be challenging to achieve. As will be discussed in Chapter 3, whilst there are many reasons why it may be desirable for care to be acceptable and patient-centred, this is not a pre-requisite to the delivery of coordinated care.

The Government has also committed to measuring the success of this work from the patient perspective. They plan to incorporate a patient reported measure of the experience of integration within the NHS Outcomes Framework (Department of Health, 2013). Thus making the development of such measures more urgent.

1.7: Integration, coordination and international health policy

Much of this chapter has focused upon the demographic and workforce changes experienced in England and their impact upon health policy for the NHS. However, the question of how to improve coordination of care is one faced by much of the world. Population aging and an increased incidence of long-term conditions are a common feature of most developed nations and this epidemiological transition away from infectious disease is also beginning to be observed in developing nations (Mathers and Loncar, 2007). Whilst the exact nature of any structural complexity of care delivery will differ between nations as a result of their different health systems, common themes are the increasing numbers of professionals involved in an individual's care and an increasing need for social or supportive care (Brown et al., 2008, McGuiness, 2001, Singer et al., 2011). Faced with the same challenges as England, other countries have similarly sought to improve care coordination as a key step to improving care integration.

In the US in the early 2000's the Centres for Medicare and Medicaid Services (CMS) funded 15 Medicare Coordinated Care Demonstration sites from 2002 - 2006. Like the English Integrated Care Organisations (ICOs) these sites defined their own target populations, usually a long term condition and coordination interventions. These interventions also included patient education and behavioural change interventions, patient activation, strategies to improve information transfer between clinicians and the use of care coordinators (Brown et al., 2008). In common with the evaluation of ICOs the results were mixed, with only two of the demonstrator sites realising reductions in hospital admissions and Medicare expenditure and few changes observed in patient behaviours despite intensive education programmes.

The US has also explored the concept of the 'medical home' as a coordination strategy, especially for children with complex needs. Analogous to the GP practice in the UK the medical home has been defined as 'accessible, continuous, comprehensive, family-centred, coordinated, compassionate and culturally effective.' (Council on children with disabilities and Medical home implementation project advisory committee, 2014). Evaluation of these has demonstrated decreased hospitalisation and increased parental satisfaction with care (Palfrey et al., 2004, Homer et al., 2008). Evaluation has also focused upon documenting, costing and thereby making visible the coordination activities undertaken by these practices (Antonelli and Antonelli, 2004).

More recently the Centres for Medicare and Medicaid Services have acknowledged the work associated with coordination of care and introduced a transitional care payment from 2013. Whilst the level of this will vary with patient complexity, this payment is expected to fund specified care coordination services on discharge from acute care plus a face to face patient appointment, with the aim of reducing readmission rates (Bindman et al., 2013).

Care coordination initiatives have also been explored in Australia, for example, through the Coordinated Care Program. This was a joint initiative between the state and territorial governments which ran between 1997 and 2005. In a similar manner to initiatives in both England and the US, funded projects covered a range of target populations with differing health needs, but with an explicit focus upon strengthening primary care to address chronic disease management (Australian Government Department of Health and Aging, 2007). Again, results of these were mixed with goals in the first round of funding most likely not to have been achieved due to both failures in design and implementation (Segal et al., 2004a). As Roe and Normand (2013) note coordination interventions tend to be poorly described, functioning as a 'black box' which hampers our understanding of the mechanisms by which good patient outcomes are produced. Questions were also raised as to the reasonableness of some of the assumptions underpinning the trials regarding the potential costs and benefits (Segal et al., 2004a).

1.8: Are the anticipated benefits of coordination of care realistic?

It has been hypothesised that improvements in coordination of care will result in better patient outcomes, an enhanced patient experience and decreased costs (NHS Institute, 2013). There is a compelling logic behind these assumptions in that it is not unreasonable to conclude that good coordination should result in the patient receiving the right care in the most efficient way, which should then result in better outcomes.

However, evidence for this is currently lacking with evaluations of care coordination initiatives demonstrating conflicting results (Brown et al., 2008, Powell Davies et al., 2008, RAND Europe and Ernst and Young, 2012). One issue with the evaluation of such programmes is the question of how a relationship between coordination and outcomes can be demonstrated if care coordination cannot be measured (Bynum and Ross, 2012). This was one of the motivating factors for this work.

1.9: Appropriateness of the NHS in England for the study of coordination

As described above, England in common with other developed nations, is seeking to develop the way care is structured to respond to the challenge of an aging population with long term and often complex health needs. These patients frequently require care from a number of health and social care professionals often from different organisations which need to work together to provide care. As will be considered in greater detail in Chapter 3, this need for professionals to work together creates an interdependence between their tasks which leads to the requirement for coordination (Thompson, 1967). The study of care coordination and how it can be measured and evaluated is therefore of importance to England and other developed nations given the investment in integration initiatives and their anticipated, if largely unproven, benefits.

The mechanism required to produce good care coordination may vary within and between countries reflecting local differences in systems for health and social care provision. Yet care coordination is a phenomenon that transcends its means of production. The challenge is to define and measure care coordination in ways that are independent of mechanisms used to produce it, so making it possible to evaluate whether different systems provide better or worse care coordination. In this sense, the study of care coordination in the NHS may be of salience to many other countries beyond England. The extent to which this work is of potential international relevance will be returned to in Chapter 8 and considered with regard to more recent international developments in the measurement of coordination.

1.10: Summary

In this opening chapter I have considered the current prioritisation of integrated care and subsequent improvements in coordination by the NHS in England as a response to an aging population with a greater propensity to co-occurring disease, the effects of specialisation and proliferation of health care providers and the resulting structural complexity of health and social care structures which have resulted in patient perceptions of fragmentation and 'falling through gaps'. Running in parallel with these changes has been the adoption of patient centred care which has contributed to a prioritisation of the care experience as one which should be acceptable to patients. One of the policy responses to this has been a commitment to the measurement of the patient experience, making the results of this work timely and highlighting the importance of this work to the NHS. In this chapter I have also considered the potential relevance of this work out with the NHS and noted that achieving coordinated care is a challenge internationally. In the next chapter I will outline the aims and objectives of the work and provide an overview of the structure of the thesis.

Chapter 2: Aims and objectives

2.1: Introduction

This chapter describes and justifies the aims and objectives of this thesis. Firstly, I will outline the overarching aim of this work together with the rationale for the use of the patient perspective, the selection of the patient population and the utilisation of the primary care setting. Secondly, I will outline the stages of measure development. The specific objectives addressed in this work will be considered in relation to these. This will incorporate an outline of the thesis which details the content of the subsequent chapters.

2.2: Aim of this work

The aim of the work underpinning this thesis is to develop a patient reported measure of coordination of care for use in a primary care setting with patients with long-term conditions. It is hoped that this may ultimately prove to be useful in the comparison and evaluation of different approaches used to coordinate care.

Aspects of this aim require further consideration and justification: the use of the patient perspective, primary care as the source of respondents and the focus upon those with long-term conditions.

2.2.1: The patient perspective

Patients are not the only stakeholders in healthcare for whom coordination of care is a legitimate concern. The topic is of salience to healthcare professionals both collectively and individually, healthcare organisations, commissioners and policy-makers. As will be discussed in Chapters 3 and 5 different stakeholders see different aspects of the coordination process. Some aspects visible to one stakeholder may be invisible to another and no stakeholder has a comprehensive view of all aspects. So why focus upon the patient experience?

In the absence of evidence to suggest the optimal perspective from which to measure coordination I have elected, in common with others, to address measurement from the patient perspective. The rationale for this is as follows.

Firstly, in healthcare systems which prioritise patient centred care, as is true of the NHS, patients' views have an independent value which Epstein and Street (2011) argue 'should be justified on moral grounds alone, independent of their relationship to health outcomes.' Patient views therefore should be seen to be of value and achieving positive views should be the focus of the healthcare system (Sofaer and Firminger, 2004). Capturing the patient experience is of increasing importance to policy makers and healthcare commissioners. Patient experience forms one of the five pillars of the NHS Outcomes Framework (Department of Health, 2010b), and as noted in the previous chapter, coordination of care has been identified as one of the key themes to be measured. For this assessment to be meaningful, valid and reliable measures of the concept are required.

Secondly, patient perspectives can be used to capture aspects of care which may be missed by other observers (Rosenthal and Shannon, 1997). As will be discussed in Chapter 3, the patient experience of coordination of care may be viewed as an outcome of their providers' coordination processes. Therefore, the patient perspective may provide an alternative indicator of the success or otherwise of these processes to provider focused measures.

This rationale should not be interpreted as an attempt to privilege the patient experience of coordination above other stakeholder perspectives, such as those of healthcare professionals, but to justify it as being a reasonable perspective to adopt. As shall be discussed in further detail in Chapter 3 and returned to in Chapter 8, patient observations of coordination activities are likely to be limited and complementary measures may be required.

2.2.2: The primary care setting

As will be considered in further detail in Chapter 3, coordination is required in the presence of interdependencies between both individual clinicians and organisations involved in a person's care (Thompson, 1967). When these interdependencies occur those providing care need to deliver the care for which they are responsible and to complete additional tasks to ensure smooth coordination (Malone and Crowston, 1994). This suggests that coordination is everybody's responsibility. Despite, or perhaps because of this, different professional groups have laid claim to coordination as being a primary function of their role (Knudson, 1968, Stille et al., 2005).

Coordination of care has frequently been cited as a key responsibility for primary care (Stille et al., 2005). It is argued that primary care is uniquely positioned to undertake this role due to the ongoing nature of the relationship between patients and their primary care provider which supports the integration of information about previous events into current care (Starfield et al., 1976). This notion is further reinforced within the NHS where the general practitioner acts as a gatekeeper to secondary and specialist care services whilst maintaining responsibility for the patient's ongoing care. This gatekeeper role requires that general practice liaises with other providers in order to achieve optimal outcomes for the patient.

The centrality of this coordinating role to primary care, and general practice in particular, makes this a legitimate area in which to consider this topic.

2.2.3: Respondents with long-term conditions

Whilst coordination of care may be a central responsibility of primary care, it will be of more or less importance to different groups of patients. Those with long-term conditions frequently receive care from multiple professionals and providers. This can make the organisation and coordination of care more difficult.

This group of patients are of increasing political importance as their care accounts for a sizeable proportion of healthcare expenditure (Singh and Ham, 2006). They are frequently targeted in coordination improvement initiatives (McDonald et al., 2007, Segal et al., 2004b) as improved coordination is hypothesised to improve health outcomes and reduce duplication, waste and ultimately healthcare costs. Evaluation of these initiatives from the patient perspective has tended to focus upon satisfaction with services. Less attention has been given to measuring the impact of these initiatives on actual changes in coordination of care from the patient perspective.

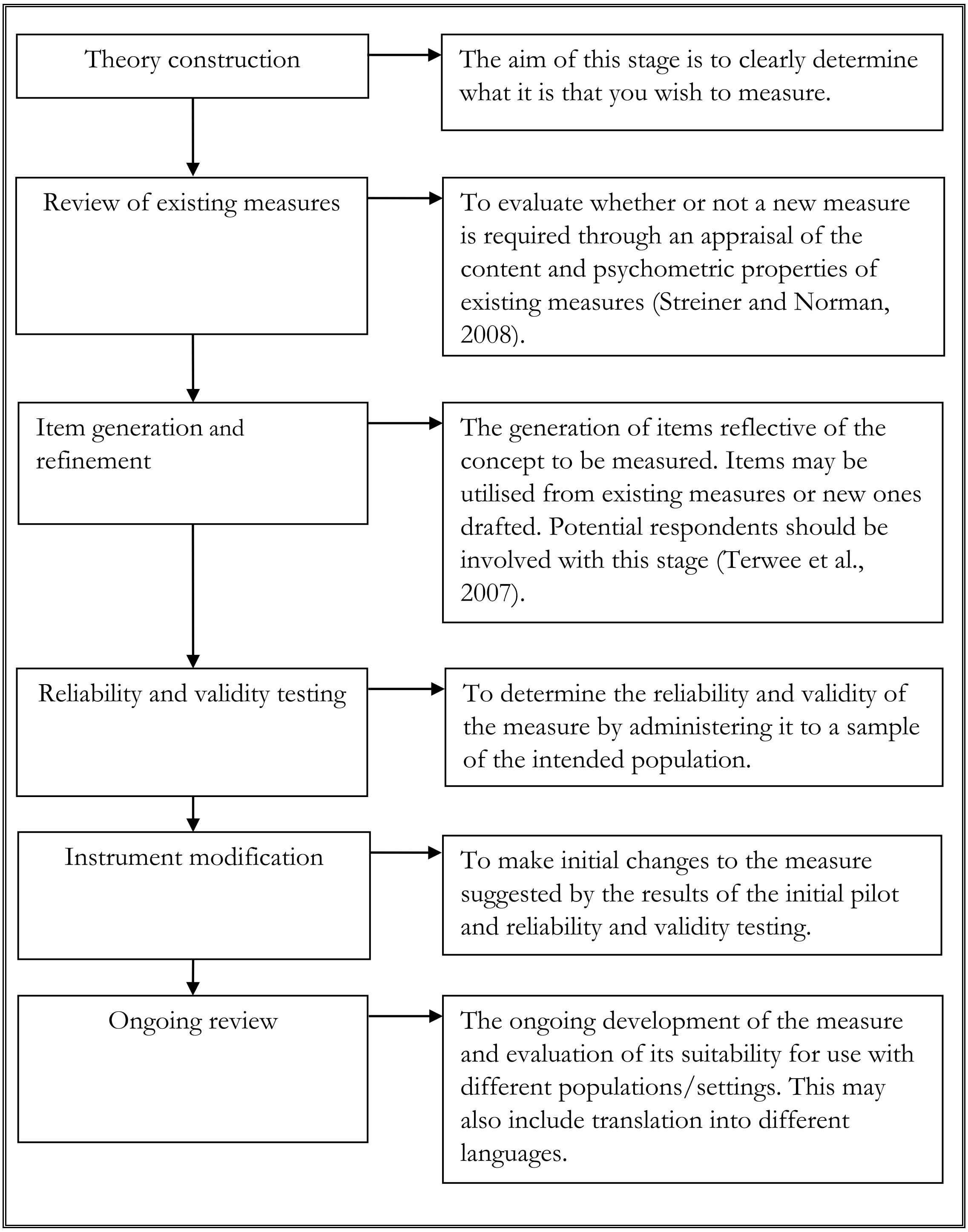
Given the targeting of these initiatives on those with long-term conditions I felt that this was an appropriate group in which to begin instrument development, although it should be noted that they are not the only group to whom coordination is an important issue.

2.3: Objectives

The specific objectives addressed in this thesis stem from the steps involved in the development of a measurement instrument. These include (De Vellis, 2003, Nunnally and Bernstein, 1994, Streiner and Norman, 2009):

- Theory construction
- Review of existing measures
- Item generation and refinement
- Testing of reliability and validity
- Instrument modification
- Ongoing review over time (see Figure 2.1).

Figure 2.1: Stages in Measure Development



The aim of this stage is to clearly determine what it is that you wish to measure.

To evaluate whether or not a new measure is required through an appraisal of the content and psychometric properties of existing measures (Streiner and Norman, 2008).

The generation of items reflective of the concept to be measured. Items may be utilised from existing measures or new ones drafted. Potential respondents should be involved with this stage (Terwee et al., 2007).

To determine the reliability and validity of the measure by administering it to a sample of the intended population.

To make initial changes to the measure suggested by the results of the initial pilot and reliability and validity testing.

The ongoing development of the measure and evaluation of its suitability for use with different populations/settings. This may also include translation into different languages.

From these steps the following specific objectives were identified:

1. The development of a conceptual framework of coordination of care.
2. The undertaking of a systematic review and appraisal of existing measures of the concept.
3. Development of a new measurement instrument.
4. Piloting and initial evaluation of this measure with a focus upon item performance, temporal stability and concurrent and construct validation.

These will be considered in more detail together with where they are addressed within this thesis in the remainder of this chapter.

2.3.1: Development of a conceptual understanding of coordination of care

Clarity regarding the boundaries and domains of the concept of interest is an essential pre-requisite to measure development (De Vellis, 2003). Conceptual difficulties have been noted in relation to coordination of care (Freeman and Hughes, 2010) and a consensus definition has proved elusive (McDonald et al., 2007). A necessary first step was therefore the development of a conceptual framework of coordination of care and the identification of its defining attributes. This framework is presented in Chapter 3 together with consideration as to how this translates into the patient experience of coordination, and the aspects which they may be able to report.

2.3.2: Systematic review and appraisal of existing measures

Prior to embarking upon the development of a new measure the existing literature should be reviewed to ensure that no existing measure adequately captures the concept (Streiner and Norman, 2009). A systematic review and critical appraisal of existing measures was undertaken and the results of this are presented in Chapter 4.

2.3.3: Development of a revised measurement instrument

Chapter 5 describes the development of the Care Coordination Questionnaire (CCQ). Within this chapter I will address the issues of the measurement model, item generation and refinement and the preparation of the draft questionnaire. Good practice in item generation, refinement and subsequent questionnaire preparation is to involve potential respondents in their design and selection. Work at this stage should also include an assessment of the way in which items are understood by potential respondents to help reduce potential bias and measurement error (Collins, 2003).

2.3.4: Piloting of the Care Coordination Questionnaire

Chapter 6 describes the methodology used to pilot the Care Coordination Questionnaire. Within this chapter I will address the issues of sample size and selection, studies undertaken to assess reliability and validity together with a discussion of the analyses undertaken.

2.3.5: Item performance, testing of reliability and validity

The results of the piloting will be reported in Chapter 7. The characteristics of the respondents will be presented first followed by the evaluation of the performance of the candidate items of coordination. The process and application of item selection and refinement will be presented. This will be followed by the presentation of the final measure and the scoring system developed for use in the reliability and validation studies.

The chapter will conclude with a presentation of the results of the reliability and validation studies described in Chapter 6.

2.3.6: Evaluation of the measure and implications for future research

In the final chapter I will summarise the work presented here and the extent to which the objectives outlined above have been achieved. Key conceptual and technical issues will be discussed together with a reflection of their effects upon the performance of the

CCQ and its utility for both research and policy evaluation. I will conclude with the presentation of a number of recommendations for future development and research.

2.4: Summary

The aim of this thesis is to develop a patient reported measure of coordination of primary healthcare. The measure has been developed for use with those with long-term conditions in primary care for the reasons described above. This thesis describes the processes used to develop the measure and the studies undertaken to make an initial evaluation of its performance. The layout of the thesis has been outlined above, and aims to address each of the specific objectives underpinning this work.

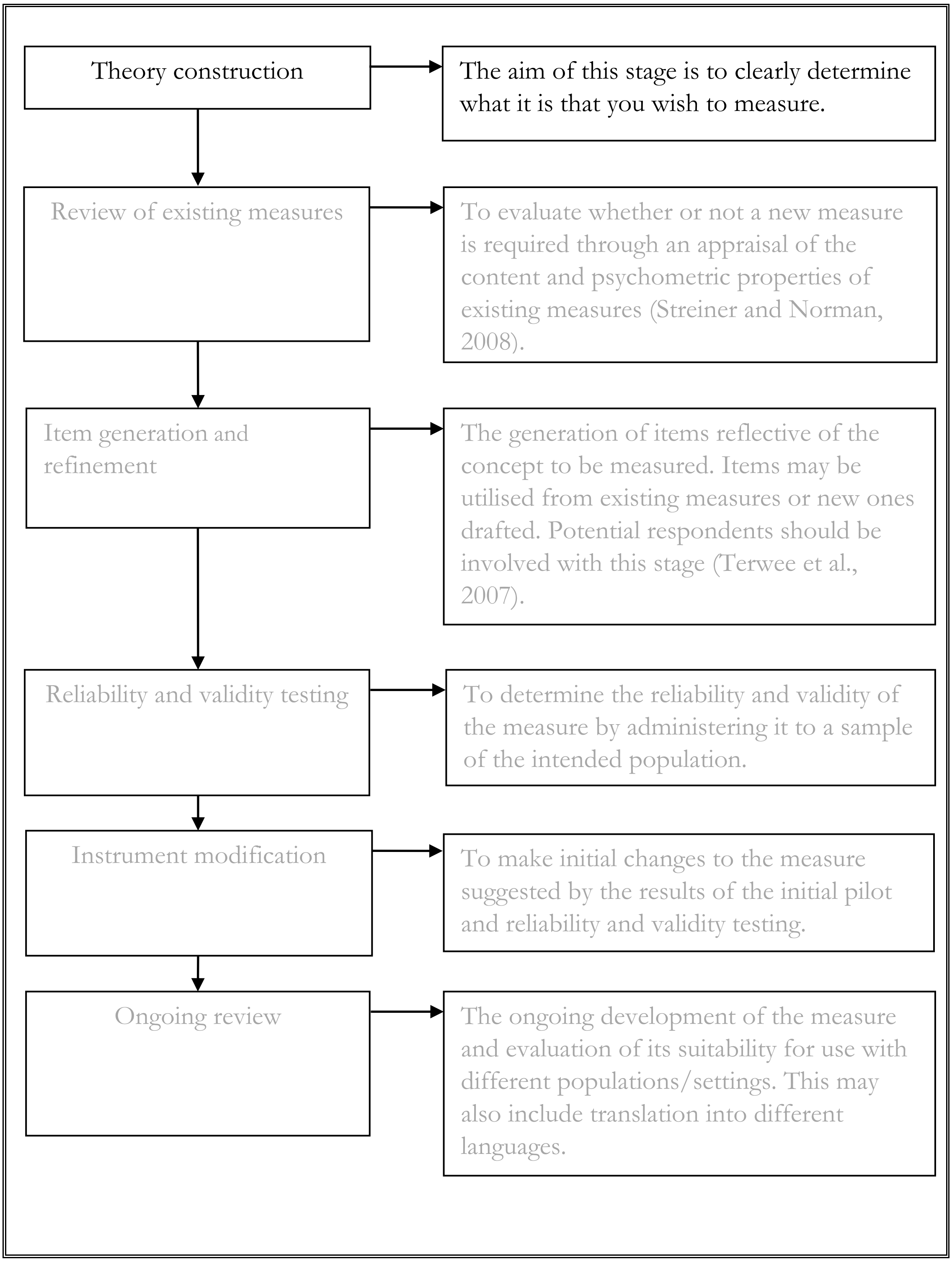
Chapter 3: Defining coordination of care

3.1: Introduction

Despite the widespread adoption of improved care coordination as a health policy objective a consensus definition of the concept remains elusive (McDonald et al., 2007), although common understanding is often assumed. The situation is further complicated by the use of the term 'coordination' in both scientific and everyday language, where a common understanding in one sphere is assumed in another (Morse, 2000).

However, conceptual clarity is an essential pre-requisite to measure development as it informs item generation and the assessment of content validity (Streiner and Norman, 2009). It is also the first step in measure development (see Figure 3.1). So, what is a concept and how do we know when we have clarified it?

Figure 3.1: Stages in Measure Development



Theory construction

The aim of this stage is to clearly determine what it is that you wish to measure.

Review of existing measures

To evaluate whether or not a new measure is required through an appraisal of the content and psychometric properties of existing measures (Streiner and Norman, 2008).

Item generation and refinement

The generation of items reflective of the concept to be measured. Items may be utilised from existing measures or new ones drafted. Potential respondents should be involved with this stage (Terwee et al., 2007).

Reliability and validity testing

To determine the reliability and validity of the measure by administering it to a sample of the intended population.

Instrument modification

To make initial changes to the measure suggested by the results of the initial pilot and reliability and validity testing.

Ongoing review

The ongoing development of the measure and evaluation of its suitability for use with different populations/settings. This may also include translation into different languages.

Concepts have been described as the ‘building blocks of theory’ and as the ‘mental image of a phenomenon’ (Walker and Avant, 2005) which aid in the organisation of environments and experiences. These images are then given ‘names’ which allow the ideas behind them to be communicated. This communication can be facilitated by the organisation of these ideas into the following structural features:

1. Definition of the concept: the giving of a label which allows the concept to be identified and communicated to others
2. Characteristics (or attributes) of the concept: the features which define the concept and as such must be present in each instance of the concept
3. Boundaries: the delineation of one concept from another, usually as a result of one or more characteristics no longer being present or new characteristics starting to appear
4. Preconditions (or antecedents): the circumstances which give rise to the appearance of the concept
5. Outcomes: the consequences experienced as a result of the concept (Morse et al., 1996).

The greater the ambiguity in relation to any of these structural features the less defined the concept.

The final stage of concept development is the identification of its empirical referents (McKenna and Cutcliffe, 2005). These are the criteria used to demonstrate the existence of the concept (McKenna and Cutcliffe, 2005). As will be discussed in section 3.5 empirical referents do not necessarily map neatly to the labels given to the conceptual characteristics, or need to be consistent across different stakeholders.

This chapter aims to address current understanding of the concept of coordination and coordination of care through consideration of the usage of the concept in both the health and organisational literature. From this a conceptual definition will be proposed which is delineated from related concepts such as continuity, integration and patient centred care. This will be presented using the structural features described above. Finally, consideration will be given to the identification of the empirical referents from a patient perspective. This will include consideration of the limits of the observability of coordination i.e. how it is likely that no single stakeholder has a comprehensive overview of the process.

3.2: Methods

Whilst a variety of approaches to concept analysis have been described (Knafl and Deatrick, 2000) they all share a common purpose which is the development of a definition of the concept of interest which distinguishes between relevant and irrelevant attributes and identifying a set of criteria to judge whether or not the concept is present in a particular situation. Common to these methods are an initial immersion in the literature surrounding a topic, selective literature review and thematic analysis of any definitions, attributes, preconditions and outcomes of the concept.

The approach to concept analysis proposed by Walker and Avant (2005) was followed with the exception of the development of fictional model cases. This is a step wise approach to concept analysis which involves:

1. Selection of the concept
2. Determining the aims of the analysis
3. Identifying all uses of the concept
4. Determining the defining attributes
5. Identification of fictional model, borderline and related cases
6. Identification of antecedents and consequences
7. Definition of empirical referents.

The aim of this concept analysis was to develop a definition of coordination which could be used to support measure development.

3.2.1: Search strategy

A scoping search was undertaken of four of the main medical, nursing and health management bibliographic databases: Medline, a biomedical database which includes over 3,000 medical, dental and nursing journals; CINAHL Plus, which includes over 3,000 nursing and allied health journals; the Cochrane database of systematic reviews and HMIC, a health care management database. Search terms included combinations of 'coordination of care' and its synonyms including integration and continuity, service organisation and MESH headings related to patient care management. The search strategy is attached as Appendix 1. This was supplemented by targeted searching of websites of key research funders and other research teams known to be working in this area. Initial reading also prompted more detailed consideration of the organisational literature and key texts were obtained. The aim was to sample the literature surrounding the concept in order to explore and incorporate into the conceptual definition a diversity of views.

Papers were considered for inclusion where they included a description of coordination or of strategies to improve coordination. Papers were excluded where they described developmental coordination and its management, or where the term was used in its everyday sense.

3.2.2: Data extraction and analysis

Each publication was read and text extracted which related to the structural features of coordination, namely any definitions, attributes, preconditions and consequences. During this process of data extraction an additional category of coordination mechanisms was added to systematically capture approaches used within the health system to address coordination problems. Information was also extracted regarding the patient group and/ or the health care setting of interest for each publication where this was available.

Once all papers had been reviewed, the text extracted under each structural heading was reviewed and organised into themes. These themes were then given a descriptive label using those proposed by McDonald et al. (2007) as a starting point.

From this, a definition of coordination of care was developed, along with a description of its attributes, preconditions and consequences. The category of coordination mechanisms was then reviewed to ensure that they could be related back to a previously identified attribute rather than adding new information to my understanding of the concept.

Once I had defined coordination, this definition was compared with existing definitions of the related concepts of continuity and integration to identify the boundaries of the concept. These terms were selected for comparison as they are frequently used both interchangeably with, and complementary to, the term coordination (Singer et al., 2011, Yates, 2004). The definition was also compared with existing definitions of patient centred care as this is a key concept in current healthcare delivery and has been suggested as an attribute of coordinated care (Ehrlich et al., 2009).

3.3: Results

The scoping searches resulted in a vast quantity of potentially relevant literature covering a range of disciplines and type of publication. Two recent concept analyses (Ehrlich et al., 2009, McDonald et al., 2007) were also identified which reflect the differing approaches taken within health services research to understanding the phenomenon. 73 studies were included in the concept analysis with the wider literature being used in this chapter to support and illustrate the proposed definition, attributes, consequences and antecedents.

Data were original grouped into the themes proposed by McDonald et al. (2007) of 1) deliberate organisation of care activities including planning, 2) interdependence, 3) knowledge of roles and resources, 4) information exchange/communication. Further analysis and wider reading suggested that interdependence should be considered as an antecedent to coordination rather than one of its defining attributes. As is discussed further in section 3.3.3 an additional attribute of 'responsiveness to change' is also proposed.

3.3.1: Definitions and uses of coordination

Dictionary definitions of coordination propose three definitions. Firstly, coordination is 'the organisation of the different elements of a complex body or activity so as to enable them to work together effectively. Secondly, 'the ability to use different parts of the body together smoothly and efficiently'. And thirdly, within chemistry to describe the linking of atoms (Oxford Dictionaries, 2014). It is the first of these definitions that is of most relevance here. This suggests that coordination is primarily a managerial task. It is unsurprising then that the greatest consistency in the use of the term was noted in relation to the organisational literature, where there is a long history of researching the topic (Okhuysen and Bechky, 2009) and where a shared understanding of the concept was more evident than in the health literature.

Within the health literature the terms 'coordination', 'coordination of care', 'care coordination' and 'coordinated care' have been used in a number of ways to describe:

1. processes for organising patient care – coordination of care (Kroll and Neri, 2003, Meijer and Vermeij, 1997, Stille et al., 2005),
2. a type of care which is offered to specified groups of patients – care coordination (Brown et al., 2008, Chen et al., 2000, Palsbo and Ho, 2007) and
3. a patient level experiential outcome of the organisation of health services – coordinated care (Freeman et al., 2000).

It has been suggested that this variety of usage has led to a lack of clarity about the meaning of the term in a given context (Beringer, 2005, McGuiness, 2001). Indeed, a common theme in the understanding of coordination in the health literature was to note that there was no agreed definition (McDonald et al., 2007). It was not uncommon for studies reporting interventions intended to improve coordination of care to omit an explicit definition and to begin with a description of the intervention itself which often included aspects of care common to other health care processes such as assessment of needs, care planning and review (Ehrlich et al., 2009, Chen et al., 2000). The utility of these processes in addressing perceived coordination shortcomings is rarely explicitly addressed, suggesting that their worth is self-evident: a potentially flawed assumption given the variety of uses to which the term 'coordination' is applied.

Coordination has also been widely studied within the fields of management and organisational studies. Definitions of coordination within this literature are more consistent with it generally being viewed as a process which enables the integration of interdependent tasks (Okhuysen and Bechky, 2009, Thompson, 1967). Malone and Crowston (1994) define it simply as 'managing dependencies'.

Dependencies or interdependencies arise as 'a condition where actions taken within one unit affect the actions and work outcomes of another unit' (McCann and Ferry, 1979). As such they occur when no single work unit has the ability to complete the task independently. Interdependence is a frequent characteristic of healthcare where responsibilities for the management of different aspects of the patient's care are fragmented or distributed across disparate professionals or provider organisations (Liu et al., 2010) as a result of specialisation or organisational structure.

By defining coordination as the management of interdependence, the organisational literature is able to differentiate between coordination and the mechanisms used to achieve it. Malone and Crowston (1994) propose that these mechanisms should be viewed as interchangeable tools which are more or less appropriate for the management of particular dependency problems, rather than as a definition of the phenomenon itself. The risk of defining the phenomenon by the mechanisms used to deliver it is that coordination becomes defined as 'what we do to coordinate'. This fails to recognise that whilst coordinating mechanisms can, and do, differ across different levels of health care delivery the essential conceptual attributes remain the same.

3.3.2: Preconditions to coordination

Preconditions are the circumstances which give rise to the appearance of the concept of interest (Morse et al., 1996).

Organisational theory is clear that the need for coordination arises from the state of interdependence. Three types of interdependence are commonly identified: pooled, sequential and reciprocal (Thompson, 1967). Pooled interdependence requires no direct interaction between the differing parts of the organisations but recognises that unless each part performs adequately then the whole organisation is put at risk. Sequential interdependence builds upon pooled interdependence but there is now a direct interaction between the differing parts of the organisation. That is, the behaviour of A affects the ability of B to act. This type of interdependence can be identified, described and ordered i.e. A affects B which in turn affects C and so on. This effect is unidirectional. Reciprocal interdependence describes a dynamic situation in which 'the outputs of each become the inputs for the others' (Thompson, 1967). The actions of each participant need to be adjusted to the actions of others in the group and also to changing and unpredictable circumstances. Each participant provides a contingency for each other and it is this flexibility which differentiates reciprocal interdependence from sequential.

These types of interdependence are broadly hierarchical in terms of task complexity, uncertainty and information processing requirements. Thompson (1967) proposed three coordinating mechanisms which can be used to manage these interdependencies: standardisation, planning and mutual adjustment.

Standardisation involves the establishment of rules and routine. These may be explicit or embedded within the culture of the organisation. They are supported by stability and repetition. As a coordinating strategy, standardisation is best suited to managing predictable interdependencies such as those observed in pooled and sequential interdependence. Planning requires the establishment of schedules to guide action. It is less dependent upon routine than standardisation and can therefore be used in more dynamic environments. Care planning, and care pathways in particular, are examples of this within healthcare. Mutual adjustment is used in situations which are unpredictable and involves the 'transmission of new information during the process of action' (Thompson, 1967). This has also been referred to as coordination by feedback (March and Simon, 1958), as it recognises the need for actions to be reviewed in the light of their effectiveness and adjustments made where necessary.

Others have categorised coordinating mechanisms into two groups: programming and feedback (March and Simon, 1958). Programming approaches are broadly comparable to Thompson's (1967) standardisation and planning. As such, they are best suited to routine, predictable situations where work flows and necessary skills can be specified in advance.

Feedback approaches, which include supervision and peer interaction, are required for the management of less predictable circumstances (Allred et al., 1995, Young et al., 1997). This type of coordinating mechanism is more time consuming than the programme approaches and places greater demands on communication links and the decision-making processes utilised by participants. For these reasons, Thompson (1967) hypothesised that they would be used infrequently.

However, more recent literature, prompted by transitions from manufacturing to service economies, has challenged historical assumptions about the predictability of interdependence (Gittell, 2002, Okhuysen and Bechky, 2009). Attention has turned to the study of coordination as an emergent, context dependent response to unpredictable interdependence challenges (Faraj and Xiao, 2006, Young et al., 1997). This has been accompanied by increased interest in the nature of the relationships required to develop and sustain coordination efforts both within, and external to, the organisation (Gittell, 2009, Havens et al., 2010).

The notion of coordination as an ongoing activity has also led to different conceptualisations of its temporal nature. Classic approaches to interdependence suggest that as the nature of interdependence can be pre-determined so can the coordinating response or mechanism, for example, plans can be developed, schedules determined. Ongoing activities, however, are temporally unfolding and as such are heavily dependent upon the environmental context in which the activity is being performed as well as the content of the activity (Faraj and Xiao, 2006). However, the state of interdependence remains the precondition for coordination: without it coordination is unnecessary.

The notion of interdependence as a pre-requisite for coordination is also identified within the health literature, although it is less clearly expressed. Commonly cited preconditions in the health literature are the need for multiple professionals who are required to work together (Harrison and Verhoef, 2002, Hawley et al., 2010, McDonald et al., 2007) and the absence of continuity (Bodenheimer, 2008). The implication is that no single professional is able to perform all required care activities themselves, that they need to access the expertise of others to meet patient needs and that this requires them to work interdependently.

Another approach in the health literature is to focus upon the types of patients who would benefit from receiving coordinated care (Chen et al., 2000). Typically these are patients who are chronically ill, with complex ongoing needs or at risk of adverse outcomes (Chen et al., 2000, Department of Health, 2008b, Palsbo et al., 2006, Sofaer et al., 2000). Again, requiring care from multiple providers is a characteristic common to these groups of patients, as is the need for these providers to work together.

3.3.3: Characteristics of coordination

The characteristics of a concept are the features which define it and are present in instances where the concept occurs (McKenna and Cutcliffe, 2005). Four themes were identified as being key features of coordination. Firstly, that it is purposeful activity; secondly, that it requires communication and information exchange; thirdly, that participants require knowledge of their roles, the roles of others and the resources available to them, and finally, that coordination is responsive to changing needs and circumstances. These will now be considered in more detail.

3.3.3.1: Purposeful activity

Coordination has been described as a process (Beringer, 2005, Van De Ven et al., 1976, American Academy of Pediatrics, 1999), a conscious activity (Longest and Klingensmith, 1994), a function of an organisation (National Quality Forum (NQF), 2006) and as an intellectual exercise (Stille et al., 2005). Implicit within these phrases are ideas of the organisation of activities or events which require thought and planning. Within the organisational literature coordination is conceived of as a strategy to manage linkages between individuals, work units and/or organisations who are participating in a joint endeavour (Allred et al., 1995, Van De Ven et al., 1976).

Central to the notion of joint endeavour and of purposeful activity is that participants are all working towards the same goal (Chen et al., 2000, Claiborne, 2006, Faraj and Xiao, 2006). Suggested goals range from the generic successful manufacture of a product or service (Malone and Crowston, 1994) to the more specific appropriate delivery of health services (McDonald et al., 2007), achievement of agreed patient outcomes (Gilbert and Counsell, 1995), synchronisation of services (Knudson, 1968) or reduction of unnecessary costs (Kibbe, 2002). Whilst there is some overlap here between the goals of coordination and its hypothesised outcomes, especially within the health literature, there is a consensus across the literature that these goals should be shared across all participants (Aliotta, 2003, Gittell, 2009, Knudson, 1968) to ensure a 'unity of effort' (Allred et al., 1995). Goal articulation aids the identification of the tasks and sub-tasks necessary for its completion and the order in which they should be performed. This establishes a sense of predictability across participants, which reduces uncertainty and aids integration of activities (Faraj and Xiao, 2006).

The deleterious effects of the failure to agree shared goals are illustrated in the case study presented by Allen et al. (2004), where failure to agree explicit goals beyond 'acting in the patient's best interests' led to communication breakdowns, power play across the care team and confusion and distress for the patient and their family.

3.3.3.2: Communication and information exchange

Almost all definitions reviewed stress the importance of communication and information exchange to coordination. For some this was the only explicitly identified attribute (Allred et al., 1995, Cassady et al., 2000, Fletcher et al., 1984, Mares et al., 2008).

The burden of communication increases with the complexity of the task (Okhuysen and Bechky, 2009) and the number of participants (Stott, 1995). The increased burden of adding additional professionals to an individual's care team is non-linear and can be described using the equation $(n^2-n)/2$ (Stott, 1995). To illustrate this, a scenario with five participants would require 10 lines of communication. However, a conservative estimate of the number of physicians involved in an individual Medicaid patient's care is seven (Pham et al., 2007, Pham et al., 2009), which would require 21 lines of communication.

Relational coordination theories propose that communication needs to be frequent, timely and accurate (Gittell, 2009). Frequent communication aids with the creation of relationships and a common understanding of work (Okhuysen and Bechky, 2009). The timeliness and accuracy of communication is obviously important in healthcare where delays and inaccuracies may have deleterious effects upon the patient, which have been well documented (Edmonds et al., 2007, Havens et al., 2010). Relational coordination theory also proposes that communication between participants should be focused upon problem solving rather than blame when things go wrong (Gittell, 2009).

Whilst communication and information exchange between professionals and providers is important, this attribute should also include communication with the patient (Coleman et al., 2002, Harrison and Verhoef, 2002, Hawley et al., 2010). The organisational literature notes that customers of service industries (such as health care) are usually the key, and sometimes the only, source of information necessary for successful manufacture of the service in terms of how they specify their problem, the outcomes they want to achieve and their intended level of participation in any shared production of the service (Siehl et al., 1992).

This sharing of information and knowledge is necessary for the creation of a common understanding of the work (Allred et al., 1995), responding to emerging interdependencies (Okhuysen and Bechky, 2009) and the resolution of problems (Faraj and Xiao, 2006).

3.3.3.3: Knowledge of roles and responsibilities

In order to organise activities, participants need to be able to identify and access the resources required in both human and material terms. In this context both roles and resources should be interpreted broadly and include those attributable to professionals and patients. Each participant should know what they are expected to do and what can be expected of others (Beaudin et al., 1999, Faraj and Xiao, 2006, MacPhail et al., 2009). This aids the creation of accountability for acts or omissions on the part of each participant. Understanding where one 'fits' in the context of the activity to be performed can also help with fostering of mutual respect, a key aspect of relational coordination (Gittell, 2002, Gittell, 2009).

For those charged with managing interdependencies, knowledge of participant roles and skills facilitates the appropriate allocation of tasks necessary to the attainment of the stated goals. Faraj and Sproull (2006) termed this 'expertise coordination'.

References were also identified in relation to the roles undertaken by patients and customers in the co-production of a product or service (Harrison and Verhoef, 2002). Different care philosophies envisage different patient roles, with the current predominant view of chronic disease management in particular, valuing active participation and self-management (Bayliss et al., 2003). It has also been proposed that active patient participation is 'an important hallmark of coordinated care' (McGuiness, 2001). An idea which has been adopted by some patient groups in their considerations as to what coordinated care looks like (National Voices, 2013). However, this should not be interpreted as patient participation being necessary for coordination. Those who are unable or unwilling to participate in the organisation of their care still require that interdependent activities dispersed across multiple participants are organised into a coherent care package. Patients can be categorised as expert and novice customers whose participation needs to be managed in order to ensure success (Bateson, 2002). When patients act as co-producers of their health care this creates interdependency between them and their providers. Effective management of this requires that patient roles are not assumed but are explicitly understood and accepted. As Larsson and Bowen (1989) note, active participation may be limited both by a lack of ability and a lack of role clarity and preparation. Failure to address this may result in patients feeling abandoned and distressed (Harrison and Verhoef, 2002) and ultimately represents a production failure.

The completion of tasks and care activities requires knowledge of the resources required to do this and the ability to access them (Antonelli et al., 2008, Manser et al., 2008, McDonald et al., 2007). Resources need to be managed, and as with knowledge of roles and skills, this has been suggested as a key aspect of task allocation (Malone and Crowston, 1991). The ability to link patients with the resources they need is a common aspect to many coordination definitions and forms a key aspect of many coordination mechanisms (American Academy of Pediatrics, 1999, Bruce et al., 2011).

3.3.3.4: Responsiveness to change

An acid test of coordination in temporally unfolding situations such as healthcare, is the extent to which interdependencies are identified and managed in response to either unexpected or unpredictable events (Beaudin et al., 1999). Failure to do this results in coordination gaps (Rathnam et al., 1995). Definitions within the health literature stress the importance of follow-up, review and the extent to which care is adapted to changing needs (Antonelli et al., 2008, Chen et al., 2000, Cockerill et al., 2006, Glasgow et al., 2005).

This adaptability is less frequently referenced within the classical organisational literature, although it is of relevance to more recent discussions of coordination in highly uncertain environments (Faraj and Xiao, 2006).

3.3.4: Consequences of coordination

The process of coordination requires that participants perform both the tasks necessary for the production of a product or service (production tasks) and additional coordination tasks (Malone and Crowston, 1994). Where this is achieved it should result in an outcome for the consumer, evidenced by the successful manufacture of the desired product or service. When either the coordination or production tasks are absent or ineffective then the product or service is not delivered or is deficient in some way, for example, in terms of quality or timing, i.e. there is a production failure. Successful coordination is therefore associated with increased quality and efficiency (Aliotta, 2003, Allred et al., 1995, Gittell, 2009).

In terms of coordination of healthcare, these consequences can be divided into those which impact on the patient and those which impact upon the wider health system. Anticipated patient benefits include increased satisfaction with care (Cockerill et al., 2006, McDonald et al., 2007), improved patient and carer experience and a reduction in care giving burden (Sofaer et al., 2000), enhanced clinical outcomes (Ehrlich et al., 2009) and fewer unmet needs (Van Achterberg et al., 1996).

From a health system perspective coordination has been hypothesised to reduce medical errors (Stille et al., 2005), eliminate duplication of services and other forms of waste (Bennet et al., 1997, Ehrlich et al., 2009), and reduce preventable admissions (Sofaer et al., 2000). Ultimately, it is hoped that this will achieve a reduction in healthcare costs, especially those associated with the management of chronic disease (Claiborne, 2006).

3.3.5: The boundaries of coordination

Other researchers have noted the use of the terms continuity and integration either interchangeably with or in a complementary manner to that of coordination within the literature (Edmonds et al., 2007, Singer et al., 2011, Sofaer et al., 2000, Yates, 2004). This usage suggests that they are either different terms used to capture the same conceptual ideas or they are different, albeit related, concepts. Definitions and characteristics associated with each term were examined to identify similarities and differences with those attributed to coordination thereby delineating the boundaries of coordination as a concept.

Another relevant concept is patient centred care. Considering the relationship between patient centred care and coordination is particularly important as patient centred care has been suggested as a key attribute of coordination of care (Ehrlich et al., 2009). The attributes proposed here do not include this concept, and taken from an organisational perspective, being patient-centred might not be conducive to effective coordination. However, patient centeredness is also a contested concept. As with continuity and integration, definitions of the term were examined and reflected upon in order to better understand the potential relationship with coordination.

3.3.5.1: Continuity and coordination

It has been proposed that continuity and coordination lie on a conceptual continuum with coordination only being required in the absence of traditional continuity (Bodenheimer, 2008). Others have proposed that whilst improved continuity leads to better coordination, they are conceptually different (Haggerty et al., 2003). In order to clarify and articulate these conceptual differences it is necessary to consider the meaning of continuity.

Continuity is frequently referenced as a key aspect of primary care, and general practice in particular (Starfield et al., 1976). Despite this, a range of conceptual definitions have been proposed whose boundaries have expanded and contracted with time. As with coordination, there has been a tendency in the literature for meaning to be presumed rather than made explicit (Reid et al., 2002).

A scoping review undertaken to support the commissioning of a research programme into continuity of care identified at least ten potential definitions of continuity in the literature (Freeman et al., 2000). From these the authors synthesised their own definition of continuity as the patient experience of smooth, coordinated progression through their care. To achieve this there needed to be processes for the transfer of patient information, communication between professionals and services, services needed to be flexible and adjust to individual needs, the numbers of professionals involved in a persons' care should be kept to a minimum and that there should be a therapeutic relationship with at least one individual professional (Freeman et al., 2000).

This definition would appear to encapsulate coordination as an aspect of continuity rather than as a discrete concept. Many of the characteristics of coordination proposed above are also noted here as characteristics of continuity, namely, communication and information exchange, adaptability of services and multiple providers. The only point of differentiation is that of relational continuity: an ongoing therapeutic relationship between the patient and at least one named professional.

Since 2000, a consensus appears to be emerging in the primary care literature that continuity may be considered as comprising of three types: informational continuity, managerial continuity and relational continuity (Freeman et al., 2007, Freeman and

Hughes, 2010, Glasgow et al., 2005, Haggerty et al., 2003, Reid et al., 2002). Informational continuity refers to the use of information about past events in the patient's care to plan current care. Managerial continuity refers to ensuring that care is consistent across providers. Relational continuity refers to the ongoing relationship between a patient and either a single care provider or a team of providers.

Again, there is considerable overlap between these definitions and the characteristics of coordination. And again, it is relational continuity which emerges as the main point of differentiation between the two concepts.

This difference was also noted by Krogstad et al. (2002) although they labelled it as 'frontstage' and 'backstage' continuity. Frontstage continuity is analogous to relational continuity in that it refers to consistency of healthcare professional and implies an ongoing patient-provider relationship (Reid et al., 2002). Backstage continuity is a feature of the organisational system in which care is being delivered. Considered from a patient perspective it incorporates knowing the plan for their care, receiving consistent information from different professionals and follow-up of any problems: similar ideas to those expressed as managerial and informational continuity.

The ideas captured by the label relational continuity, namely, the development and maintenance of an ongoing therapeutic relationship, ensuring consistency of personnel and limiting personnel to the minimum number required to meet care needs fall out-with the definition and characteristics of coordination as a process for the management of interdependence. Salisbury et al. (2009) have proposed that there is a further need to disentangle the length of the relationship with a provider from its therapeutic nature arguing that the former does not ensure the latter. They further argue that informational and managerial continuity should be relabelled as 'coordinated care' and go on to state:

> 'These three concepts of longitudinal continuity, relationship and coordination are related but distinct and should be measured separately.' (Salisbury et al., 2009)

If this is the case, how accurate is it to suggest that coordination is only required in the absence of traditional continuity (Bodenheimer, 2008)? Traditional continuity has been defined as an ongoing relationship between a single professional and a patient that extends over time, a definition which has been incorporated into ideas of relational continuity and is described by Salisbury et al. (2009) as longitudinal continuity. Where care can be delivered by a single professional this eliminates the need for coordination as there are no inter-professional interdependencies which need to be managed. Once a further professional or provider is required to meet the care needs of a patient then interdependencies begin to emerge and the participating professionals are required to perform coordinating tasks as well as production tasks (Malone and Crowston, 1994).

For the purpose of this thesis I adopted the view that whilst there is significant overlap between coordination and managerial and informational continuity, the point of differentiation between the two concepts is that of relational continuity. Where there is complete relational continuity between a patient and a single professional coordination is not required. As such, this is the point at which a boundary can be drawn between the two concepts.

3.3.5.2: Integration and coordination

Integration is another poorly defined concept, with multiple definitions, which is often used interchangeably with the term coordination (Kodner and Spreeuwenberg, 2002, Leutz, 1999, Nolte and McKee, 2008, Singer et al., 2011). They also share many definitional features such as the need for organisations to work together in order to achieve improvements in clinical and efficiency outcomes.

Broadly, the review literature on integration divides into that which views it as an organisational and managerial function (Kodner and Spreeuwenberg, 2002, Leutz, 1999, Nolte and McKee, 2008, Suter et al., 2008) and that which focuses upon the integration of patient care as an outcome of integration, whilst noting that organisational integration does not guarantee a positive patient experience (Lewis et al., 2010, Singer et al., 2011).

Considering integration from an organisational and managerial perspective Leutz (1999) described three, broadly hierarchical, levels of integration: linkage, coordination and full integration. These three types of integration sit on a continuum of increasingly formal governance arrangements and access to pooled financial and other resources (Suter et al., 2008) with coordination being the mid-point between linkage and full integration. Here coordination is defined as a structured collaboration between participants who operate within separate organisational structures and with separate resources. This organisational structure is best suited to meeting the needs of those patients with moderate care needs who are receiving care from two providers either simultaneously or sequentially (Leutz, 1999).

Other integration typologies have been described where integration may be considered as functional, organisational, professional and clinical (Nolte and McKee, 2008, Fulop et al., 2005). Functional integration is the extent to which support functions such as human resources, financial management are coordinated and shared across units. Organisational integration functions upon the structural features of any integration such as networks, contracting arrangements and mergers. Professional integration picks up on joint working between professionals and clinical integration as the extent to which patient care activities are coordinated across different professionals and providers (Nolte and McKee, 2008).

Where the focus is the integration of patient care, then coordination has been proposed as a key characteristic of this process (Lewis et al., 2010, Singer et al., 2011). Here the focus is upon the patient experience of the coordination of services between professionals, between provider organisations and with community support services. However, there is also conceptual overlap with ideas of longitudinal and relational continuity and patient centred care (Singer et al., 2011).

Implicit within these definitions is the idea that coordination is a necessary step towards full organisational integration. This raises the question as to the role of coordination once full integration has been achieved. Full integration requires the creation of new delivery units in order to provide care to designated groups of patients. In order to meet patient need it is likely that these delivery units will continue to be made up of a number of individuals and professional groups who will be required to work interdependently therefore the need for coordination remains. Being in a single organisational unit may make this easier to achieve, but coordination tasks will still need to be performed.

3.3.5.3: Patient centred care and coordination

The suggestion that care should be patient centred is a guiding principle for the development of healthcare in many countries worldwide, including the US (Institute of Medicine, 2001) and the UK (Department of Health, 2012). However, the conceptual nature of patient centred care is contested resulting in differences in definitions, defining attributes and its role in healthcare (Kitson et al., 2012, Michie et al., 2003, Grob, 2013, Hudon et al., 2012). There are also differences in interpretation between professional groups (Kitson et al., 2012).

This has resulted in patient centred care being described as an attribute of coordination (Ehrlich et al., 2009) and vice versa (Gerteis et al., 1993), suggestive of a potential overlap between the two concepts. This emerges as a reflection of the current political priority given to being patient centred within many health systems and from the purpose of coordination itself. The current value given to patient centred care should result in the patient being acknowledged as an individual whose views should be respected and incorporated into decisions made about their care and the way it is organised (Epstein and Street, 2011).

One of the desirable characteristics of a product or service is that it is acceptable to its consumers. In the context of patient centred healthcare this may be interpreted as seeking to understand and be respectful of individual preferences. However, this should not be interpreted to mean that being patient centred is necessary to achieving coordination of care. Those who are unable to express preferences or participate in their healthcare still require that any interdependencies arising between their care givers are managed effectively. Moreover a case could be made that care can be successfully coordinated with no reference to patient preferences, but that in a healthcare system which values patient centred care this is a potential point of intersection.

3.4: Working definition of coordination

In summary, I propose that coordination is best understood as the management of interdependencies arising between work groups engaged upon a common task. In relation to the coordination of health care I propose that it should be considered as:

> 'a process for the organisation of patient care activities which involves multiple professionals or provider organisations'

This process is supported through four key characteristics. Firstly, it is a purposeful activity. Secondly, it requires participating professionals and provider organisations to communicate and exchange information both with each other and with the patient and their carers. Thirdly, the organisation of patient care activities requires both knowledge of the roles and skills of available health care providers and the ability to access the necessary resources. Finally, the organisation of these activities needs to be able to respond and adapt to changes in patient need and the environment in which care is delivered.

In seeking to manage interdependencies the organisational literature describes two main approaches: programming and feedback. A number of different mechanisms are available under each of these headings to achieve this, which may be used interchangeably. This differentiation between coordination and the mechanisms which may be used to achieve it is important when considering measure development as ideally a measure should be capable of being used to compare the effectiveness of different interventions.

However, this working definition retains an abstract quality. The attributes described encompass both professional and patient behaviours, some of which may be invisible to each other. Indeed, it is likely that there is no single stakeholder who has a comprehensive overview of either the coordination activities or their effectiveness. Healthcare professionals may be able to report on their own behaviours and those of other health professionals with whom they interact but not necessarily on the wider team involved with the patient or whether the patient perceives the resulting care as coordinated. Likewise, patients may be able to report on their perceptions of whether their care is coordinated, some of the activities involved in coordination and some of the behaviours of their healthcare professionals which may be suggestive of coordination problems. Many interactions among health professionals will however remain invisible to patients. Therefore, measurement of the concept from any single stakeholder perspective is likely to be partial at best.

In order to progress to measure development the definition of coordination needs to be operationalised through the identification of its empirical referents.

3.5: Identification of the empirical referents of coordination of care

Empirical referents are the observable manifestations of a concept which are used to demonstrate its existence (McKenna and Cutcliffe, 2005). They operationalise the conceptual definition. Often the empirical referents are identical to the conceptual characteristics (Walker and Avant, 2005) but this is not always the case, especially in relation to more abstract, process concepts such as coordination (Walker and Avant, 2005).

The utility of using the conceptual characteristics of coordination of care as empirical referents was explored by using these headings to evaluate the item content of existing measures of coordination. The results of this analysis are reported in more detail in Chapter 4 but it is worth noting here that these were unsatisfactory as item content frequently cut across more than one attribute simultaneously. This necessitated a reappraisal of how coordination of care might be evidenced from the patient perspective.

3.5.1: Patient observations of coordination of care

If effective coordination is ‘nearly invisible’ (Haggerty et al., 2013), how then does coordination become visible? To consider this I developed a short paper in which I reflected upon the following questions in relation to each of the identified coordination characteristics: firstly, how might coordination failure manifest itself in a healthcare context and secondly, are patients able to observe and report on these failures in a consistent manner? At this stage ‘failure’ was broadly defined and included effects upon both patients and professionals. The aim was to develop examples of failure for each characteristic and how it might be observed by patients in a relatively uncritical manner in order to stimulate discussion and reflection across my supervisory team.

This exercise suggested that three broad types of coordination failures can be identified in healthcare. Firstly, expected care activities may not take place due to a failure to plan or problems in the delivery of the plan. Secondly, care activities are delivered but they are not acceptable to the patient in terms of, for example, quality, timing or cost in time, money or personal and family effort. Thus, for patients, the coordination of their care is closely entwined with the clinical quality of their care (Hawley et al., 2010, Walsh et al., 2010). Thirdly, patients may experience and thus be able to report on inter-provider behaviours which are indicative of underlying coordination problems. For example, they may be given conflicting advice by different healthcare providers.

Attribution of these failures to a specific characteristic of coordination was challenging. The same failure could be identified in relation to more than one of the key characteristics. For example, a lack of purpose may reflect the absence of a shared objective, or of a failure to communicate this to all participants. From the patient perspective, identification of the exact cause of the failure may be of limited value as what they experience is the result: a sub-standard or missing service.

These three types of coordination failure were considered in more detail and then used to inform item development for the questionnaire.

3.5.2: Planning of care

The first identified cause of coordination failure arises from an omission of required care activities. Key to mitigating against this is having an agreed and coherent plan of care which is shared across all providers so that the necessary activities can be identified and organised. Care which is unplanned lacks purpose. It has the potential to result in a series of disjointed tasks which may or may not be related to each other or to the attainment of an overarching objective.

This plan of care should address the arrangements for care activities to be performed as well as identify the care activities required. This requires a shared understanding of what the activities are, who will deliver them, when they will be delivered (in what order) and in what timeframe and where they will be delivered.

At this point it is worth reflecting on the definition of a 'plan of care'. For the purpose of this thesis I differentiate between a 'plan of care' and a 'care plan'. The former refers to a situation in which there is an implicit or explicit shared understanding between the participants in a patient's care and the patient as to the care they can expect to receive. This may or may not be codified into a written document or 'care plan'. As such, the availability of a codified care plan may be used as evidence that there is a plan of care, but its absence should not be interpreted as indicative of a lack of a plan for a person's care.

3.5.3: Problems with the delivery of care

Once care activities have been identified there is a natural evolution into the experience of the delivery of this plan. For example, did care happen at the time and in the manner in which the patient was expecting? Did the patient see those healthcare professionals he was expecting?

3.5.4: Observations of inter-provider behaviours

The final area of potential coordination failure from the patient perspective relates to patient observations of inter-provider behaviours and their consequences. As noted earlier, not all coordination tasks performed by professionals will be visible to patients. It would be difficult, for example, for patients to observe and report on communication between their providers which takes place in their absence. However, provider failures in this area may lead to coordination failures which are visible to the patient either as a breakdown in a process or as a result of their consequences, for example, through being given conflicting advice.

The phrase 'inter-provider behaviours' refers to the way providers present patients with a consistent approach to their care and how they portray their relationships with each other. It is limited to the aspects of provider behaviour that patients can directly experience, for example, being given conflicting advice or providers being critical of one another rather than asking them to speculate on hidden activities.

Thus the empirical referents of coordination used to structure measure development and guide item selection and refinement (see Chapter 5) in particular were:

1. Is there a plan of care based upon an assessment of needs?
2. Is this plan acceptable from the patient perspective?
3. Is this plan subsequently delivered in the expected manner? This includes both the care activities, the timeframe for each activity and the health professional expected to undertake the task.
4. Has this plan been stressed due to healthcare provider or patient initiated changes or unexpected adverse events?
5. How easy was it to adapt the plan to these changes?
6. Have healthcare providers been observed to act in ways which might indicate problems with coordination?

3.6: Strengths and weaknesses of this conceptual framework

The main strength of the conceptual framework presented here is that it has the potential to be relevant to all levels of healthcare delivery and different healthcare delivery settings as it seeks to differentiate the concept i.e. the organisation of patient care activities from the mechanisms used to achieve it such as writing care plans. The selected methodology allowed for consideration of a broader body of literature including both theoretical and empirical work from health, organisational and computer sciences. This has supported a broader understanding of the concept and enabled a more critical consideration of the dominant approach within healthcare: the focus upon the mechanisms used to achieve coordinated care. Had a more traditional systematic review methodology been adopted some of the insights from other disciplines would not have been considered.

The main methodological limitation of the conceptual framework presented here is that concept development is necessarily a subjective process and alternative conceptualisations and frameworks may be proposed (McKenna and Cutcliffe, 2005). The definition proposed here builds upon the work of McDonald et al. (2007) who also took a more multidisciplinary approach to coordination. As such it contrasts with other conceptualisations within the health literature which define coordination as an approach to care management for specified groups of patients (Chen et al., 2000, Ehrlich et al., 2009). These approaches tend to focus upon the mechanisms which may be used to deliver coordination of care at the micro (patient care level), meso (organisational level) and macro (policy and structural level) levels of health service delivery, resulting in lists of activities to be performed. Examples include integrated funding arrangements, case conferencing, shared records, care plans and co-location of services (Powell Davies et al., 2008).

Whilst these activities are familiar to patients, health professionals and commissioners I would argue that this approach risks conflating the definition of coordination with the mechanisms used to achieve it. This fails to appreciate the interchangeable nature of coordinating mechanisms described in the organisational literature (Malone and Crowston, 1994). Furthermore, overt specification of the processes to be used to address interdependence risks stifling innovation and the development of alternative solutions. Translation of this conceptual approach into a measurement tool risks the development of an instrument which is of limited application in the evaluation of diverse health systems and alternative coordinating mechanisms.

The focus upon specified groups of patients also raises the question of to what extent coordination is a requirement of all patients. If coordination of care is defined only in the context of long-term conditions does this imply that coordination is not required in acute care settings? Evidence from the organisational literature does not support this position as the need for coordination emerges from the interdependence between multiple individuals engaged in a shared pursuit. In many cases coordinating the acute care environment may be more challenging as a result of the numbers of professionals involved and the potential for patient care needs to be highly dynamic (Faraj and Xiao, 2006). The broad definition of coordination proposed here is equally applicable to acute care delivery as primary care. However, there may be differences in the detail of its empirical referents depending upon 1) the context in which care is delivered and 2) the stakeholder perspective of interest.

3.7: Summary

In this chapter I presented a conceptual framework of coordination of care which draws upon both the organisational and health literature and can be differentiated from the related concepts of continuity, integration and patient centred care. The process for defining empirical referents used to inform measure development has also been presented. This was a two-stage process which entailed firstly, testing the utility of the attribute headings by attempting to use them to evaluate the conceptual coverage of existing measures. This process is presented in further detail in the next chapter where I present a systematic review of existing patient reported measures of coordination. When this proved unsuccessful, the second stage involved consideration of coordination failure from the patient perspective as a process which cuts across the discrete attributes, resulting in different empirical referents. The results of this will be returned to in Chapter 5 where measure development is described.

Chapter 4: Measuring coordination from the patient perspective

4.1: Introduction

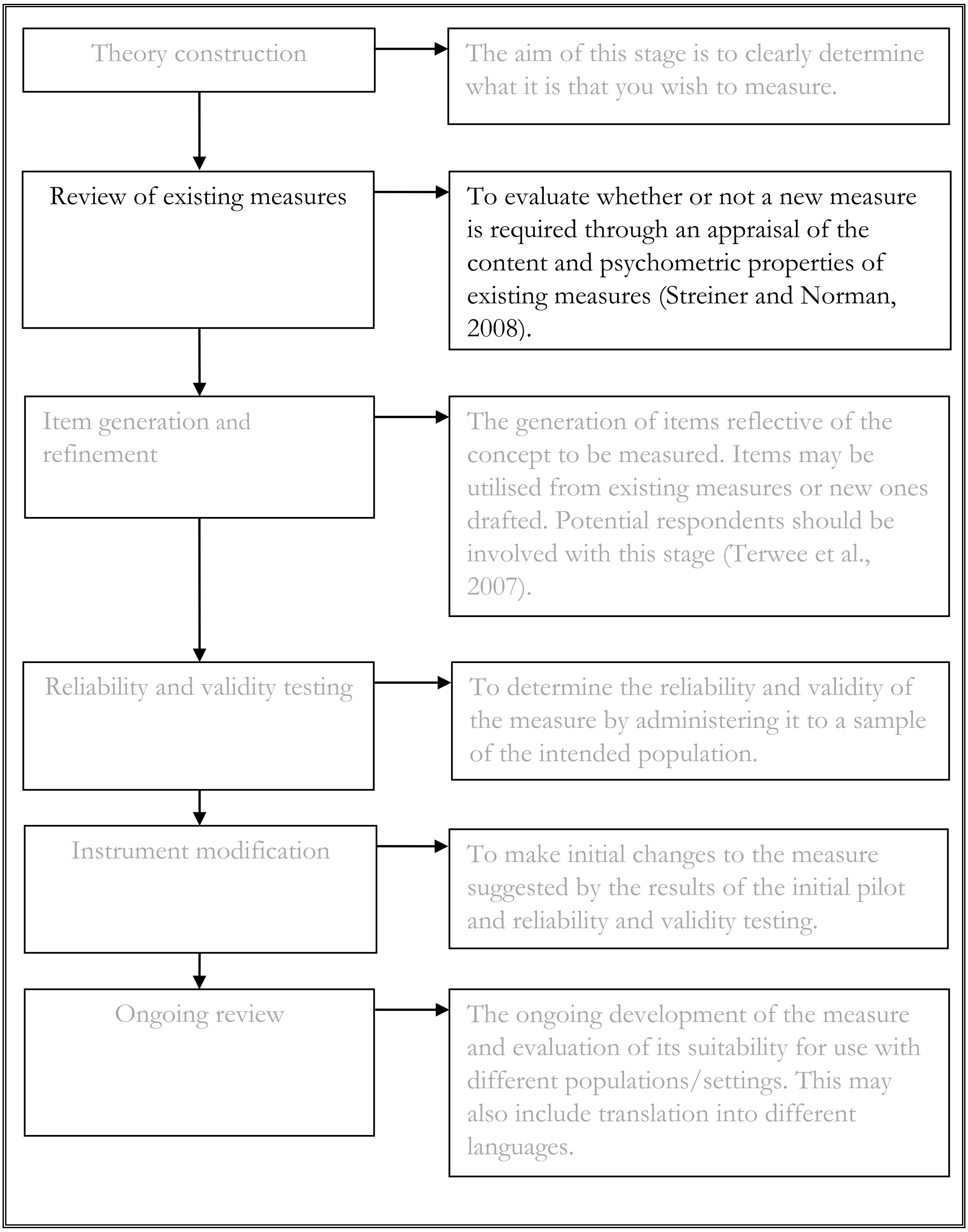
In this chapter I present the results of a systematic review undertaken prior to instrument development to assess whether there were any existing measures of the concept which were suitable for my purposes i.e. in that they purported to measure coordination or a closely related construct; were appropriate in that they reflected my conceptual definition; and were suitable for use with those with chronic conditions in a primary care setting. The evaluation of existing measures is an important step when considering the development of a new measure for two reasons. Firstly, if an existing measure is appropriate then time is not wasted in developing and testing an unnecessary new measure. The use of an existing instrument contributes to its ongoing development through the generation of additional information about its psychometric properties in different populations. Secondly, information gathered as a result of reviewing available measures can provide useful insights for the development of a new measure if required (Streiner and Norman, 2009). The activities described in this chapter relate to stage 2 in Figure 4.1.

Firstly, I describe the methodology used to undertake the review. This will focus upon how the measures were identified and the criteria used to evaluate the instruments' item content, psychometric properties and the methodological quality of the included studies.

Secondly, I present the results of these analyses. Included measures will be briefly described followed by consideration of their appropriateness, psychometric properties and methodological quality. This will incorporate an assessment of bias resulting from item development and questionnaire design.

Finally, I consider the suitability of these measures for use with my identified patient population. The strengths and weaknesses of individual measures will be considered together with a broader discussion of any key issues which emerge in relation to attempting to measure coordination from the patient perspective.

Figure 4.1: Stages in Measure Development



Theory construction

The aim of this stage is to clearly determine what it is that you wish to measure.

Review of existing measures

To evaluate whether or not a new measure is required through an appraisal of the content and psychometric properties of existing measures (Streiner and Norman, 2008).

Item generation and refinement

The generation of items reflective of the concept to be measured. Items may be utilised from existing measures or new ones drafted. Potential respondents should be involved with this stage (Terwee et al., 2007).

Reliability and validity testing

To determine the reliability and validity of the measure by administering it to a sample of the intended population.

Instrument modification

To make initial changes to the measure suggested by the results of the initial pilot and reliability and validity testing.

Ongoing review

The ongoing development of the measure and evaluation of its suitability for use with different populations/settings. This may also include translation into different languages.

4.2: Aims and objectives of this review

The primary aim of this review was to determine whether or not a new measure of coordination of care needed to be developed.

To achieve this three specific objectives were identified:

1. To evaluate the content of existing patient reported measures of coordination of care against the attribute definitions of coordination presented in Chapter 3.
2. To report and evaluate the psychometric properties of the identified measures.
3. To evaluate the methodological quality of the studies reporting these instruments.

4.3: Methods

4.3.1: Identification of existing measures

A search strategy was devised to reflect firstly, the concept of coordination of care, including synonyms such as integrated and transitional care and secondly, measurement properties, tools or questionnaires. Search terms used to reflect the concept of coordination were informed by the search undertaken to develop the conceptual framework. Full details are given in Appendix 2.

This search strategy was applied to the following databases: MEDLINE, EMBASE and Health and Psychosocial Instruments to February 2011.

The resulting titles and abstracts were reviewed against the following inclusion and exclusion criteria by a single reviewer.

Articles were included where:

- They reported the development or validation of a self-report adult patient completion instrument.
- All of the instrument, or a sub-scale, purported to measure coordination of care or integration of care.

- The measure was intended to be used either in a primary care setting or to evaluate transitional care between organisations.

Articles were excluded where:

- They reported the development, validation or use of a provider completed instrument.
- The instrument was intended to be used to evaluate the coordination of secondary care only.
- The instrument was intended to evaluate patient's experience of the transition between child and adult services.
- The instrument aimed to measure relational continuity only.
- The instrument aimed to measure patient satisfaction only.
- The instrument was written in a language other than English.

4.3.2: Data extraction

4.3.2.1: Evaluation of item content

Wording of the individual items in each measure were extracted into an excel spreadsheet. The wording of these items were then reviewed by two reviewers (RFT and EH) who independently allocated each item as being reflective of either one of the attributes of coordination described in Chapter 3 (i.e. purposeful activity, communication and information exchange, knowledge of roles and responsibilities and responsiveness to change) or not being reflective of coordination. A short operational statement was developed for each attribute to assist with this (Table 4.1). Following independent allocation of items the reviewers met to compare results and to reach a consensus where there were differences in the attribute to which an item had been allocated. Where a consensus could not be reached further arbitration was sought from a third reviewer (BS). The aim was to allocate each item to a single attribute. A content matrix was then constructed to summarise the attributes covered by each instrument.

Items which did not appear to be reflective of coordination of care were also noted and recorded as extraneous items.

Table 4.1: Operational definitions of coordination attributes

Attribute	Operational definition
Purposeful activity	Coordination of care requires investment in time and planning. There should be evidence that care is planned and incorporates objectives agreed across providers and with the patient themselves
Knowledge of roles and resources	Patients should be aware of the responsibilities of each of their care providers. Providers should demonstrate an understanding of how their responsibilities fit with those of others. Where the patient is expected to perform certain activities there should be evidence that this has been discussed and agreed.
Communication/ information exchange	Information regarding the care of a patient should be shared between the providers involved with that care and the patient themselves.
Responsiveness to change	Where care needs or circumstances change there should be evidence that this has been acknowledged and that care has been adjusted accordingly. The sharing of information about this change is incorporated into the attribute of communication.

4.3.2.2: Appraisal of the psychometric properties of the instruments

I then undertook an assessment of the reliability and validity of the instruments.

These properties were evaluated using the criteria proposed by Terwee et al. (2007). A positive, indeterminate, negative rating or no information available rating was awarded following evaluation of each measurement attribute against the stated criteria. The measurement attributes reviewed were internal consistency, test-retest reliability, content validity, structural validity, criterion validity and construct validity (hypothesis testing).

Reliability is a measure of the variability in responses to the measure which are due to differences between individuals. It can be assessed in relation to the internal consistency of the measure: the extent to which items addressing the same dimension correlate with each other; and in relation to the stability of the measure: the extent to which results are reproducible on different occasions where there are no changes to the variables of interest i.e. test-retest reliability (Streiner and Norman, 2009). A positive rating was given for internal consistency where evidence was produced of factor analysis conducted on a sufficient sample size, where a Cronbach alpha was calculated for each dimension and where this was reported as being between 0.70 and 0.95 (Terwee et al., 2007).

Factor analysis is a method of identifying the variables which underlie a set of items (Kline, 1994). It can be both explanatory and confirmatory. In explanatory factor analysis the aim is to identify separate dimensions in the absence of an *a priori* hypothesis as to what these would be. Identified dimensions can then be used as sub-scales. In confirmatory factor analysis the aim is to evaluate *a priori* hypotheses. In this case it is being used as an assessment of content validity (Floyd and Widaman, 1995). Whilst there has been debate as to the appropriate sample size for factor analysis (Field, 2009), Terwee et al. (2007) suggest that this should be ≥100 and include a minimum of seven respondents per item.

Cronbach alpha is a calculation of the internal consistency of the items in a measure or sub-scale. It relates to the extent to which items addressing the same underlying dimension correlate with each other (Streiner and Norman, 2009). Higher values demonstrate greater internal consistency.

Test-retest reliability examines the extent to which the same results are obtained on repeated use of the instrument in the absence of any change. A positive rating was given where an intraclass correlation coefficient was calculated and reported as >0.70 (Terwee et al., 2007). Intraclass correlation coefficients are a measure of the consistency between respondents, with a higher value indicating greater agreement. A negative rating was awarded where the intraclass correlation was less than 0.70. An indeterminate rating was awarded when there was doubt about the design or method of the study e.g. time interval not stated or stability of respondents not assessed.

Validity testing is a process which seeks to confirm that the instrument is measuring that which it was intended to measure (Frost et al., 2007). It is generally accepted that there are three types of validity testing: content, criterion and construct validation (Streiner and Norman, 2009), although Terwee et al. (2007) also consider structural validity.

Content validity is the extent to which the measure adequately represents the attributes of the concept of interest and is thus a reflection of the comprehensiveness of the items included in the measure. It is aided by a rigorous approach to theory generation and subsequent item development. This can be accompanied by an assessment of face validity, which is the extent to which patients and experts perceive the instrument to be measuring that which it purports to measure (Frost et al., 2007). A positive rating was given when there was a clear description of the target population, the concepts being measured, the process of item selection and evidence that this included the target population and/or experts (Terwee et al., 2007).

Structural validity is the degree to which instrument scores are a reflection of the dimensions of the concept of interest. It is assessed through the amount of variance explained by the factors. A positive rating was awarded where the factors identified explained ≥50% of the variance. A negative rating was given when the identified factors explained less than 50% of the variance and an indeterminate rating where no information regarding variance was reported.

Criterion validity is established through the comparison of the new measure with an existing 'gold standard' measure. A positive rating was given when evidence was presented supporting selection of the measure identified as the 'gold standard' and where the reported correlation, or extent of agreement, between the existing and the new measure was ≥0.70 (Terwee et al., 2007).

Construct validation is an ongoing process which seeks to assess the theory underpinning a measure and its hypothesised relationship with other variables. Cronbach and Meehl (1955) recommend that this should consist of three steps:

- Firstly, articulation of a set of theoretical concepts and their relationships.
- Secondly, the development of scales to measure these constructs.
- And thirdly, the testing of these relationships, usually through experimental or quasi-experimental approaches.

If the results are as predicted then construct validity of the measure has been demonstrated in the sample and context in which the study was performed. A positive rating was given where there was evidence that specific hypotheses had been formulated and where three-quarters of these hypotheses were found to be supported when tested (Terwee et al., 2007).

4.3.2.3: Quality assessment of studies

This was assessed using the COSMIN checklist (Terwee et al., 2012). This is a standardised tool for assessing the methodological quality of studies of measurement properties. It consists of nine boxes relating to an individual measurement property. The checklist incorporates individual standards against which each property should be assessed and rated using a 4 point scale (poor, fair, good, excellent). An overall score is calculated by taking the lowest rating of any of the items. Data was extracted in relation to the measurement properties of internal consistency, reliability, measurement error, content validity, structural validity, criterion validity and hypotheses testing consistent with the assessment described above. Cross-cultural validity and responsiveness were not evaluated. The full COSMIN checklist and associated rating scale is available from http://www.cosmin.nl/the-cosmin-checklist_8_5.html.

4.3.2.4: Assessment of bias

Bias in studies reporting questionnaire design can arise as a result of the design of the study and as a result of the design of the questionnaire. As the primary aim of this review is to determine whether there is an existing measure of coordination reflective of the conceptual definition given in Chapter 3 the main focus is upon the items included in each instrument. Therefore, the assessment of bias focused upon that arising as a result of item and questionnaire design.

Forty eight common types of bias in questionnaires have been identified which group into three categories: item wording, questionnaire design and questionnaire administration (Choi and Pak, 2005). Issues with item wording include ambiguity, complex questions, technical jargon, double-barrelled questions, inappropriate response options and leading questions. Problems with questionnaire design include flawed structures e.g. inappropriate skip instructions, confusing response formats and questionnaire length. Potential sources of bias arising from questionnaire administration include non-blinding of any interviewers, faking good and faking bad, inaccurate recall and failing to account for cultural differences.

Involvement of potential respondents in the development and pretesting of a questionnaire should help to limit bias arising from item wording and questionnaire design. Therefore data was extracted in relation to whether the questionnaire had been piloted and whether cognitive interviewing had been used to evaluate item comprehension.

Cognitive interviewing is a systematic approach in which potential items are tested with potential respondents. The aim of this is to gain an understanding of the thought processes respondents use to reach an answer, and to identify items or phrases which are misunderstood (Willis, 2005). This may result in items being reworded or eliminated at the design stage of questionnaire development. Piloting the measure with a sample of the target population aims to generate sufficient information to evaluate the performance of the items. Again this may result in items being reworded or eliminated (De Vellis, 2003).

Response rates were also extracted as in the absence of evidence of piloting or cognitive interviews these may be used as a proxy measure of respondent burden and the acceptability of items (Fitzpatrick et al., 1998).

The unit of analysis for the above was the individual study.

4.3.2.5: Synthesis of instrument psychometric properties and methodological quality of studies

The psychometric properties of the reported instruments and the methodological quality of studies were combined using the methodology proposed by Uijen et al. (2012). This methodology takes into account the results of different studies for each instrument, the direction of these results (either positive or negative) and the methodological quality of the studies and results in a single overall rating for each measurement property. These are detailed in Table 4.2.

Table 4.2: Overall quality ratings for the measurement property

Rating	**Criteria**
+++ or ---	Consistent findings in multiple studies of good methodological quality OR in one study of excellent methodological quality
++ or --	Consistent findings in multiple studies of fair methodological quality OR in one study of good methodological quality
+ or -	One study of fair methodological quality
+/-	Conflicting findings
?	Only studies of poor methodological quality or indeterminate psychometric properties

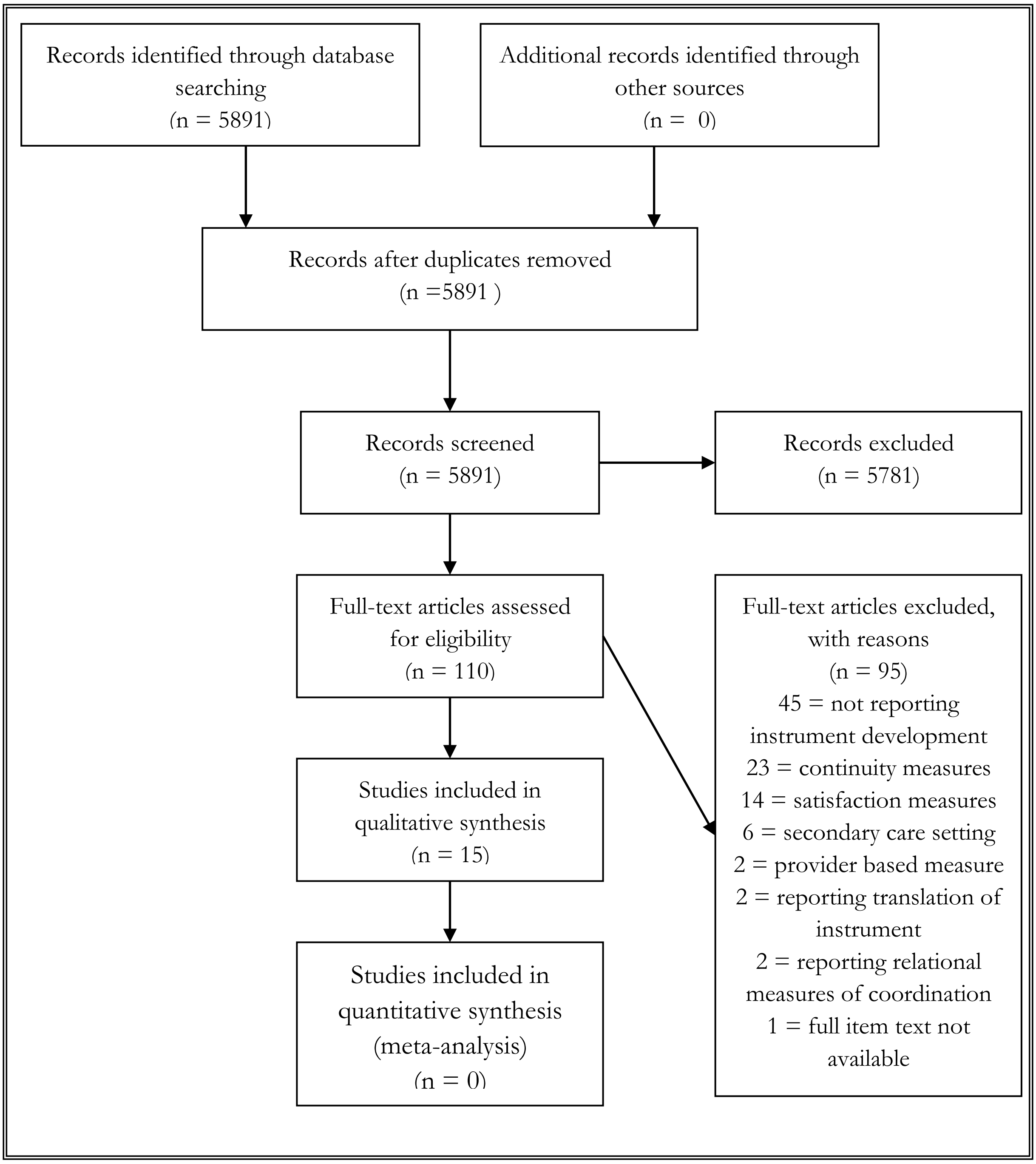
+ = positive result, - = negative result, ? = indeterminate result

The unit of analysis was the measurement instrument.

4.4: Results

The database search identified a total of 5891 potential studies of which 5781 were excluded following a review of their abstracts. Full text review was undertaken of 110 studies which resulted in the exclusion of 95 studies. The reasons for exclusion primarily related to not reporting the development and validation of an instrument to measure coordination. See Figure 4.2.

Figure 4.2: Search strategy results



A total of 15 studies were identified for inclusion in this review, reporting 15 measures. Of these, five studies reported the development of instruments intended to focus either entirely or predominantly upon the measurement of coordination of care. One instrument, the Client Perceptions of Coordination Questionnaire (McGuiness and Sibthorpe, 2003), focused upon the coordination of primary care, one focused upon healthcare hassles (Parchman et al., 2005) and three upon the coordination of healthcare transitions e.g. discharge from secondary care (Coleman et al., 2005, Baker et al., 1999, Grimmer and Moss, 2001). A further study which reported the development of a measure to examine coordination of services for those with dementia was excluded due to the full item content being unavailable, despite contacting the author.

Ten studies reported measures which incorporated a single sub-scale to measure coordination of care within a wider assessment of patient experience, either in primary care in general (Flocke, 1997, Safran et al., 1998, Safran et al., 2005, Scholle et al., 2004, Lee et al., 2009), chronic disease management (Glasgow et al., 2005), the activities of a care coordination organisation (Palsbo and Ho, 2007), or for use with specific populations (Defossez et al., 2007, Ayanian et al., 2005, Clark et al., 2008).

Summary details of these instruments are given in Tables 4.3a for measures of coordination and 4.3b for measures incorporating a coordination subscale. Descriptions of the study populations are presented in Tables 4.4a for measures of coordination and 4.4b for measures incorporating a coordination subscale.

Table 4.3a: Summary of coordination of care measures

Study	Instrument	Country of development	Setting	Target population	Administration mechanism	No. of items and sub-scales	Definition of coordination
McGuiness and Sibthorpe, 2003	Client Perceptions of Coordination Questionnaire	Australia	Primary care	Adults with complex or chronic health needs	Postal or interview	31 items/6 sub-scales	6 domains of coordination: identification of need, access to care, patient participation, patient-provider communication, inter-provider communication and a global assessment of care.
Coleman et al., 2005	Care Transitions Measure	US	Transition from secondary to primary care	Adults over the age of 18 years with selected medical/ surgical conditions	Telephone interview	15 items/1 domain	4 domains of transition: information transfer, patient and caregiver preparation, support for self-management and empowerment to assert preferences.
Baker et al., 1998	Patient Career Diary	UK	Primary and secondary care	Adults referred from primary to secondary care for medical/ surgical conditions	Postal and distributed directly to patients during clinics	109 items/7 sub-scales	5 issues identified during focus groups: getting in, fitting in, knowing what's going on, continuity and limbo.
Parchman et al., 2005	Hassles Scale	US	Primary care	Veterans with one or more chronic illnesses	postal	16 items/1 domain	Health care hassles are troubles or bothers that patients experience during their encounters with the health care system.
Grimmer and Moss, 2001	PREPARED	Australia	Transition from secondary to primary care	Adults aged over 65 years with a variety of medical/ surgical conditions	postal	16 items/5 sub-scales	Four key process domains: information exchange, medication management, preparation for coping after discharge and control of discharge circumstances.

Table 4.3b: Summary of measures incorporating a coordination scale

Measure	Author	Country of development	Setting	Target population	Administration mechanism	No. of items and sub-scales	Definition of coordination/ integration
Flocke, 1997	Components of Primary Care Index	US	Primary care	adults	interview	19 items/4 sub-scales	The patient's perception of their physician's knowledge of other visits and visits to specialists, as well as the follow-up of problems through subsequent visits or phone calls.
Safran et al., 1998	Primary Care Assessment Survey	US	Primary care	Adults enrolled in health plans	postal	51 items/11 sub-scales	Primary physician's role in coordinating and synthesising care received from specialists and/or while patient was hospitalised.
Scholle et al., 2004	Primary Care Satisfaction Survey for Women	US	Primary care	Adult women	Distributed in clinics	24 items/3 sub-scales	Not given
Glasgow et al., 2005	Patient Assessment of Chronic Illness Care	US	Primary care	Adults enrolled in a managed care organisation	postal	20 items/5 sub-scales	Arranging care that extends and reinforces office-based treatment, and making proactive contact with patients to assess progress and coordinate care.

Continued on the next page

Measure	Author	Country of development	Setting	Target population	Administration mechanism	No. of items and sub-scales	Definition of coordination/ integration
Safran et al., 2005	Ambulatory Care Experiences Survey	US	Primary care	Adults enrolled in a commercial health plan	Postal and telephone interview	34 items/11 sub-scales	Not given.
Palsbo and Ho, 2007	Disability Care	US	Care coordination organisation	Adults with a disability	interview	44 items/6 sub-scales	Not given
Ayanian et al., 2005	Cancer Care	US	Primary care	Adults with cancer	postal	31 items/6 sub-scales	Not given
Clark et al., 2008	Consumer Perceptions of Care	US	Community care	Adult women with mental health disorders	interview	22 items/4 sub-scales	Not given
Defossez et al., 2007	REPERES-60	France	Primary care	Women with breast cancer	postal	60 items/ 13 sub-scales	Organisation and follow-up of medical care
Lee et al., 2009	Korean PCAT	Korea	Primary care	Adults	interview	21 items/5 sub-scales	Not given

Table 4.4a: Summary of study populations: coordination of care measures

Study	Instrument	Study population	Setting	N	Mean age (sd)	Male (%)
McGuiness and Sibthorpe, 2003	Client Perceptions of Coordination Questionnaire	People identified by their GP as having chronic or complex health needs and enrolled into a trial of a coordinated care initiative, including children	Primary care	1193	60.5	43
Coleman et al., 2005	Care Transitions Measure	Adult patients discharged from one of three hospitals in a vertically integrated health system	Primary/ acute care	201	67.18	40
Baker et al., 1998	Patient Career Diary	Adult patients attending secondary care outpatient appointments	4 health authority areas in the UK	601	55.4(16.9)	51
Parchman et al., 2005	Hassles Scale	Adult patients with one or more chronic illnesses	South Texas Veteran's health care system	720	?	82
Grimmer and Moss, 2001	PREPARED	Patients aged over 65 years discharged from hospital	Community catchment area of a metropolitan tertiary public hospital	834	?	?

Table 4.4b: Summary of study populations: measures incorporating a coordination scale

Study	**Instrument**	**Study population**	**Setting**	**N**	**Mean age (sd)**	**Male (%)**
Flocke, 1997	Components of Primary Care Index	Patients attending their family physician during 2 observation days, including children	138 family physician offices in Northeast Ohio	2899	42(23)	38
Safran et al., 1998	Primary Care Assessment Survey	Adults employed by the Commonwealth of Massachusetts and enrolled in any of their health plans	Primary care	6094	48.6	44.2
Scholle et al., 2004	Primary Care Satisfaction Survey for Women	Adult women attending their primary care clinician during the period of the study	Primary care sites affiliated with the Universities of Michigan, Pittsburgh and Wake Forest	1202	41.8(16.6)	0
Glasgow et al., 2005	Patient Assessment of Chronic Illness Care	Adults aged 50 years and over and self-reporting one or more chronic conditions	Seven primary care clinics run by Group Health Cooperative in the states of Washington and Idaho	283	64.2 (10.5)	44

Continued on next page

Study	Instrument	Study population	Setting	N	Mean age (sd)	Male (%)
Safran et al., 2005	Ambulatory Care Experiences Survey	Adult patients	67 family practice sites	9625	47.2 (12.5)	33
Palsbo and Ho, 2007	Disability Care	Adults with a disability between the ages of 18-64 years	A disability care coordination organisation in Minnesota	150	?	50.7
Ayanian et al., 2005	Cancer Care	Patients with colorectal cancer approximately 9 months after diagnosis	Californian cancer Registry	1079	?	48.3
Clark et al., 2008	Consumer Perceptions of Care	Adult women with co-occuring mental health and substance misuse disorders	Nine community based sites	2729	35.8(8.9)	0
Defossez et al., 2007	REPERES-60	Adult women with breast cancer	Public and private cancer centres	850	58(12.4)	0
Lee et al., 2009	Korean Primary Care Assessment Tool	Patients who had visited their primary care provider ≥6 times in the preceding 6 months	16 primary care clinics	722	50.2(20.3)	38.6

4.4.1: Evaluation of item content

Following the categorisation of the items in each measure into the attributes of coordination of care described in Chapter 3 a content matrix was created to summarise the results of this. This is reproduced in Table 4.5. Allocation of all items to a single attribute of coordination was challenging and some could not be resolved despite recourse to a third reviewer.

As can be seen only one of the measures includes items relating to each of the identified attributes; the Client Perceptions of Coordination Questionnaire (McGuiness and Sibthorpe, 2003). The Patient Career Diary (Baker et al., 1999) covers all but one attribute. The remainder are less complete in terms of coverage, partly as a reflection of their theoretical underpinning. For example, the focus of the Hassles Scale (Parchman et al., 2005) is upon the negative consequences or outcomes of a lack of coordination rather than the aspects of the process of coordination which can be observed by patients.

Many of the measures also included extraneous items, either as a consequence of the contested nature of the boundaries of coordination of care or the scope of the measure. Extraneous items were defined as items which did not reflect the definition of coordination of care used here. Extraneous items were observed in the Client Perceptions of Coordination Questionnaire (McGuiness and Sibthorpe, 2003), the Hassles Scale (Parchman et al., 2005), PREPARED (Grimmer and Moss, 2001) and the Patient Career Diary (Baker et al., 1999).

Table 4.5: Content matrix resulting from item analysis

Study	Instrument	Attribute of coordination					
		Purposeful activity	**Knowledge of roles and resources**	**Information exchange**	**Responsiveness to change**	**Overall coordination item**	**Other items – not coordination**
McGuiness and Sibthorpe, 2003	CPCQ	+	+	+	+	+	+
Coleman et al., 2005	CTM	+	+	+			
Baker et al., 1998	PCD	+	+	+		+	+
Parcham et al., 2005	Hassles Scale	+		+			+
Grimmer and Moss, 2001	PREPARED	+	+	+			+
Flocke, 1997	CPCI			+			
Safran et al, 1998	PCAS	+		+			
Scholle et al., 2004	PCSSW		+	+			+
Glasgow et al., 2005	PACIC		+	+			+
Safran et al., 2005	ACES			+			+
Palsboe and Ho, 2007	Disability Care	+		+			
Ayanian et al., 2005	Cancer Care	+	+	+			
Clark et al., 2008	CPC	+		+			+
Defossez et al., 2007	REPERES-60			+			+
Lee et al., 2009	Korean PCAT		+	+			

CPCQ = Client Perceptions of Coordination Questionnaire, CTM = Care Transitions Measure, PCD = Patient Career Diary, CPCI = Components of Primary Care Index, PCAS = Primary Care Assessment Survey, PACIC = Patient Assessment of Chronic Illness Care, ACES = Ambulatory Care Experiences Survey, CPC = Consumer Perceptions of Care, Korean PCAT = Korean Primary Care Assessment Tool

Measures where the focus was not coordination of care per se had a tendency to focus upon communication/information exchange within the coordination/integration sub-scale. Wider attributes of coordination may have been addressed elsewhere in the measure but are not included here.

In summary, only one measure included at least one item relating to each of the attributes of coordination although, in common with other measures, it also contained additional items unrelated to the concept as defined here. The identification of these additional items should not be interpreted as a criticism of the measures, which were congruent with their conceptual underpinnings, but they raise questions as to the usefulness of these measures to assess coordination of care as it is defined here.

4.4.2: Psychometric properties of the instruments

Ratings for reliability and validity are summarised in Table 4.6. These ratings demonstrate that the studies and resulting measures were of varying quality, with six (Parchman et al., 2005, Coleman et al., 2005, Scholle et al., 2004, Glasgow et al., 2005, McGuiness and Sibthorpe, 2003, Defossez et al., 2007) being awarded a positive rating for internal consistency, content validity and construct validity. Five studies were awarded a negative rating for internal consistency, due primarily to the retention of scales with a Cronbach alpha of <0.70.

There was limited reporting of test-retest reliability. Where this was reported an intermediate ranking has been awarded, usually due to the utilisation of a correlation calculation other than the intraclass correlation. McGuiness and Sibthorpe (2003) conducted test-retest analysis using different response options which may have influenced the results (Streiner and Norman, 2009).

No measures reported criterion validity.

A positive rating was awarded for content validity to all but one of the measures.

Construct validation was generally well reported with specific hypotheses being articulated and tested for all but three of the measures. An indeterminate rating was awarded where the hypothesis was not explicitly stated, although it was often implicit within the use of the measure in the study.

It should also be noted that many of these measures are in the early stages of development which may contribute to the apparent lack of information in relation to their psychometric properties.

Table 4.6: Assessment of reliability and validity

Study	Measure	Internal consistency	Test-retest reliability	Content validity	Structural validity	Criterion validity	Construct validity
McGuiness and Sibthorpe, 2003	CPCQ	✗	?	✓	✓	0	✓
Coleman et al., 2005	CTM	✓	0	✓	?	0	✓
Baker et al., 1998	PCD	?	0	✓	?	0	✓
Parchman et al., 2005	Hassles Scale	✓	0	✓	?	0	✓
Grimmer and Moss, 2001	PREPARED	?	0	✓	✓	0	✓
Flocke, 1997	CPCI	✗	0	✓	✓	0	✓
Safran et al., 1998	PCAS	?	?	0	?	0	✓
Scholle et al., 2004	PCSSW	✓	0	✓	✓	0	✓
Glasgow et al., 2005	PACIC	✓	?	✓	✓	0	✓
Safran et al., 2005	ACES	?	0	✓	?	0	?
Palsbo and Ho, 2007	Disability Care	✗	?	✓	?	0	?
Ayanian et al., 2005	Cancer Care	✗	0	✓	?	0	✓
Clark et al., 2008	CPC	✓	?	✓	✓	0	✓
Defossez et al., 2007	REPERES-60	✓	✗	✓	✗	0	✓
Lee et al., 2009	Korean PCAT	✗	0	✓	✗	0	0

✓ = positive rating

✗ = negative rating

? = indeterminate rating

0 = no information given

CPCQ = Client Perceptions of Coordination Questionnaire, CTM = Care Transitions Measure, PCD = Patient Career Diary, CPCI = Components of Primary Care Index, PCAS = Primary Care Assessment Survey, PCSSW = Primary Care Satisfaction Survey for Women, PACIC = Patient Assessment of Chronic Illness Care, ACES = Ambulatory Care Experiences Survey, CPC = Consumer Perceptions of Care, Korean PCAT = Korean Primary Care Assessment Tool.

4.4.3: Quality assessment of studies

The results of this assessment are presented in Table 4.7. Three studies were rated as excellent in relation to their evaluation of the internal consistency of the instrument examined, 8 were rated as excellent in relation to content validity and 2 in relation to structural validity. No studies were rated as excellent in relation to hypothesis testing. No studies examined criterion validity or measurement error. Only three studies reported reliability, although the methodological quality was poor to good. Cross-cultural validity and responsiveness were not assessed.

Studies were generally marked down against the COSMIN checklist (Mokkink et al., 2010) where their reporting failed to include explicit detail as to the percentage of missing items and how these were managed in subsequent analyses.

Table 4.7: Methodological quality of studies by measurement property (COSMIN checklist)

Study	Instrument	Internal consistency	Reliability	Measurement error	Content validity	Structural validity	Hypothesis testing	Criterion validity
McGuiness and Sibthorpe, 2003	CPCQ	Excellent	-	-	Fair	Fair	Fair	-
Coleman et al., 2005	CTM	Good	-	-	Good	Good	Good	-
Baker et al., 1998	PCD	Fair	-	-	Good	Fair	-	-
Parchman et al., 2005	Hassles Scale	Fair	-	-	Excellent	Fair	Fair	-
Grimmer and Moss, 2001	PREPARED	Poor	-	-	Fair	Fair	Fair	-
Flocke, 1997	CPCI	Fair	-	-	Excellent	Fair	Fair	-
Safran et al., 1998	PCAS	Good	-	-	Poor	Poor	Fair	-
Scholle et al., 2004	PCSSW	Good	-	-	Excellent	Good	Good	-
Glasgow et al., 2005	PACIC	Fair	Fair	-	Excellent	Fair	Fair	-
Safran et al., 2005	ACES	Poor	-	-	Excellent	Poor	-	-
Palsbo and Ho, 2007	Disability care	Fair	-	-	Excellent	-	-	-
Ayanian et al., 2005	Cancer care	Fair	-	-	Fair	Fair	Fair	-
Clark et al., 2008	CPC	Good	Good	-	Excellent	Good	Good	-
Defossez et al., 2007	REPERES-60	Excellent	Good	-	Excellent	Excellent	Good	
Lee et al., 2009	Korean PCAT	Excellent	-	-	Good	Fair	Not reported	-

CPCQ = Client Perceptions of Coordination Questionnaire, CTM = Care Transitions Measure, PCD = Patient Career Diary, CPCI = Components of Primary Care Index, PCAS = Primary Care Assessment Survey, PCSSW = Primary Care Satisfaction Survey for Women, PACIC = Patient Assessment of Chronic Illness Care, ACES = Ambulatory Care Experiences Survey, CPC = Consumer Perceptions of Care, Korean PCAT = Korean Primary Care Assessment Tool,

4.4.4: Assessment of bias resulting from questionnaire

The results of this assessment are presented in Table 4.8.

Ten studies (McGuiness and Sibthorpe, 2003, Coleman et al., 2005, Baker et al., 1999, Parchman et al., 2005, Grimmer and Moss, 2001, Flocke, 1997, Scholle et al., 2004, Glasgow et al., 2005, Ayanian et al., 2005, Lee et al., 2009) reported that piloting was undertaken to support instrument development. One study (Scholle et al., 2004), supplemented this with cognitive interviewing in order to make a formal assessment of their respondents understanding and interpretation of items. A further study (Palsbo and Ho, 2007), undertook cognitive interviews but not piloting. Issues identified during piloting and cognitive interviewing resulted in items being reworded and/or changes being made to the design of the questionnaire, such as font size and layout.

Response rates ranged from 30-99%. Most authors acknowledged the low response rates where these occurred but only Baker et al. (1999) made changes to the layout, presentation and distribution of the Patient Career Diary during development and piloting in an attempt to improve response rates.

Despite piloting, some comprehension and interpretive issues were identified with the Client Perceptions of Coordination Questionnaire (McGuiness and Sibthorpe, 2003). Specifically these related to the interpretation of the phrase ‘service provider’ and the timeframe over which respondents were asked to recall the activity.

Table 4.8: Assessment of steps taken to reduce bias resulting from questionnaire design

Study	Measure	Piloting	Cognitive Interviewing	Response rates (%)
McGuiness and Sibthorpe, 2003	CPCQ	✓	0	78 – 94%
Coleman et al., 2005	CTM	✓	0	99%
Baker et al., 1998	PCD	✓	0	47-59%
Parchman et al., 2005	Hassles Scale	✓	0	59%
Grimmer and Moss, 2001	PREPARED	✓	0	60%
Flocke, 1997	CPCI	✓	0	74%
Safran et al., 1998	PCAS	0	0	69%
Scholle et al., 2004	PCSSW	✓	✓	69%
Glasgow et al., 2005	PACIC	✓	0	76%
Safran et al., 2005	ACES	0	0	30%
Palsbo and Ho, 2007	Disability Care	0	✓	43%
Ayanian et al., 2005	Cancer Care	✓	0	72%
Clark et al., 2008	CPC	0	0	Not given
Defossez et al., 2007	REPERES-60	0	0	87%
Lee et al., 2009	Korean PCAT	✓	0	84%

✓ = evidence presented, 0 = no information given

CPCQ = Client Perceptions of Coordination Questionnaire, CTM = Care Transitions Measure, PCD = Patient Career Diary, CPCI = Components of Primary Care Index, PCAS = Primary Care Assessment Survey, PCSSW = Primary Care Satisfaction Survey for Women, PACIC = Patient Assessment of Chronic Illness Care, ACES = Ambulatory Care Experiences Survey, CPC = Consumer Perceptions of Care, Korean PCAT = Korean Primary Care Assessment Tool,

4.4.5: Synthesis of instrument psychometric properties and methodological quality of studies

The results of this assessment are presented in Table 4.9. Three instruments, the Primary Care Satisfaction Survey for Women (Scholle et al., 2004), the Patient Assessment of Chronic Illness Care (Glasgow et al., 2005) and the Consumer Perceptions of Care (Clark et al., 2008) scored positively on the quality of at least four measurement properties. A further six instruments, the Client Perceptions of Coordination Questionnaire (McGuiness and Sibthorpe, 2003), the Care Transitions Measure (Coleman et al., 2005), the Hassles Scale (Parchman et al., 2005), PREPARED (Grimmer and Moss, 2001), the Components of Primary Care Index (Flocke, 1997) and REPERES-60 (Defossez et al., 2007) scored positively for at least three measurement properties.

Table 4.9: Quality of measurement properties

Instrument	Internal consistency	Reliability	Content validity	Structural validity	Hypothesis testing
CPCQ	---	na	+	+	+
CTM	++	na	++	?	++
PCD	?	na	++	?	na
Hassles Scale	+	na	+++	?	+
PREPARED	?	na	+	+	+
CPCI	--	na	+++	+	+
PCAS	?	na	?	?	+
PCSSW	++	na	+++	++	++
PACIC	+	?	+++	+	+
ACES	?	na	+++	?	na
Palsbo and Ho (unnamed)	-	na	+++	na	na
Ayanian et al. (unnamed)	-	na	+	?	+
CPC	++	?	+++	++	++
REPERES-60	+++	--	+++	---	++
Korean PCAT	---	na	++	-	na

+++ or ---: consistent positive or negative findings in multiple studies of good methodological quality or one study of excellent methodological quality, ++ or --: consistent positive or negative findings in multiple studies of fair methodological quality or one study of good methodological quality, + or -: positive or negative findings in one study of fair methodological quality, +/-: conflicting findings, ?: studies of poor methodological quality or indeterminate psychometric properties.

CPCQ = Client Perceptions of Coordination Questionnaire, CTM = Care Transitions Measure, PCD = Patient Career Diary, CPCI = Components of Primary Care Index, PCAS = Primary Care Assessment Survey, PCSSW = Primary Care Satisfaction Survey for Women, PACIC = Patient Assessment of Chronic Illness Care, ACES = Ambulatory Care Experiences Survey, CPC = Consumer Perceptions of Care, Korean PCAT = Korean Primary Care Assessment Tool.

4.5: Discussion

4.5.1: Summary of results

In this review 15 studies were identified which reported the development of 5 measures of coordination of care and a further 10 instruments which included a sub-scale labelled as either coordination or integration. Definitions of coordination used to guide item development varied between the studies, with some linked to specific approaches to the delivery of care e.g. PACIC (Glasgow et al., 2005) is intended to measure the patient perspective of care delivered using the Chronic Care Model. These differing definitions are reflected in the evaluation of item content against the operational definitions in Table 4.5. All measures included items felt to be reflective of the attribute of information exchange or communication between participants. Most measures also included items reflective of the attributes of purposeful activity (n=9) and knowledge of roles and resources (n=8). Only one measure, the CPCQ, included items reflective of the attribute of responsiveness to change. Only one of the existing measures, the Client Perceptions of Coordination Questionnaire (McGuiness and Sibthorpe, 2003), contained items of relevance to all the attributes.

The number of measurement properties assessed for each instrument varied from two to five with four being most commonly reported: internal consistency, content validity, structural validity and hypotheses testing. Reliability was reported in three of the fifteen studies. Nine instruments scored positively on the quality of at least three measurement properties of which four were developed to measure coordination of care (McGuiness and Sibthorpe, 2003, Coleman et al., 2005, Parchman et al., 2005, Grimmer and Moss, 2001).

4.5.2: Limitations of this review

There are some limitations associated with this review and utilising the attributes of the conceptual framework to evaluate conceptual coverage which need to be considered. Firstly, although a systematic approach was taken to the identification of existing measures there is the potential that some may have been missed. In an effort to address this the search strategy utilised terms that are frequently used in an interchangeable manner with coordination and multiple databases but the potential for measures to have been missed remains.

Secondly, data related to psychometric properties was extracted by a single reviewer. There is a degree of subjectivity in some aspects of the interpretation of these criteria. Completion of this by a second reviewer would have made these judgements more explicit.

Thirdly, there is a lack of agreed standards for the assessment of psychometric criteria and as Terwee et al. (2007) note themselves, those used here ‘are open to discussion and refinement’. However, they do allow for an articulation as to how each assessment has been made. The COSMIN Guideline (Terwee et al., 2012) which was used to evaluate methodological quality reflects an approach to agree some standards for the methodological evaluation of studies reporting measurement instruments but they also require a degree of interpretation. The lowest score counts approach may also have resulted in some studies being judged a little harshly. For example, Glasgow et al (2005) clearly articulated the hypotheses they intended to test but this study was only awarded a fair rating in relation to the methodological quality of hypothesis testing due to a lack of clarity in relation to the way missing responses were accounted for in the analysis.

Finally, there were limitations to the utility of using the attributes of the conceptual framework to assess the conceptual coverage of the measures. Frequently, items did not fit neatly into being reflective of a single attribute and this necessitated judgements being made as to how items should be categorised, including some items not being categorised to a single item. There is the potential that different reviewers may reach different conclusions. Fifteen items were unable to be allocated to a single attribute, despite recourse to a third reviewer. Convincing cases could be made for these items to be allocated to at least two attributes. This limitation suggested that the attributes of coordination required further operationalization in order to identify how the concept might manifest itself to patients. This process was discussed in Chapter 3, section 3.5 and subsequently formed the basis for item generation and measure development presented in the next chapter.

4.5.3: Selecting an instrument to use

An ideal measure of coordination of care would address all the identified characteristics of the concept, be acceptable to patients, and would demonstrate reliability and validity with regard to internal consistency, test-retest reliability, and content, structural and construct validity. Fitzpatrick et al. (1998) highlight that conceptual coverage of a measure is the key consideration when deciding upon whether an existing measure is appropriate for your intended purpose of whether a new measure needs to be devised. Therefore the primary aim of this review was to evaluate the closeness of fit between the content of existing measures with the conceptual definition developed in Chapter 3. This is ultimately a subjective assessment (Fitzpatrick et al., 1998, Streiner and Norman, 2009). In this review conceptual coverage was assessed through the sorting of individual items into the key attributes of coordination identified during concept development.

Only one measure, the Client Perceptions of Coordination Questionnaire (McGuiness and Sibthorpe, 2003), contained items of relevance to all the attributes of coordination. This measure was also developed in a sample of patients with complex and ongoing care needs in an Australian primary care population. Given the similarities between the English and Australian health system in relation to the organisation of care around a general practitioner, this measure has potential for transferability to an English general practice population. The instrument and its measurement properties were therefore considered in further detail.

4.5.3.1: Theoretical underpinnings, item wording and assessment of bias

When developing the CPCQ McGuiness and Sibthorpe (2003) noted the lack of a theoretical framework of coordination in healthcare and proposed that the following were important dimensions: care from multiple providers, the need for health and social care, and the evaluation of care over time. They noted that existing measures did not include items related to patient involvement in care or perceptions of need. Following work with experts and focus groups with patients they identified six domains of coordination: identification of need, access to care, patient participation, patient-provider communication, inter-provider communication and a global assessment of care. Items were subject to a number of field tests before pilot testing.

Despite this, some issues with jargon were identified during the pilot test. A particular issue was noted with the interpretation of the phrase 'service provider' with misinterpretation or misunderstanding affecting 5% of responses (McGuiness and Sibthorpe, 2003). This was intended to be interpreted as a professional involved with a patients care who was not their general practitioner. However, some respondents noted that they did not have 'service providers' but then went on to answer the relevant items. Community services in particular were not interpreted as 'service providers'. Interestingly, this phrasing was not noted as an issue in the US measures which used similar wording, suggesting that the interpretation of this wording may be a reflection of different health care structures.

Closer reading of some of the items in this measure also highlighted some other potential issues. Some items required respondents to make judgements about their care. For example, 'how often did providers seem to be unnecessarily repeating tests or assessments?' This item requires that respondents firstly recall the tests or assessments they have had and then make a judgement as to whether or not they were necessary. Whilst respondents should be able to report their perceptions there could be questions about the accuracy of this perception in the absence of objective evidence from an alternative source. Perceptions of care are also influenced by expectations and as such the same experience may be evaluated differently by different individuals (Lyratzopoulos et al., 2012).

Some items were also noted as potentially ambiguous. For example, 'how often was it difficult to get transport to services?' Does this question apply to personal transport or that provided by the health service or a failure to recognise that the respondent needed support to get to any appointments? Equally there are questions as to whether respondents might include issues such as parking spaces, fees and the accessibility of drop off points in relation to the service being accessed.

Ambiguity, jargon and items relating to judgements of care without comparable reporting of what happened can contribute to bias and measurement error (Choi and Pak, 2005). The CPCQ also included items such as, 'how often did you feel you could cope with life?' which were noted as not necessarily being reflective of coordination of care. These extraneous items also have the potential to introduce measurement error (Streiner and Norman, 2009).

The question of the time period over which respondents were asked to reflect upon their care also caused some difficulties for the Client Perceptions of Coordination Questionnaire (McGuiness and Sibthorpe, 2003). Anticipating that patients would experience frequent changes to their care needs and subsequent plan of care respondents were asked to reflect upon the care received in the previous three months, for example 'In the last 3 months, how often have service providers responded appropriately to changes in your needs?' In their sample, 34% of respondents did not perceive a change in their needs during this period. It is unclear whether this was due to a misunderstanding of the phrase 'change in your needs', a reflection of the relative stability of respondents care needs or that three months is too narrow a timeframe. Recall timeframes are particularly challenging in those with chronic disease as there is evidence to suggest that they develop generic memories in relation to frequently occurring events which leads to an underreporting of healthcare encounters (Means et al., 1989). However, other measures have successfully utilised longer recall windows of six months e.g. the Patient Assessment of Chronic Illness Care (Glasgow et al., 2005).

Cognitive interviewing could offer some useful insights into the most appropriate recall timeframe in relation to changes in care needs, understanding the interpretation of phrases such as 'service provider' and confirming or otherwise any potential ambiguity in items.

McGuiness and Sibthorpe (2003) reported four measurement properties (internal consistency, content validity, structural validity and hypothesis testing) of which three were evaluated positively. Internal consistency was given a negative rating due to the retention of two sub-scales with reported Cronbach alpha of 0.31 (client capacity) and 0.49 (client comprehension). Terwee et al. (2007) recommend that Cronbach alpha should be between 0.70 and 0.95. The client capacity scale included four items: difficulty with transport, involvement of carers, their ability to cope with life and discussion of test results. The client comprehension scale included three items: confusion about providers, understanding of conditions and tests being repeated unnecessarily. Many of these items, and the ideas behind them, are of relevance to the characteristics of coordination.

Given the issues with item content, comprehension and potential problems with internal consistency I decided against simply adopting the CPCQ unchanged and undertaking a validation study in an English primary care population.

4.6: Summary

The measurement of coordination from the patient perspective is an emerging area of interest in healthcare with most of the instruments identified here having been developed in the last decade. The scope of the content of these instruments reflects the different definitions of coordination discussed in Chapter 3 and the blurring of boundaries between coordination, continuity, integration and patient centred care. As a result existing instruments either did not seem to achieve conceptual coverage or included extraneous items. Psychometric properties were generally promising given the relatively early stage of development of most instruments.

One measure, the Client Perceptions of Coordination Questionnaire (McGuiness and Sibthorpe, 2003), was identified which appeared to offer conceptual coverage but this was weakened by poor internal consistency for some sub-scales, the inclusion of potentially ambiguous items, extraneous items and the requirement implicit in many items for respondents to make technical evaluations of their care. Given this, it was felt that there was scope for the development of a new instrument. However, this review also highlighted that, prior to any instrument development, further work would be required to articulate how the attributes of coordination are experienced by patients. This was reported in Chapter 3, section 3.5.

The next chapter describes the development of a new instrument to measure coordination of care, including the steps taken to address some of the issues of item comprehension noted in this review.

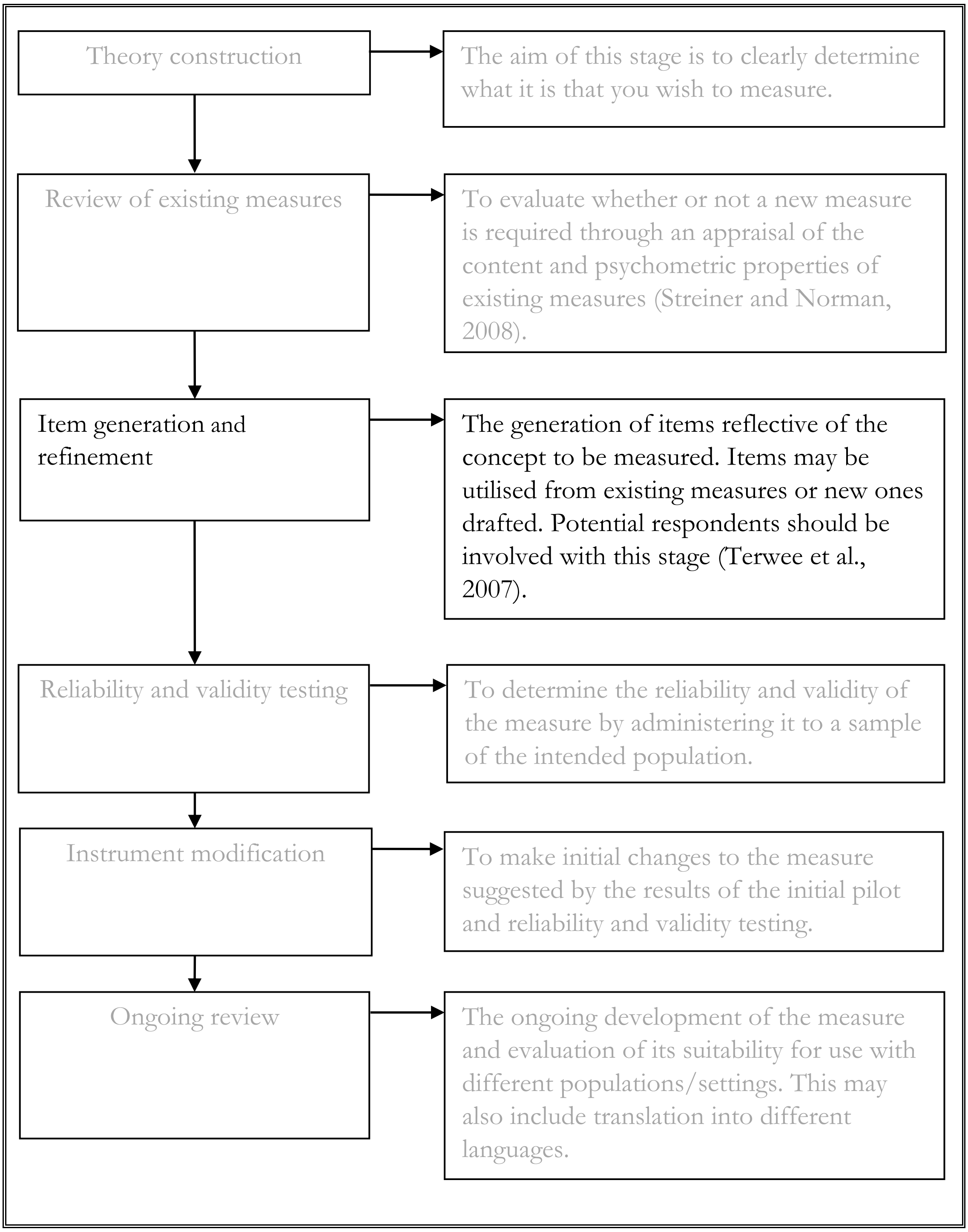
Chapter 5: Development of a new measure of patient observations of coordination: the Care Coordination Questionnaire (CCQ)

5.1: Introduction

The process of designing and testing a questionnaire can be split into a number of stages: theory construction, review of existing measures, item generation and refinement, testing of reliability and validity, instrument modification and ongoing review over time (Streiner and Norman, 2009, Nunnally and Bernstein, 1994, De Vellis, 2003) (see Figure 5.1). In Chapter 3 I presented an analysis of the concept, including its definition, defining attributes and empirical referents. In Chapter 4 I then reviewed existing measures of the concept. These results suggested that the utility of existing measures were limited by their varying conceptual definitions and resulting item content. Concerns were also noted about the wording and interpretability of some items. The limitations of existing measures suggested that there was scope for a new measure to be developed.

In this chapter I describe the development of this new measure of patient experiences of coordination of care: the Care Coordination Questionnaire (CCQ) (step 3 in Figure 5.1). From the outset the content and structure of this measure was determined by the conceptual framework described in Chapter 3. I will begin this chapter by detailing the implications of this for the content, format and structure of the pilot questionnaire. I then address the measurement model selected, the task of item generation and the pre-testing of items prior to the preparation of the draft questionnaire. Current best practice advocates the involvement of potential respondents in this process (Collins, 2003) through engagement with item generation and the pre-testing of potential items to ensure that they are understood and can be answered. I conclude by presenting the structure and item content of the questionnaire which was used in the piloting and validation study reported in Chapters 6 and 7. Whilst these stages are presented here as linear processes, in reality they occurred in an iterative fashion as new developments necessitated a reappraisal of earlier decisions.

Figure 5.1: Stages in Measure Development



The aim of this stage is to clearly determine what it is that you wish to measure.

To evaluate whether or not a new measure is required through an appraisal of the content and psychometric properties of existing measures (Streiner and Norman, 2008).

The generation of items reflective of the concept to be measured. Items may be utilised from existing measures or new ones drafted. Potential respondents should be involved with this stage (Terwee et al., 2007).

To determine the reliability and validity of the measure by administering it to a sample of the intended population.

To make initial changes to the measure suggested by the results of the initial pilot and reliability and validity testing.

The ongoing development of the measure and evaluation of its suitability for use with different populations/settings. This may also include translation into different languages.

5.1.1: Ethical approval

Ethical approval for all the studies reported in this chapter was obtained from the University of Manchester Ethics Committee.

5.2: Implications for questionnaire content and structure arising from the conceptual definition

From the outset the content and structure of the questionnaire was guided and determined by the assumptions and boundaries arising from the conceptual framework. This had three key consequences for the content, format and structure of the developing questionnaire. Firstly, the framework proposes that whilst coordination tasks are undertaken by all participants the achievement of coordination is a system-wide phenomenon. The nature of interdependent working requires that each individual professional or provider perform coordination tasks in addition to their production tasks but any omission is likely to be experienced as a collective or systemic failure. Additionally, as many coordination tasks are performed as backstage activities they may not be observable to patients. This suggested that items should relate to the totality of the respondent's experience and prompt them to make an overall evaluation rather than attempting to differentiate between the performance of individual professionals or providers.

This approach contrasts with many existing measures which tend to be sub-divided into comparable sets of items for each professional or provider (Baker et al., 1999, McGuiness and Sibthorpe, 2003, Kautz et al., 2007) or to focus solely upon the contribution of a single provider (Coleman et al., 2005). McGuiness (2001) argues that the focus upon individual professionals and providers is superior to an overall assessment for two reasons: firstly, patients find it difficult to combine their experiences and make an overall judgement and secondly, there may be a performance difference between providers in terms of the acceptability or effectiveness of the care provided. In light of this, I planned to test the ability of patients to make overall judgements during item refinement; specifically cognitive interviewing. The second objection has obvious face validity in that there may be performance differences between providers but it is questionable as to whether these differences can be accurately identified by patients due to their limited opportunities to observe coordination activities. Therefore, their attribution of acts or omission to individual providers may be flawed. Again, cognitive interviewing provided an opportunity to explore some of these issues.

Secondly, the conceptual framework set the boundaries for the content of the measure. As a result of this some aspects of coordination proposed by other researchers fall outside of the scope of this measure. Specifically, the framework excludes references to coordination mechanisms for the reasons discussed in Chapter 3. It also excludes the coordination roles undertaken by patients themselves as this measure is seeking to capture the functioning of the system rather than individuals.

Finally, items were phrased as questions related to the frequency with which events were experienced rather than as statements with which respondents were asked to agree or disagree.

5.3: The measurement model

Two approaches to measurement models have been described in the literature: items or indicators as causes of latent variables and items or indicators as effects of latent variables (Bollen and Lennox, 1991). The differences in the causal nature of indicators in these measurement models have important implications for item generation and sampling, item selection and reduction, the demonstration of reliability and validity and the statistical tests used to inform these decisions. In this section I will describe both models and then consider which is most appropriate for the measurement of coordination.

5.3.1: Items as effects of latent variables

Patient responses to effect or reflective items are influenced by the underlying phenomenon being measured (latent variable). That is, it is a patient's location on the underlying phenomenon itself which (at least partially) determines how they respond to each item. Correlations between these items occur as a result of them being reflections of the same underlying phenomenon. Three implications arise from this:

1. There is a universe of potential items from which a sample is drawn to comprise the measure,
2. Each item should positively correlate both with the phenomenon and with other items and this may be evaluated through the assessment of the homogeneity of the items using Cronbach's alpha, inter-item correlation and factor analysis,
3. The specific items are interchangeable and items may be omitted without affecting the construct validity of the measure (Streiner, 2003).

5.3.2: Items as causes of latent variables

A causal measurement model is one in which it is the items themselves which are a direct measure of the phenomenon of interest i.e. rather than being influenced by an underlying phenomenon they are the phenomenon itself. As such, causal indicators have different performance characteristics to effect indicators and this has implications for measure development and evaluation.

Firstly, there is no assumption that these indicators should correlate with each other (Streiner, 2003). There may be some correlation between them, but this is not essential and may vary with different populations. It is their relationship with the latent variable which is important and this exists irrespective of any inter-item relationship.

The consequence of this is that statistical tests based upon an assumption of homogeneity are inappropriate for use in measure development using this model and may result in important items being inappropriately deleted (Juniper et al., 1994).

Secondly, items are not sampled from a universe of potential items and are not interchangeable. Measures developed using causal indicators require a census of possible items (Bollen and Lennox, 1991) which capture all facets of the phenomenon of interest (Diamantopoulos and Winklhofer, 2001). The omission of potential indicators may change the nature of the phenomenon of interest.

5.3.3: Coordination as a causal measurement model

Throughout the thesis coordination has been identified as a process for the organisation of patient care which is responsive to changes in the needs of patients. It becomes necessary when multiple participants are required to work interdependently, be they individual professionals or provider organisations. The management of these interdependencies requires that participants are orientated to a shared goal, understand their own and others roles, can access the necessary resources, they exchange information and they are responsive to changes in both patient need and their practice or work environment. These attributes work synergistically to enable the management of interdependence by facilitating common understanding and accountability between participants. However, as discussed in the previous section patient perceptions of these attributes may be limited and, due to their cross cutting nature, they do not lend themselves for use as discrete domains for the development of items. Earlier in this chapter I proposed that patients make judgements about the coordination of their care on the basis of healthcare production failures along their care pathway and specifically in relation to the planning and delivery of care and how this is managed. They are also able to observe some aspects of the way their providers work together.

Previous measures of coordination in both healthcare and organisational studies have assumed that this phenomenon can be measured using an effect model. That is, that underlying 'good' coordination of care would be reflected in good communication, participants being more orientated to a shared goal, displaying greater understanding of each other's roles and so on and that a change in the level of coordination affects all these attributes equally.

However, in common with other authors (Diamantopoulos and Siguaw, 2006) I propose that coordination is best considered within a causal measurement model. Within this approach coordination is generated by good communication, being orientated to a shared goal etc and at the level of the patient experience it results from good planning, effective delivery of care, the management of problems and changes together with observations of inter-professional behaviour. Demonstrating a greater or lesser ability in any one of these areas would result in greater or lesser coordination but there is no compelling reason why performing well in one area would imply performing well in another. In fact this dissonance may well be the reason for any perceived production failure. Logically and theoretically there may be some covariance between these items, especially with regard to those related to planning and those related to care delivery, but equally they may be independent.

5.4: Item generation

The aim of item generation was to develop a pool of items from which the selection for the draft CCQ would be made. There were two key objectives: firstly, ensuring the adequate representation of the theoretical framework and secondly, to make an initial assessment of the wording of potential items. In line with current best practice recommendations this phase of instrument development involved potential respondents in the development and testing of items (Collins, 2003).

5.4.1: Methods of item generation

Items were generated in two ways. Firstly I created a repository of existing items and secondly items were drafted from focus group findings with potential respondents. This dual strategy was used in order to build upon existing work, avoid duplication of effort and to ensure that all patient observable aspects of coordination were identified. Focus group findings provided an opportunity to check upon the comprehensiveness of items suggested by the theoretical framework.

5.4.1.1: Development of a repository of existing items

Existing measures provide a useful source of potential items for three reasons: firstly, it obviates the need to develop new items; secondly, they have already been through a testing process and thirdly, there are limits to the different ways of asking about a phenomenon (Streiner, 2003). However, they should not be used uncritically and as previously noted in Chapter 4, I had already identified some issues with the clarity and interpretability of some existing items.

A total of 347 items were identified from existing measures. Following identification of duplicate items 272 unique items were retained. These items were collated into a single spreadsheet and indexed according to one of the three areas of patient observable coordination failure.

The item wording was also reviewed against the following criteria (Streiner and Norman, 2009, De Vellis, 2003):

- Is a single idea being expressed?
- Is the item worded in plain English? If not, can the terminology be simplified?
- Is the item ambiguously worded?
- Is the item double barrelled? That is, does it ask about more than one issue but require the respondent to select one answer?
- Does the item contain value laden words?
- Is this a question the respondent could reasonably be expected to have the answer to?
- Are the response options applicable to the wording of the item?

Where an item failed to meet these criteria it was either discarded from the pool or rewritten. Where it was unclear whether these criteria were met, particularly with regard to terminology, the item was highlighted for further exploration with potential respondents (see section 5.5.2 in this chapter for discussion of this).

Following this selection process, the item pool consisted of those items which reflected the aspects of coordination which patients can observe and which were felt to be either clear and unambiguous or highlighted for further exploration of their interpretation.

5.4.1.2: Focus groups

Focus groups have a long history in the development of survey instruments dating back to the 1920s (Finch and Lewis, 2010) and have been used successfully by other researchers for this purpose (Vogt et al., 2004, Fern, 2001).

Potential respondents to a measure can be a useful source of items and engaging with them to develop items can help to ensure item relevance and that they are worded in the natural language used by potential respondents to talk about the phenomenon (Finch and Lewis, 2010). They are an efficient method through which to obtain the views of a number of people at the same time, to explore these views through discussion amongst participants and to identify commonalities of experience.

In the context of the development of the CCQ; by this stage I had a pool of potential items but I was unsure as to whether they reflected the full range of coordination failures patients may observe and whether they made sense to potential respondents. Focus groups provided an opportunity to check the comprehensiveness of the theoretical framework and to gain an understanding of how potential respondents talk about the coordination of their health care.

Procedure and participants

Participants were selected on the basis that they were current users of the health service and that their care was delivered by two or more health and social care professionals. Participants were adult volunteers who were capable of providing consent to participation and who were able to speak English. They were recruited via an advertisement which was shared with local patient and community support groups. Those interested in taking part were asked to contact the research team for an informal discussion about the research and were provided with a written information sheet.

Written consent was obtained at the beginning of each focus group. Examples of these documents are given in Appendices 3 and 4.

A topic guide was developed which focused upon participant experiences of coordination, their understanding of the attributes of coordination and included discussion of the relevance and clarity of potential items as they emerged. This is reproduced in Appendix 5. The focus group was facilitated by myself and one of my supervisory team (EH). They were held in public venues near to the participant's homes. Each group started with a welcome, introductions and an explanation of the purpose of the discussion. The topic guide was then used to guide the discussion and, towards the end of the group, as a checklist to ensure that the discussion had been comprehensive.

Analysis

A Framework approach (Ritchie and Lewis, 2003) was undertaken towards analysis. This is a deductive approach to qualitative data analysis in which the conceptual framework was used to structure the thematic framework into which the data was then sorted.

Using the methodology proposed by Vogt et al. (2004), which was the only published methodology identified which described the analysis of focus groups specifically for item generation purposes, each focus group recording was listened to twice. Firstly, I listened to the recording in its entirety in order to familiarise myself with the content. I then listened to the recording a second time with the intention of identifying quotes which related to the *a priori* domains of patient observations of coordination failure. These quotes were transcribed verbatim. At the end of each recording the verbatim quotes were compared to existing items in the pool. If no existing item was identified which captured the idea expressed in the quote then a new item was generated and added to the pool.

This light touch qualitative approach was purposively selected as the aim was to understand the observable limits of coordination from the patient perspective and to use this to inform item selection. The aim of this phase of work was not to develop a definition of coordination from the patient perspective. As discussed in Chapter 3, coordination of care is primarily an organisational process concept which can only be partially observed by individual stakeholders. Attempting to define it from any one of these necessarily limited perspectives would have resulted in potentially important facets of the concept being missed. Had the aim of this work been to develop a patient generated definition of the concept of coordination then an alternative qualitative methodology would have been adopted.

5.4.2: Results of item generation

5.4.2.1: Items from existing measures

272 unique items were identified from existing measures and surveys. Once these had been reviewed against the criteria described above (section 5.4.1.1), a total of 262 items remained in the pool.

5.4.2.2: Focus groups

Five focus groups were held with a total of 30 participants. The smallest group had two participants and the largest nine. Sixty percent (n=18) of participants were male. The majority were aged between 65-74 years and all described their ethnicity as either white British or white English. Demographic details are given in Table 5.1.

Table 5.1: Demographic characteristics of focus group participants

Gender	**Number (%)**
Male	18 (60)
Female	12 (40)
Age (years)	
<54	3 (10)
55-64	10 (33.3)
65-74	12 (40)
75-84	5 (16.6)

Five participants described their care as being managed in the GP practice only. Of those who received care outside of the GP practice, the numbers of professionals/services involved ranged from 1-10, with a mean of 2.8. Twenty-two participants reported being under the care of one or more hospital consultants (mean = 2.09, range 1-6).

A total of 30 verbatim quotes were made which related to the *a priori* domains of patient observations of coordination failure. Extracted statements and the items resulting from them are detailed in Table 5.2.

Table 5.2: Examples of verbatim quotes and potential items

Quote	Potential item
"you're really trying to wind back and find somebody who can really consider the person and work out what the problems are"	In the last 6 months how often did your healthcare professionals explain to you how they planned to address your health problems? In the last 6 months how often were your preferences taken into account when decisions were made about your healthcare?
"You then see the consultant and into that booklet then goes the plan of action for you, that you've agreed and therefore it doesn't matter who writes in the book you've got it and you know what your plan should be."	How often in the last 6 months did you leave an appointment unsure about what was going to happen next in your care?
"We've sent a hospital bed and we sent a special chair and then the district nurse said it isn't there. It hasn't arrived yet."	How often in the last 6 months did you get the care that your healthcare professionals said that you would?
"GP will say you don't need.. you know because I did have a nebuliser originally. Now they didn't mind how much I had of the medication in the nebuliser but they don't want you, you know, to use inhalers erm which is the same medication as much. And then when I told the consultant he said I can use the inhaler as often as I like"	How often in the last 6 months did your healthcare professionals appear to disagree with each other about the best care for you?
"the rest of the team know what's going on"	How often in the last 6 months did one of your healthcare professionals seem unaware of what others were doing for you?

5.4.3: Next steps

At this stage a total of 292 potential items had been identified. These comprised of both questions and statements with a range of response options.

From this broad item pool I then developed a short list of items to go forward for further testing with potential respondents through cognitive interviewing. In order to do this I applied the following principles:

1. Ensuring a balance of items within and across the *a priori* domains. At this stage it was unclear as to whether one domain was more important than another in terms of understanding the patient experience, therefore I wished to give equal weight to each domain in terms of the numbers of items progressed to cognitive testing.
2. The number of items going forward needed to be manageable within a cognitive interview length of approximately one and a half hours.
3. Rationalisation of response options. I wished to keep the number of different response options to as few as possible both as an aid to respondents and for subsequent analysis.
4. Minimal duplication. Where there were a number of items asking about the same aspect of care I elected to retain those which were the most easily understood and most closely adhered to the principles suggested by the conceptual framework.

A total of 43 items were progressed to cognitive testing: 17 in the domain of care planning, 19 in relation to care delivery and six in relation to inter-provider behaviour. There was also one overall evaluation item.

5.5: Item refinement and selection

At this stage the items which remained were equally distributed across the *a priori* domains, were reflective of the format and structure suggested by the conceptual framework and had been subjected to an initial review of their clarity and interpretability. However, the ultimate test of an item's clarity is how it is interpreted by potential respondents. Items which are incomprehensible, misunderstood or to which the respondent cannot give their preferred answer introduce response error which can ultimately affect the reliability and validity of the resulting measure (Streiner and Norman, 2009, De Vellis, 2003, Nunnally and Bernstein, 1994).

5.5.1: Methods of item refinement

5.5.1.1: Cognitive interviewing

Responding to questionnaire items is a complex cognitive process. Tourangeau (1984) described a four stage process which people go through when determining their response. Firstly, they need to understand the question. This includes understanding both what the question is asking and any specific words and phrases used in it. Secondly, they need to be able to remember the relevant information. Thirdly, they need to make a judgement on this recalled information, which may be influenced by the effort put into answering the question thoughtfully and whether they respond accurately or wish to present themselves in a certain way e.g. social desirability bias. Finally, they need to be able to match their answer to one of the available response options. Thus there is the potential for items to be misunderstood in whole and in part, respondents may not be able to recall the information necessary to make an accurate response, their response may not be accurate and the response options available may not adequately reflect the response they wish to make. All of these issues may lead to measurement error.

Some of these issues can be addressed at the item drafting stage but it is recommended that items are pre-tested for comprehension as some potential problems only become apparent when items are used (Choi and Pak, 2005, Collins, 2003, Willis, 2005). One approach to this pre-testing is cognitive interviewing. This is a formal process which seeks to identify potential problems with items in a questionnaire by asking potential respondents about their comprehension of the item, the recall of necessary information and how they selected a response option (Willis, 2005). During the systematic review presented in Chapter 4 a number of potential problems were noted in relation to items addressing coordination of care. These included the optimal recall period, understanding of terminology and the ability of respondents to make an overall evaluation of the performance of all their providers. In order to see if any of these issues could be remedied prior to the piloting of any questionnaire I undertook a series of cognitive interviews. There is evidence to suggest that only a small number of interviews are required to identify problems with item wording (Willis, 2005).

Participants and procedure

Ten interviews were conducted between November 2010 and January 2011 with adult volunteers who were current users of the health service and whose care was delivered by two or more health and social care professionals. As with the focus group study participation was limited to those who were able to provide consent and those who spoke English. Two interviewees had earlier participated in one of the focus groups. Additional participants were recruited through advertisements distributed to local patient groups.

All participants had an informal discussion about what participation would involve, supplemented with written information and were asked to sign a consent form. Examples of these documents are given in Appendices 6 and 7. Interviews were conducted either in the participant's home or at the University. Each interview followed a standard format and began with a training exercise to familiarise participants with the process (Willis, 2005). During the first seven interviews participants were given a printed PowerPoint slide for each item. They were asked to read this and the associated response options and then to 'think aloud' whilst they considered their response.

During 'think aloud' interviews the participant is encouraged to verbalise his/her thinking, without internal editing, as they attempt to answer the selected question (Collins, 2003, Drennan, 2003, Beatty and Willis, 2007). This can be challenging for respondents (Collins, 2003) therefore each interview began with a training exercise designed to familiarise participants with the process and to encourage them to verbalise their thoughts (Willis, 2005). The exercise selected was one I had used myself in cognitive interview training in which participants were asked how many windows there are on the front of their house.

An alternative method of cognitive interviewing is verbal probing (Beatty and Willis, 2007, Drennan, 2003, Collins, 2003). In this approach respondents are asked specific questions in relation to their comprehension of the question and/or how they determined their answer in order to elicit further information. These probes may be pre-scripted or spontaneous (Beatty and Willis, 2007). Concurrent probes were used here to clarify and better understand the information shared during 'think aloud'.

During the final three interviews participants were asked to 'think aloud' whilst completing a paper draft of the questionnaire. This enabled limited pre-testing of the layout of the questionnaire and the skip instructions.

All interviews were recorded and written notes taken. Each interview lasted approximately two hours.

Analysis

Analysis of participant responses was undertaken concurrently with data collection in an iterative manner. Simple modifications to item wording and response options were suggested during interviews. A report was written for each interview which highlighted problematic item wording together with suggested modification in order to maintain an audit trail of item modification. Respondent comments were then collated for each item in order to identify those which were consistently identified as problematic. Where these items were not necessary to the item pool in order to maintain conceptual coverage they were discarded. Where deletion would have compromised conceptual coverage then the item was reworded and tested further.

5.5.2: Results of item refinement

The majority of participants in the cognitive interviews were female (n=7) and were aged between 55-64 years. All described their ethnicity as white. All had more than one long-term condition. Full demographic details are given in Table 5.3.

Table 5.3: Demographic characteristics of cognitive interview participants

Gender	Number (%)
Male	3 (30)
Female	7 (70)
Age (years)	
<54	2 (20)
55-64	3 (30)
65-74	2 (20)
75-84	2 (20)
≥85	1 (10)

The majority of items considered during cognitive testing appeared to be interpreted by participants in the intended manner. Prior to the interviews I identified the following items as potentially problematic: the recall period, making an overall evaluation across providers and some aspects of the terminology used in items.

5.5.2.1: Recall period

The recall period explored during cognitive interviews was that of six months. This period was selected as the experience of other researchers was that three months was too short for many events to have occurred (McGuiness, 2001) and a concern that 12 months might be too long a period for respondents to recall with confidence and they would begin to rely upon 'generic memory' in selecting their response (Means et al., 1989). Interviewee responses and the issues they covered during 'think aloud' suggested that a 6 month recall period was generally long enough for them to have experienced the aspect of care of interest whilst being short enough for them to remember what had happened to them. Some participants commented that they would have preferred a longer timeframe. When this happened this tended to be prompted by either a key failure occurring just outside of the six month window or that they had been well over the last six months and so had not tested the organisation of their care, particularly in relation to responding to change. The six month recall window was retained in the draft CCQ used for piloting.

5.5.2.2: Making an overall evaluation of different professionals' performances

Another issue explored during cognitive testing was participants' ability to make an overall evaluation of performance across all health professionals. Presentation of the items began with an item which required participants to identify the places where they had received healthcare in the previous six months. They were then instructed to think about all the professionals they had seen in these places when deciding upon their answers to the subsequent items.

The majority of respondents appeared able to balance the contributions of all their healthcare providers in determining their response and to make a global judgement, even when they had varied experiences with individual providers. Only one respondent expressed discomfort with making an overall evaluation and commented that she would have preferred to be able to make a response based upon individual provider behaviours. However, she subsequently made an overall evaluation, which was weighted towards the poorer of her experiences.

5.5.2.3: Terminology

Prior to the cognitive interviews I had identified key aspects of the terminology used in the items which I wanted to explore. These were the interpretation of the phrases 'healthcare professional' and 'provider', 'special needs' and 'organisation of healthcare'.

At this stage the wording of items used the phrases 'healthcare professional' and 'provider' or 'service provider' interchangeably. Interpretation of these items was explored both during 'think aloud' and through specific probing. In response to specific probes about who or what respondents thought these phrases related to they gave examples of the individual professionals they had seen. This suggested that these respondents also interpreted these wordings as interchangeable phrases. However, for the pilot questionnaire I wished to limit the number of different phrasings. Therefore, I elected to use the term 'healthcare professional' throughout as this appeared to be a term which respondents were comfortable with and had less potential for ambiguity than the alternatives.

The second aspect of terminology explored through specific probes was that of 'special needs'. Personalisation of care had emerged during the focus groups as an important aspect of coordination to patients in relation to both the planning and delivery of services and items were developed which sought to address this. Specifically these items were:

- How satisfied are you that the care you received [over the last six months] took account of your wider personal circumstances?
- Thinking about your healthcare over the last six months, how satisfied were you that the care you received took account of any special needs that you had?

Again, specific probes were used to supplement the 'think aloud' to understand the interpretation of 'special needs' and its alternatives, 'special conditions' and 'wider personal circumstances'. Prior to the interviews I had concerns about the use of the phrase 'special needs' as it is also used to refer to individuals with a learning disability or educational difficulty.

All but one of the participants interpreted 'special needs' as needs which were unique to them and which arose from their medical condition(s) or their living arrangements. Respondents gave examples of not receiving appropriate meals for their diabetes whilst in hospital, acknowledgement or otherwise of limited mobility by healthcare professionals and assistance to make modifications to their home. This suggested an interpretation in line with that which was intended. The one participant who interpreted this as relating to a learning disability had family members who worked as carers for this client group, suggesting that this interpretation may be a professional one. The phrases 'special conditions' and 'wider personal circumstances' were subject to more variation in interpretation and in some cases confusion as to what was intended. I therefore elected to retain the use of 'special needs'.

5.5.2.4: Other issues identified during the interviews

After the first five interviews had been completed the findings were reviewed in order to identify any emerging problems with item wording and response options. Items identified as potentially problematic are detailed in Table 5.4 together with a description of the nature of the problem.

Table 5.4: Potentially problematic items identified during cognitive interviewing

Item	Nature of the problem
Thinking about your healthcare over the last 6 months, how satisfied were you that your healthcare professionals made a plan for your healthcare which was specific to you?	Different interpretations of the word 'plan' - was felt to be too specific a term to use and one participant suggested that 'arrangements' may be better. Planning was interpreted as a specific activity which involved bringing all healthcare providers together and did not encompass loose ongoing arrangements.
How often did your providers ask you what you would like to happen when they made decisions about your healthcare?	Misinterpretation of the phrase 'would like to happen' - one participant commented that she didn't want anything to happen as it implied to her that her health was getting worse.
Thinking about your healthcare over the last 6 months, how often did you know what was going to happen next in your healthcare?	Misinterpretation of the phrase 'going to happen next' – some participants interpreted this as referring to future health needs and commented that they didn't know what was going to happen next. Others understood that it was looking back over the previous six months but did not include their understanding of their routine care when considering their response.

The interview schedule for the next two interviews was adjusted to ensure that sufficient attention was paid to these items and potential solutions. Where reasonable alternatives already existed for problematic items then these were deleted from the item pool.

5.5.2.5: Structure and content of the draft CCQ

After the first seven interviews had been completed I reviewed my written notes and the 'think aloud' recordings for each item with the aim of reducing the numbers of items in the pool to those which would be included in the pilot of the CCQ and to create a mock-up of the questionnaire. I intended to use this questionnaire in the final three interviews in order to check the clarity of the layout and completion instructions.

At this stage the process of item reduction focussed upon the identification and removal of unclear, ambiguous and duplicate items. The remaining items were then arranged into groups which represented the frequency with which aspects of care had been experienced; satisfaction with the organisation of care, items related to inter-provider behaviours, making changes to the organisation of care and responses to problems with the organisation of care.

The draft questionnaire began with a question to determine the number of places where the respondent had received healthcare. It was then followed by a block of 14 items which related to the frequency with which specific aspects of care occurred in the previous 6 months. These items related to both the planning and delivery domains of coordination. This was followed by five items asking about respondent's satisfaction with aspects of planning and delivery of care. The next two groups of items related to making changes to the organisation of care and responses to a breakdown in the organisation of care. During cognitive testing it became apparent that these were not applicable to all respondents. Therefore there were prefaced with filter questions asking whether there had been any changes to care or breakdowns in the organisation of care in the last 6 months. Skip instructions directed respondents to the next applicable item where appropriate. All respondents were asked to complete items about their observations of healthcare professional behaviours and an overall assessment of the coordination of their care. A sans serif 14 point font was used to enhance readability.

This draft of the questionnaire was used in the final three cognitive interviews. These three participants appeared able to follow the instructions as written and to navigate the form successfully.

This draft progressed on to piloting with no further modification. It consisted of 280. items arranged into five sections: the respondents' experiences with their healthcare, making changes to care, service responses to errors or failures, healthcare professional's behaviours and an overall evaluation of the organisation of care. Each item had five response options ranging from always to never for questions of frequency, very dissatisfied to very satisfied for questions of acceptability and very easy to very difficult for items relating to the ease with which aspects of care were accessed. The global coordination item asked respondents to rate the coordination of their care from excellent to poor. Skip instructions were used at three points to avoid the use of a not applicable response option and to improve the layout of the questionnaire.

A copy of the pilot questionnaire used in the postal survey described in Chapter 6 is included in Appendix 8.

5.6: Summary and conclusion

By the conclusion of this phase of this study a draft of the Care Coordination Questionnaire had been developed for piloting. The content, scope and boundaries of this questionnaire were determined by the conceptual framework detailed in Chapter 3 and the empirical referents of coordination and coordination failure from the patient perspective. Items were generated under three themes which cross-cut the attributes of coordination: care planning, care delivery and observations of inter-provider behaviour. In line with current best practice recommendations potential respondents were engaged in both item development and pre-testing. Items themselves were developed through an iterative process involving the examination of existing measures and through focus groups with potential respondents. Cognitive testing was utilised in order to try to address some of the problems of item comprehension identified by other researchers in this field, with some success. As described above, the resulting draft measure comprised of 28 items which address both the frequency with which events indicative of poor coordination occur and their impact upon the acceptability of the service.

In the next chapter I go on to present the methods used in the piloting of this questionnaire and the analyses undertaken to test its psychometric properties.

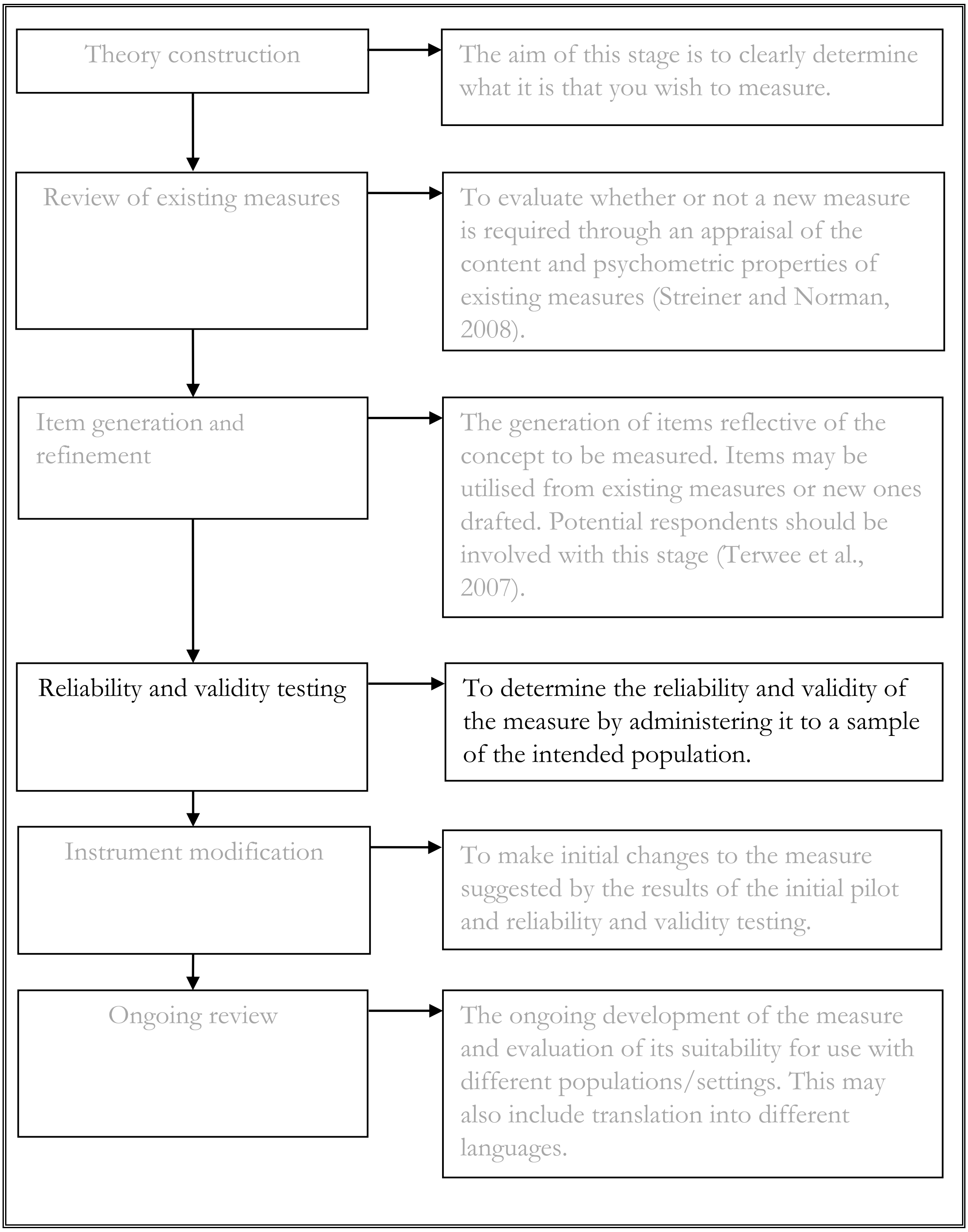
Chapter 6: Piloting of the CCQ

6.1: Introduction

In Chapter 5 I described the development of a potential new measure of coordination of care: the CCQ. In its final draft format this comprised of 28 items arranged into six sections: experiences with healthcare, satisfaction with the organisation of care, making changes to care, service responses to errors or failures, healthcare professionals' behaviours and an overall evaluation of the organisation of care.

In this chapter I describe the studies undertaken to evaluate the psychometric performance of the draft instrument and the initial testing of reliability and validity. I begin this chapter by considering the desirable attributes of a measurement tool. I then go on to present the specific aims for this phase of the research together with the studies intended to address them. This will also involve a discussion of the underpinning measurement model. The stages of measure development addressed in this chapter are highlighted in Figure 6.1.

Figure 6.1: Stages in Measure Development



The aim of this stage is to clearly determine what it is that you wish to measure.

To evaluate whether or not a new measure is required through an appraisal of the content and psychometric properties of existing measures (Streiner and Norman, 2008).

The generation of items reflective of the concept to be measured. Items may be utilised from existing measures or new ones drafted. Potential respondents should be involved with this stage (Terwee et al., 2007).

To determine the reliability and validity of the measure by administering it to a sample of the intended population.

To make initial changes to the measure suggested by the results of the initial pilot and reliability and validity testing.

The ongoing development of the measure and evaluation of its suitability for use with different populations/settings. This may also include translation into different languages.

6.1.1: Ethics

The study described here received ethical approval from NRES Committee NW Greater Manchester West (11/NW/0233). See Appendix 9.

6.2: Desirable attributes of a measurement tool

The desirable attributes of a measurement tool, namely conceptual coverage, reliability and validity were considered in detail in Chapter 4. To recap briefly, conceptual coverage refers to the comprehensiveness of the items in a measure and the extent to which they reflect the phenomenon of interest. In relation to the CCQ the development process was presented in Chapter 5 and in line with current recommendations included potential respondents in the drafting and testing of items (Mokkink et al., 2010, McColl et al., 2001, Collins, 2003).

Reliability refers to the extent to which an instrument is consistently measuring 'something'. It comprises of three measurement properties: internal consistency, reliability and measurement error (Mokkink et al., 2010). Internal consistency refers to the extent to which items are measuring different aspects of the same phenomenon. It is of relevance where instruments are developed within an effect model of instrument development (Streiner, 2003). Reliability coefficients describe the stability of the measure. This is the extent of agreement between responses given to the measure on two separate occasions. Measurement error is evaluated by using this reliability coefficient and the standard deviation of the instrument scores to calculate the standard error of measurement (SEM).

Validity refers to the extent to which an instrument measures the phenomenon it is intended to measure (Streiner and Norman, 2009). Two important forms of validity, in addition to content validity, are concurrent validity and construct validity. Concurrent validity is established through the comparison of the performance of a new measure against an alternative and previously validated measure of the same, or a closely related, concept of interest (Streiner and Norman, 2009).

Construct validity is an ongoing process which seeks to assess the theory underpinning a measure and its hypothesised relationship with other variables (Cronbach and Meehl, 1955). As a minimum a measure needs to be able to discriminate between respondents with different levels of the construct of interest, known as extreme groups or discriminative validity. Additionally, the measure should correlate with other variables to which theory suggests there should be a relationship (convergent validity) and not correlate with variables where theory does not suggest a relationship (discriminant validity).

6.3: Aims of piloting of the CCQ

The aims for this stage of the research were identified to assist in the evaluation of the extent to which the draft CCQ demonstrated the desirable attributes of a measurement tool considered above.

Five initial aims were identified:

1. Evaluation of individual item performance and completion of item selection for the next iteration of the measure.
2. Development of a scoring system for the measure.
3. Testing of the temporal stability of the measure through the subsequent administration of the candidate items 4 weeks after distribution of the initial questionnaire.
4. Evaluation of concurrent validity through comparison of scores on the CCQ with those on the 'best' existing measure of coordination identified through the review of existing measures: the Client Perceptions of Coordination Questionnaire (CPCQ).
5. Exploration of the construct validity of the CCQ through comparison of mean scores between groups of respondents.

6.4: The pilot study

6.4.1: Study design summary

This research employed a cross-sectional study design comprised of a postal survey of a random sample of adult primary care patients with one or more of the following long term conditions: multiple sclerosis, sickle cell anaemia or thalassaemia, haemophilia, systemic lupus erythematosus, rheumatoid arthritis, haemochromatosis, hypertension, diabetes and chronic obstructive airways disease (COPD). A total of 980 patients were surveyed from six general practices in the North-West of England between September 2011 and January 2012. Participating practices were identified by the North West Primary Care Research Network.

Participants were sent an initial questionnaire pack comprising of the draft CCQ and the CPCQ together with additional questions relating to their clinical conditions, numbers of providers and some demographic questions. A single reminder was sent to non-responders between 2-4 weeks after the initial questionnaire pack.

A test-retest questionnaire comprising of the draft CCQ was posted to consenting respondents two weeks after the return of the completed initial questionnaire to test the temporal stability of the CCQ.

Item performance was evaluated through an examination of missing responses, maximum endorsement frequency, potential redundancy and correlation with the global level of coordination evaluation item. The results of these analyses informed item reduction. The structure of the remaining items was then explored using structural equation modelling and exploratory factor analysis with the resulting factor weights being used to generate an overall coordination score.

Test-retest reliability was calculated through an estimation of the intra-class correlation coefficient.

Concurrent validity was assessed through comparative performance of the CCQ with the Client Perceptions of Coordination Questionnaire. Convergent validity was assessed through the correlation of the CCQ score with the global evaluation item and a set of items related to satisfaction with coordination. The relationships between CCQ scores and the reported numbers of providers and long term conditions were also explored using one-way analyses.

6.4.2: Sample

The sampling strategy was designed following consideration of the types of patients to whom the issue of coordination is of salience and who, as a group, would incorporate a range of coordination requirements. Salience is an important factor in achieving maximal response rates, whilst the inclusion of respondents with a range of coordination requirements is necessary to test the discriminative properties of the candidate items of the CCQ.

The conceptual framework suggested that coordination is most salient to those patients who are under the care of multiple health professionals, as the interdependence between them is an antecedent to the need for coordination. I therefore elected to recruit respondents with chronic conditions which frequently require input from multiple professionals. However, in order to provide a good test of the instrument I also wanted the pilot sample to include people with varying coordination requirements. To do this I identified two groups of potential respondents: firstly those with more unusual, but potentially complex conditions who were likely to receive care from both primary and secondary service providers and secondly, those with more common long term conditions where the complexity of care, and therefore coordination requirements, may be expected to vary with disease severity. Patients under the age of 55 years were excluded from this latter group in order to increase the likelihood of them requiring care for comorbid conditions which might reasonably be expected to increase their coordination requirements.

Participating practices were asked to create registers of patients who met the following criteria:

1. Over 18 years old and diagnosed with at least one of the following conditions:
    a. Multiple sclerosis
    b. Sickle cell anaemia or thalassaemia
    c. Haemophilia
    d. Systemic lupus erythematosus
    e. Rheumatoid arthritis
    f. Haemochromatosis

2. **Or,** aged over 55 years old and diagnosed with at least one of the following conditions:
    a. Hypertension
    b. Diabetes mellitus
    c. Chronic obstructive pulmonary disease (COPD).

Patients were excluded where:

1. They were known to be unable to read English
2. It would have been inappropriate to survey them due, for example, to recent bereavement, inability to consent. This determination was made by a clinician within the participating practice.

6.4.2.1: Sample size

Sample size was calculated on the basis of the numbers of completed questionnaires required to evaluate concurrent validity between the CCQ and the CPCQ, demonstrated by a small, but significant, positive correlation. The CPCQ was also designed for use with a primary care population in the context of a care coordination trial and therefore there should be some positive correlation between the two, but I did not expect the magnitude of this to be strong given the differences in the conceptual definitions underpinning the measures.

A sample size of 343 completed and usable questionnaires was required to detect a correlation of 0.15 at 80% power and at the 5% significance level. Based upon reported response rates I assumed a response rate of 35%. Therefore I needed to survey a total of 980 participants, equating to 164 patients per practice.

These 164 patients were selected from the practice registers by dividing the total number of eligible patients at each practice by the total number required (164), and using the resulting figure (n) to select every *nth* patient to receive the questionnaire.

6.4.3: Data collection procedures

The generation of potential participant lists, sample selection and the mail out of questionnaire packs were undertaken by participating practices following the provision of written instructions, either independently or with the support of the Primary Care Research Network. Practices were provided with a questionnaire pack for each patient in the sample. This included a copy of the questionnaire and a pre-paid return envelope to the University of Manchester.

Each questionnaire pack was given a unique ID number. Practices were asked to record this ID number against the contact details for each patient in the sample. This ID number was used to track responses and to enable follow-up reminders to be sent, whilst ensuring that no patient identifiable information such as contact details left the practice.

Practices were requested to send a second questionnaire pack to non-responders two weeks after the initial mail out. Practices were provided with the packs which were identified by the same ID number as the original questionnaire pack. Patients who did not wish to participate and wished to avoid receiving reminders were asked to return the blank questionnaire in the pre-paid envelope and were removed from the reminder list.

6.4.3.1: Temporal stability (test-retest) data collection

Assessment of temporal stability requires that a questionnaire be administered on two separate occasions. A second questionnaire was sent to participants who indicated on their response to the initial questionnaire that they would be willing to complete this, and who provided their contact details. This questionnaire was posted to participants two weeks after the return of the original questionnaire together with a pre-paid return envelope.

Data collection took place between September 2011 and January 2012.

6.4.4: Questionnaire content

The initial questionnaire comprised of the candidate items of coordination (the draft CCQ) and questions relating to the patients clinical characteristics and questions relating to their demographic characteristics. These will now be considered in more detail.

The candidate items of coordination were those developed for the draft CCQ in order to reflect the conceptual definition of coordination and are described in detail in Chapter 5.

Respondents were asked to provide information about the number and type of long term conditions they had, the number of provider organisations from which they had received care in the preceding six months and their perceived health status. These characteristics were used to describe the sample.

Demographic information relating to age, gender, ethnicity, education, employment and home accommodation was also collected. This was used to describe the sample in socio-economic terms.

The Client Perceptions of Coordination Questionnaire (CPCQ) (McGuiness and Sibthorpe, 2003) was included in order to measure concurrent validity. It is a 31 item measure of coordination of care divided into six sub-scales: acceptability, received care, GP care, nominated provider care, client comprehension and client capacity. It was developed in Australia for use with primary care patients participating in a coordination of care trial. These patients had a range of chronic conditions and had been identified as being in need of care coordination support. From the review of existing measures described in Chapter 4 it represented the 'best' existing measure.

The questionnaire also included a cover letter. This explained the purpose of the study, the confidential nature of responses and completion instructions. These instructions had been tested for comprehension during cognitive interviewing. The complete questionnaire is reproduced in Appendix 8.

6.5: Data analysis

Analyses were determined by their contribution to meeting the stated aims of this phase of the research and their congruence with the underpinning measurement model.

6.5.1: Impact of the measurement model upon statistical analyses

The different measurement models were described in Chapter 5 and a case was made for the measurement of coordination using a causal model. Measures developed using a causal model approach are underpinned by different assumptions to those of effect models. In particular, the classical test theory approach of utilising inter-item correlation, assessment of internal consistency and factor analysis in item selection and reduction are not appropriate (Streiner, 2003, Streiner and Norman, 2009).

The analyses described below are reflective of the approaches recommended for measure development within a causal model. They were focused upon:

1. Item performance and ongoing development of the questionnaire
2. Evaluation of the temporal stability of the questionnaire
3. Exploration and evaluation of the validity of the questionnaire.

These will be addressed in turn.

6.5.2: Item performance and ongoing development of the questionnaire

6.5.2.1: Item performance

It is necessary for items to demonstrate acceptable performance in terms of missing responses and maximum endorsement frequency. The items will then be evaluated for potential redundancy and correlation with the global item.

Missing responses may be an indication that the items are irrelevant, misunderstood or unacceptable in some way to those being asked to respond to them.

Maximum endorsement frequency is where an item is responded to in the same way by a large number of respondents. This means that responses to the item can be predicted which can have a negative effect upon the psychometric properties of the resulting measure as well as adding to its length.

Redundancy, and subsequent removal, of items should be approached with caution in a causal measurement model. Within this measurement approach items are not interchangeable and inappropriate removal of an item may change the nature of the latent variable. However, each item should also bring a distinct influence to bear on the latent variable.

To assess potential redundancy items were considered for removal where they inter-correlated >0.75. Item wording and performance in terms of missing responses, maximum endorsement frequency and correlation with the global evaluation item were reviewed prior to making a decision about which item to remove.

Item collinearity was also evaluated as recommended by Diamantopoulos and Winklhofer (2001). Excessive collinearity makes it difficult to separate the influence of individual items on the latent variable. A variance inflation factor was calculated to assess the extent of multi-collinearity. A threshold of 10 is usually taken as indicative of serious multi-colinearity (Acock, 2008) when items should be considered for removal.

Correlation with the global item *'Overall, how would you rate the coordination of your care over the last 6 months'*? A Spearman rho correlation was calculated for each item and the global item. Items that did not significantly correlate with this item (p<0.05) were considered for removal.

6.5.2.2: Model analysis

The structure of the CCQ was evaluated using both structural equation modelling (SEM) and exploratory factor analysis. Both these methods are processes for the simplification of complex data through the identification of relationships between variables through examination of covariance and correlation matrices (Kline, 1994, Kline, 2011). The main difference between the two techniques is that SEM can be used to test the plausibility of *a priori* hypotheses in a set of empirical data, whereas exploratory factor analysis explores the correlation coefficients in the empirical data to see whether they are measuring aspects of the same underlying dimensions (Field, 2009).

Within SEM the relationship between variables is specified *a priori* and used to generate a model to be tested (Kline, 2011). This model is then 'fitted' to an empirical dataset and is accepted or rejected depending upon how well it corresponds with the data (Kline, 2011). Three uses of SEM have been proposed (Joreskog, 1993). Firstly, it can be used in a strictly confirmatory sense in that a single model is accepted or rejected. Secondly, it can be used to test alternative *a priori* models. Thirdly, it can be used for model generation. This approach is used when the initial model does not fit the data and allows for the model to be modified and retested on the same empirical data (Joreskog, 1993). The aim is to create a model which is theoretically sound, is parsimonious and has an acceptable fit with the data (Kline, 2011).

SEM is an attempt to model and test causal relationships between variables (Field, 2009). It differs from correlation and regression in that measurement error and directional relationships between every pair of variables can be built into the model. Initially the model needs to be specified. This involves determining the following:

- Model parameters
- Identification of variables
- Setting the model components
- Specifying the relationship between variables

Model parameters are the values used to indicate the relationship between variables. They may be fixed i.e. not estimated from the data or free, i.e. estimated from the data.

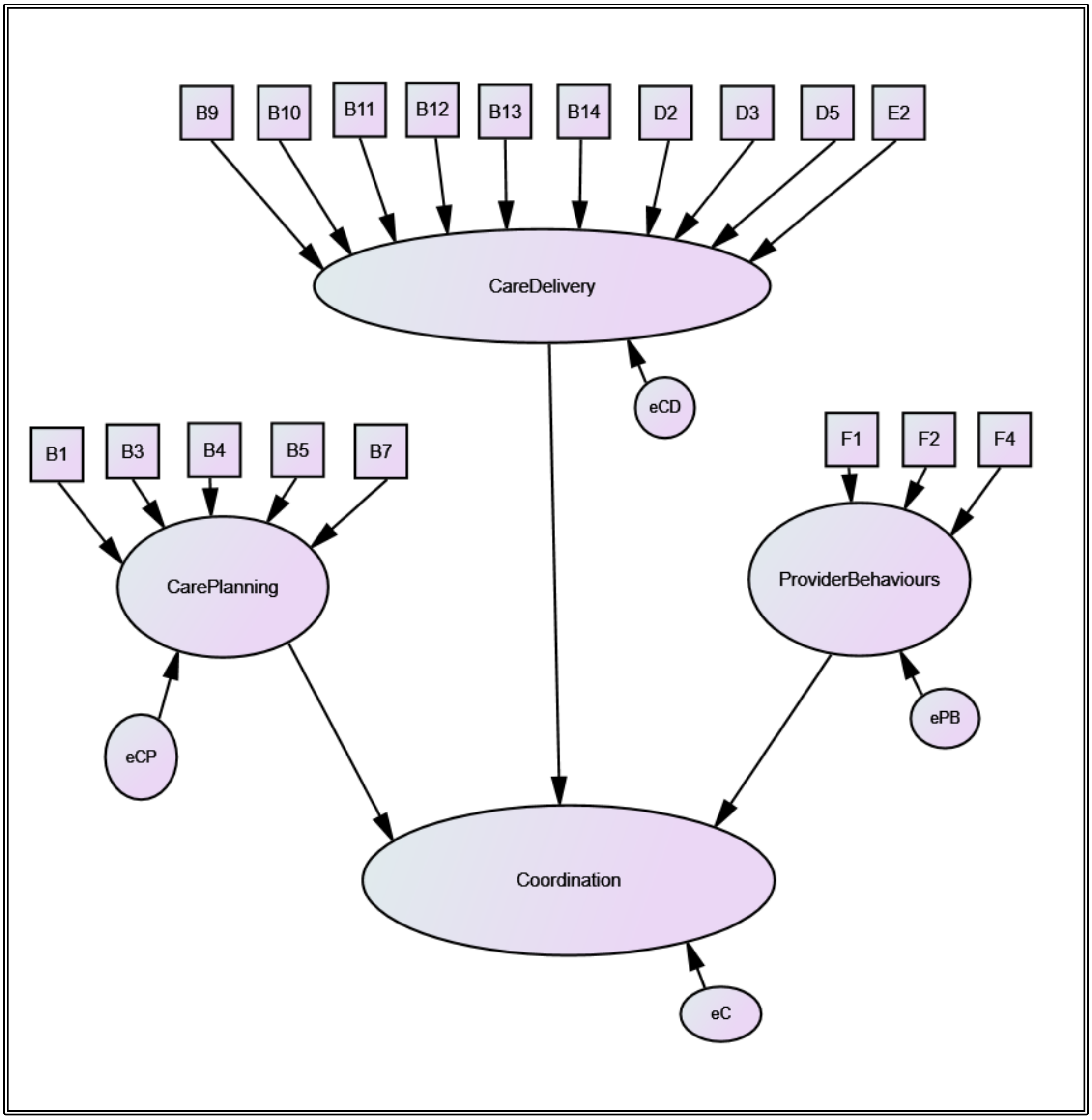
Variables may be measured or be latent variables. Measured variables are data which can be collected, such as responses to items on a questionnaire or biometric readings such as pulse rate or blood pressure. Latent variables are those which cannot be directly measured but are imputed through the relationships between measured variables.

SEM models consist of two components: the measurement model and the structural model. The measurement model specifies the relationships between the measured variables and the latent variable(s) of interest. The structural model is where relationships between the latent variables themselves are defined.

In SEM the nature of the relationships between the variables also needs to be defined. There are three types of relationship: association, direct effect and indirect effect. An association is a non-directional relationship such as a correlation or covariance. A direct effect is where one variable is assumed to be a direct cause of another. An indirect effect is where a variable causes another, but only via its effects on other, intervening, variables (Byrne, 2010).

A full structural equation model (consisting of both the measurement and structural components) was created in AMOS version 20.0 (IBM Corp, 2012) to evaluate the goodness of fit of the *a priori* hypothesised causal model of coordination as comprising of three first order latent variables representing care planning, care delivery and observations of professionals' behaviours, which then combined into a second order overall coordination measure. Items were grouped according to the latent variable they were assumed to correspond to during the item generation exercise. See Figure 6.2 for a diagrammatical representation of the model and Table 6.1 for the item detail.

Figure 6.2: Path diagram of the initial model



Key:

⬬ Latent variable. The first level latent variables are labelled ‘CarePlanning’, ‘CareDelivery’ and ‘ProviderBehaviours’. The second level latent variable is labelled ‘Coordination’. Error or disturbance is captured at the first and second factor level.

▬ Measured variable. These are labelled with the relevant item number.

→ Direction of impact of one variable on another

↔ Correlated variables. In this path diagram all measured variables are allowed to correlate.

Table 6.1: Initial item allocation for measurement model

Sub-scale	Item detail
Planning of care	B1: frequency with which healthcare professionals explained how they planned to address your health problems.
	B3: frequency with which your preferences were taken into account when making decisions about your healthcare.
	B4: frequency with which your healthcare providers took notice of your views about how to manage your health problems.
	B5: frequency with which you were unsure about what each of your healthcare providers were there to do for you.
	B7: frequency with which you left an appointment unsure what was going to happen next in your care.
Delivery of care	B9: frequency with which you got the care that you healthcare professionals said that you would.
	B10: frequency with which you had to wait longer than expected before obtaining a service.
	B11: frequency with which you saw a different healthcare professional to the one you were expecting.
	B12: frequency with which your healthcare professionals were missing information necessary to make decisions about your treatment.
	B13: frequency with which you felt like complaining about the way your care was organised.
	B14: frequency with which you have had problems with the coordination of your care.
	D2: ease of making changes to the arrangements for your care.
	D3: frequency with which unsure who to contact to make changes to the arrangements for your care.
	D5: satisfaction with healthcare professional initiated changes to the organisation of your care.
	E2: frequency with which given an explanation of errors in the organisation of care.
Observations of provider interactions	F1: frequency with which one of your healthcare providers seemed unaware of what others were doing for you.
	F2: frequency with which one healthcare professional said one thing about your care and another said something quite different.
	F4: frequency with which your healthcare providers appeared to disagree with each other about the best care for you.

AMOS (IBM Corp, 2012) uses geometric symbols to represent the different elements of the model. Latent variables are represented by circles or ellipses and measured variables by squares or rectangles. Single headed arrows represent the impact of one variable upon another and double headed arrows are used to indicate correlations between variables. The resulting visual representation of the model is called a path diagram.

In the path diagram in Figure 6.2 there are 18 observed variables which represent items in the questionnaire. These are hypothesised to generate the three first order latent variables of care planning, care delivery and observations of inter-provider behaviours. These three latent variables are then further hypothesised to generate the latent variable labelled as coordination. Error or disturbance terms are associated with each of the first order and second order latent variables. This contrasts with reflective measurement models where measurement error is associated with the measured variables (Diamantopoulos et al., 2008).

The plausibility of the specified model is then tested using a sample of data which includes all the measured variables to assess how well the model reflects the empirical data: described as goodness of fit. Goodness of fit was evaluated through examination of the Root Mean Square Error of Approximation (RMSEA) and the Comparative Fit Index (CFI).

The RMSEA is an estimate of how well the model would fit the population covariance matrix if it was available (Byrne, 2010). It has been recommended as a routine assessment of goodness of fit as it appears to be sensitive to model misspecification, interpretive guidelines appear to result in appropriate conclusions and confidence intervals can be calculated (Byrne, 2010).

The CFI is an incremental index of fit (Byrne, 2010).In this statistic the hypothesised model is compared with an independence or null model.

Using the criteria suggested by Hu and Bentler (1999), an RMSEA of less than 0.08 and CFI of greater than 0.9 were viewed as being necessary for the model to be accepted, with an RSMEA of less than 0.06 and CFI of greater than 0.95 being ideal.

I anticipated that the first-level latent variables of care planning, care delivery and provider interactions would correlate with one-another. In the two-level model these correlations are accounted for through the second-level coordination latent. However, it was also plausible that levels of correlation would be strong enough to make the first-level latent variables redundant in the model, such that a simpler one-level model with a single latent variable, ie coordination, would provide a near-equivalent, or even better, fit to the data. Therefore for comparison I also planned to test a second causal SEM model in which all the individual items together generated a single overall latent coordination measure.

Analyses were performed using maximum likelihood estimates (Kline, 2011).

Should neither of these models demonstrate an acceptable fit with the data I planned to then investigate the actual relationships between items using exploratory factor analysis (EFA). This approach has been recommended when 1) initial hypotheses are rejected and 2) no further *a priori* models are suggested by the underpinning theory; as is the case here. Factor structures identified as a result of EFA can then be tested within a confirmatory SEM model (Byrne, 2010).

It should be noted that this EFA-based approach inherently assumes an effect model of relationship between items and factors, in contrast to the causal structure assumed by the conceptually-based SEM models. Unfortunately, no exploratory method equivalent to EFA exists for the causal model scenario. The use of EFA in this context would therefore be purely for the purpose of obtaining a pragmatic organisation of the items for the purpose of deriving a measure of coordination.

Factor analysis represents an empirical approach to the identification of the numbers of latent variables or factors of a set of items. It aims to 1) condense the data from a number of items to a smaller number of factors, 2) assist in the generation of 'scores' based on these combinations of items and 3) to determine the content or meaning of the factors (De Vellis, 2003). There are a number of different kinds of factor analysis, with principal axis factoring being recommended where data is not normally distributed, as was the case in this study (Fabrigar et al., 1999).

Exploratory factor analysis was performed using principal axis factoring with oblique rotation (Oblimin) that allows for correlation between variables (Field, 2009, Kline, 2011). The aim was to arrive at a simple solution in which all variables loaded onto a single factor greater than 0.4, with the number of factors being determined though Eigenvalues of greater than 1 and examination of the resulting scree plot and extraction sums of squared loadings (Field, 2009). Ideally, resulting factors should also contain at least three variables.

EFA was used here to further explore the empirical data to identify how the variables may cluster together. These groupings would then be replicated in an SEM measurement model to evaluate goodness of fit (using the criteria described above) and to derive item weights to be used in generating a score on the CCQ.

6.5.2.3: Scoring the CCQ

Two approaches to scoring the CCQ were explored: firstly, utilising the factor score weights obtained from the structural equation model to weight individual items and secondly, averaging scores across individual items.

Weighted scores

Item responses were standardised to a scale of 0-100. The individual item weights from the SEM were also standardised by summing the weights and dividing each individual weight by this figure. All weights for the overall score then totalled 1. The standardised item responses were then multiplied by these figures and summed to obtain the overall coordination score. The resulting scores had the potential to range from 0 – 100 with zero indicating poor/no coordination.

Averaging scores across items

Item responses were standardised to a scale of 0 – 100. An overall coordination score was calculated by averaging responses to all the items included in the CCQ. Again, the resulting coordination score had the potential to range from 0 -100 with zero indicating poor/no coordination.

The resulting scores were compared and the distribution of any differences examined using histograms and Bland Altman plots.

6.5.3: Evaluation of the temporal stability of the questionnaire

Temporal stability or test-retest reliability was evaluated through the calculation of the intra-class correlation between the responses to the candidate items of the CCQ when administered on two separate occasions. An intra-class correlation coefficient of ≥ 0.7 is desirable to demonstrate stability (Terwee et al., 2007).

To evaluate test-retest reliability the underlying construct needs to be stable as otherwise changes in responses could be due to a change in the underlying construct rather than indicate that the measure is unreliable. Assessing the stability of a construct such as coordination is challenging. To try to make an evaluation of this, respondents to the retest questionnaire were asked two additional questions about whether there had been any changes in their health needs or health services since completion of the initial questionnaire. These were used as proxy measures of whether there might have been changes to the coordination of their care.

6.5.4: Exploration and evaluation of validity of the questionnaire

The initial assessment of validity planned to focus upon the attributes of concurrent validity and construct validity, specifically convergent validity.

Concurrent validity was evaluated through correlation of the responses to the draft CCQ and the Client Perceptions of Coordination Questionnaire.

The Client Perceptions of Coordination Questionnaire comprises of 6 sub-scales: overall care, received care, client comprehension, client capacity, GP care and other provider. Scores were created for each sub-scale if at least half the items had valid responses (or half plus one for scales with an odd number of items) (McGuiness, 2001). Items where the 'not applicable' response option had been endorsed were recoded to the most positive response in line with the handling of not applicable responses in the CCQ. Missing responses were given a mean value. These scale scores were then summed to give an overall score on the CPCQ.

Convergent validity was evaluated in four ways:

1. Correlation of the overall coordination score with the overall global evaluation item *'Overall, how would you rate the coordination of your care over the last 6 months?'* Within a causal measurement model there should be a significant correlation with a global item summarising the construct (Diamantopoulos and Winklhofer, 2001).
2. Correlation of the overall coordination score with the satisfaction items. Again a measure comprised of causal indicators should correlate with effect items that reflect a related construct (Diamantopoulos and Winklhofer, 2001). The satisfaction items grouped in Section C of the CCQ were subject to the item analyses described above and then fitted to a CFA model to confirm unidimensionality and to obtain factor score weights. A satisfaction score was then calculated using the weighted score approach described above.
3. Exploration of the relationship between overall coordination scores and numbers of providers. The *a priori* hypothesis was that overall coordination

scores would decrease with an increase in the number of care providers. Respondents were divided into three groups: those with one care provider, those with two care providers and those with three or more care providers. Differences in coordination scores were examined between i) one provider v two providers and ii) one provider v three or more providers using a Mann Whitney U test.

4. Exploration of the relationship between overall coordination scores and reported numbers of long-term conditions. The *a priori* hypothesis was that coordination scores would decrease with an increase in the number of long term conditions reported by respondents. The number of long term conditions was treated as a continuous variable and correlated with the overall coordination score.

6.6: Data entry

To ensure consistency of data entry a number of rules were developed in relation to the recording of missing responses, skip instruction responses and the recording of data for subsequent analyses.

- All data was entered into SPSS version 21 (IBM Corp, 2012).
- Discrete codes were used for the recording of missing information namely, a blank response, an ambiguous response where more than one response option had been annotated or the respondent had written not applicable and for missing responses that appeared systematic.
- Initially all correct skips were coded as such using a discrete code.

In preparation for data analysis some variables were recoded:

- Negatively worded items were reverse scored so that better coordination was recorded with a higher score.

- Where a respondent reported no changes being required to their care (section D) or no organisational failures in relation to their care (section E) their correct skip responses were recoded to reflect optimal coordination.
- Missing values were imputed for the generation of overall coordination and satisfaction scores for use in validity testing. These were estimated at the item level and then incorporated into the scoring calculation.

6.7: Statistical analyses

Statistical analyses and exploratory factor analyses were performed using SPSS version 21 (IBM Corp, 2012). Structural equation modelling was performed using AMOS version 20.0 (IBM Corp, 2012). The distribution of both responses to individual items and the resulting coordination scores were skewed towards the more positive response options and therefore non-parametric tests such as Spearman's rho and Mann Whitney U tests were used whenever possible.

6.8: Samples used for each analysis

Different samples were used at different stages in the analysis.

Item evaluation was performed on a sub-set of the sample who reported receiving care from two or more care providers (n = 153). The sample was divided in this way given the theoretical importance of interdependence to the concept of coordination.

SEM and exploratory factor analysis was performed using a subset of the sample who reported receiving care from two or more providers as above but was restricted to complete responses (n = 126).

Test-retest reliability analysis was conducted on a sub-set of the sample who completed a second questionnaire and for whom an overall score could be calculated for each test administration. An overall score was calculated when a respondent had correctly endorsed a response to at least one item for each factor and had correctly endorsed at least 50% of the total items (n = 94).

Concurrent validity testing was performed on a sub-set of the sample for whom it was possible to calculate a score on both the CCQ and the CPCQ (n = 176). Scores were calculated for the CCQ as described above. Scores for the CPCQ were calculated where a respondent had answered at least 50% of the items in a sub-scale (or 50% plus one where the sub-scale contained an odd number of items).

Convergent validity tests were performed on a subset of the sample in whom it was possible to calculate an overall CCQ score as described above and where information was also provided in relation to numbers of providers (n=272) and numbers of long term conditions (n=273).

6.9: Summary

In this chapter I have described the design of the cross sectional questionnaire study undertaken to finalise item selection for the CCQ and to test the psychometric properties of the resulting instrument. At this early stage of development item analyses focused upon the identification of poorly performing or redundant items and how the remaining items could usefully be combined to create a coordination score. Tests of reliability and validity focus upon temporal stability and construct validity. The specific hypotheses to be tested focus upon the relationship between results on the CCQ and the numbers of providers reported by respondents, the numbers of long term conditions and its comparable performance against responses to an existing coordination questionnaire, the CPCQ.

The results of item analyses, questionnaire structure and reliability and validity testing are presented in the next chapter.

Chapter 7: Results of piloting of the CCQ

7.1: Introduction

In this chapter I present the results of the initial analyses of the CCQ. The chapter begins by describing the key characteristics of the survey sample. Item analyses will then be presented together with the final selection of items used in the assessment of the dimensionality of the instrument. Scoring of the CCQ will then be described.

Once the final structure of the CCQ resulting from the above analyses has been described I will then present the results of the initial assessment of reliability and validity.

7.2: The survey sample

A total of 299 completed surveys were returned; a response rate of 30.5%.

7.2.1: Demographic characteristics

Table 7.1 summarises the demographic characteristics of respondents. Half were female (50.5%). Respondents had a mean age of 70.6 years (sd: 9.0) and the majority were of white ethnicity (92.3%).

7.2.2: Socio-economic characteristics

Over a third of respondents (34.8%) reported no educational qualifications with one or more O levels/CSE/GCSE being the next most frequently endorsed response (30.4%). The majority of respondents (70.2%) were retired from paid work and 71.2% owned their own home. See Table 7.2 for more detail.

Table 7.1: Demographic characteristics of respondents

Gender	Number (%)
Female	151 (50.5)
Male	138 (46.2)
Missing	10 (3.3)
Age (years)	
<55	3 (1)
55-59	22 (7.4)
60-64	62 (20.7)
65-69	50 (16.7)
70-74	55 (18.4)
75-79	38 (12.7)
80-84	36 (12.0)
85-89	15 (5.0)
>90	5 (1.7)
Missing	13 (4.3)
Mean age (sd)	70.56 (9.0)
Age range	41 - 98
Ethnicity	
White	276 (92.3)
Black or black British	1 (0.3)
Asian or Asian British	6 (2.0)
Chinese	1 (0.3)
Mixed ethnicity	1 (0.3)
Other	2 (0.7)
Missing	12 (4.0)

Table 7.2: Socio-economic characteristics of respondents

Educational qualifications	**Number (%)**
1 or more O levels/CSE/GCSEs (any grade)	91(30.4)
1 or more A levels or AS levels	35 (11.7)
Degree	29 (9.7)
NVQ	28 (9.4)
Other trade qualification	66 (22.1)
Professional qualification	73 (24.4)
No qualifications	104 (34.8)
Missing	20 (6.7%)
Employment	
In paid work (full or part time including self-employed)	43 (14.4)
Unemployed	5 (1.7)
Retired from paid work	210 (70.2)
Unable to work due to long term disability or ill-health	39 (13.0)
Looking after the family or home	14 (4.7)
In full-time education or training	0 (0)
Voluntary work	11 (3.7)
Other	4 (1.3)
Missing	12 (4.0)
Accommodation	
Owner-occupied/ mortgaged	213 (71.2)
Rented from local authority/ housing association	51 (17.1)
Rented from a private landlord	13 (4.3)
Other	9 (3.0)
Missing	13 (4.3)

7.2.3: Long-term conditions

As can be seen in Table 7.3 hypertension was the most frequently reported of the health conditions specifically sampled (62.0%) followed by diabetes mellitus (27.6%), COPD (15.5%) and rheumatoid arthritis (15.2%). Only 2.7% of respondents reported having haemophilia and 0.3% multiple sclerosis. No respondents reported having sickle cell anaemia or systemic lupus erythematosus. Five respondents did not self-report any long-term conditions despite needing to have been diagnosed with one of the conditions of interest in order to be invited to complete the questionnaire.

In addition to the selected conditions respondents reported a range of other long-term conditions including non-rheumatoid arthritis, back problems or osteoporosis (51.2%), respiratory problems, neurological conditions, gastrointestinal conditions and anxiety and depression.

There was evidence of multi-morbidity with respondents reporting a mean of 2.36 long-term conditions (sd: 1.4; range 0-10).

The majority described their health status as good (29.8%) or fair (27.4%).

Table 7.3: Morbidity of respondents

Long-term condition	**Number (%)**
Hypertension	184 (62.0)
Diabetes mellitus	82 (27.6)
COPD	46 (15.5)
Rheumatoid arthritis	45 (15.2)
Haemophilia or haemochromatosis	8 (2.7)
Multiple sclerosis	1 (0.3)
Sickle cell anaemia or thalassaemia	0 (0)
Systemic lupus erythematosus	0 (0)
Mean number of long term conditions (sd)	2.36 (1.4)
Range of long term conditions	0 - 10
Self-reported health rating	
Excellent	15 (5.0)
Very good	71 (23.7)
Good	89 (29.8)
Fair	82 (27.4)
Poor	34 (11.4)
Missing	8 (2.7)

7.2.4: Numbers of places of care

Just over half of the sample (51.2%) reported receiving care from providers other than their GP, with the majority reporting one other care provider.

As having more than one care provider was identified in Chapter 3 as a pre-requisite for coordination of care only this sub-set of responses was used in item analyses and model analysis described below.

7.3: Completion analysis

7.3.1: Systematic errors in completion

During data entry it was observed that some questionnaires had two consecutive pages of missing responses to all items. In these cases it appeared that two pages of the questionnaire had been turned over together, possibly as a result of the gloss finish on the paper. This affected 13 responses (4.3%).

7.3.2: Following skip instructions

There were three points in the CCQ where respondents were asked to follow skip instructions: items D1, D4 and E1.

A negative response to item D1:'needing to make changes to arrangements for care in the last six months' should have resulted in respondents skipping items D2 and D3 and answering item D4. Likewise a negative response to item D4: 'have healthcare professionals made any changes to the organisation of your care in the last six months' should have resulted in respondents leaving item D5 blank and moving on to answer item E1. A negative response to item E1: 'have things gone wrong with the organisation of care in the last six months' should have resulted in respondents leaving the remainder of section E blank and moving on to answer section F.

The most frequently noted error was in relation to respondents inappropriately checking item D3 (n=5). This possibly occurred due to this item appearing midway through the items to be skipped but at the top of the page following the skip instruction.

Two errors were noted in relation to a failure to skip item D2 and item E2. Three errors were noted in relation to a failure to skip item E3. No errors were noted in relation to a failure to skip item D5.

7.3.3: Missing responses

Missing responses were noted in relation to all items and demographic questions. Across the full sample these ranged from 1.3 to 7.7%. These were comprised of responses that were systematically missing as a possible result of turning over two pages at once, ambiguous or invalid responses and blank responses. A response was coded as invalid if more than one response option had been endorsed or not applicable had been written next to the item. These accounted for between 0.3 and 1.0% of missing responses.

Missing responses per item are reported in more detail in the next section of this chapter.

7.4: Item analyses

Item analyses focused upon assessment of missing responses, maximum endorsement frequency, redundancy (high correlation with other items) and correlation with the response to the global coordination item. Results of these analyses are detailed in Tables 7.5 and 7.6. Full details of the responses to each item and inter-item correlations are detailed in Appendices 10 and 11.

Analyses in this section were conducted upon a sub-set of the sample who reported receiving care from more than one care provider (n=153). Descriptive statistics are shown in Table 7.4.

Table 7.4: Descriptive statistics for each item

Item	N	Minimum	Maximum	Mean	SD
B1	151	1	5	4.46	.746
B2	143	1	5	4.17	1.000
B3	148	1	5	4.22	.902
B4	149	1	5	4.30	.866
B5	150	1	5	3.92	1.179
B6	145	1	5	4.36	.918
B7	151	1	5	4.28	.905
B8	150	1	5	4.40	.912
B9	151	1	5	4.45	.862
B10	151	1	5	3.58	1.092
B11	151	1	5	3.77	1.042
B12	151	1	5	4.37	.899
B13	150	2	5	4.47	.816
B14	151	2	5	4.48	.831
D2	149	1	5	4.75	.657
D3	151	1	5	4.77	.658
D5	142	1	5	4.70	.742
E2	148	1	5	4.75	.830
E3	148	1	5	4.75	.807
F1	147	2	5	4.39	.849
F2	147	2	5	4.44	.828
F3	147	2	5	4.80	.523
F4	147	1	5	4.78	.555
G1	150	1	5	4.35	.777

7.4.1: Missing responses

Missing responses (excluding systematic missing responses) ranged from 0 to 6.5%. Items with a missing response rate of >5% were:

Item B2: frequency with which healthcare professionals failed to understand your health problems.

Item B6: frequency with which your healthcare professionals failed to deliver the care they said they would.

Item D5: satisfaction with changes to the organisation of care made by healthcare professionals.

7.4.2: Maximum endorsement frequency

Two items had a maximum endorsement frequency of >80%:

Item F3: frequency with which one of your healthcare professionals was critical of the care given to you by another professional.

Item F4: frequency with which your healthcare professionals appeared to disagree with each other about the best care for you.

Table 7.5: Item analyses: missing responses, maximum endorsement frequency and correlation with global item

Item	Percentage missing responses	Maximum endorsement frequency >80%	Correlation with global coordination rating
B1	1.3	No	0.492
B2	**6.5**	No	0.322
B3	3.3	No	0.299
B4	2.6	No	0.404
B5	2.0	No	0.329
B6	**5.2**	No	0.439
B7	1.3	No	0.459
B8	2.0	No	0.412
B9	1.3	No	0.427
B10	1.3	No	0.463
B11	1.3	No	0.413
B12	1.3	No	0.2
B13	2.0	No	0.471
B14	1.3	No	0.546
D2	1.3	No	0.293
D3	0	No	0.191
D5	**5.9**	No	0.285
E2	2.0	No	0.266
E3	2.0	No	0.252
F1	3.3	No	0.45
F2	3.3	No	0.47
F3	3.3	**Yes**	0.282
F4	3.3	**Yes**	0.325
G1	1.3	No	1

7.4.3: Redundancy

Examination of inter-item correlations identified four items which correlated with at least one other item at >0.75. These are detailed in Table 7.5.

The variance inflation factor (VIF) of all items, with the exception of items D2, D3, D5, E2 and E3, was less than 5. The remaining items all had a VIF of greater than 10, potentially indicative of some redundancy.

Table 7.6: Potentially redundant items

Item	Number of correlations with other items >0.75	Specific items with correlations >0.75
B8	1	B9
B9	1	B8
E2	1	E3
E3	1	E2

7.4.4: Correlation with coordination rating

Individual item correlation with the global evaluation item ranged from 0.2 to 0.546. All but two correlations were significant at the 0.01 level (two tailed test), with the remaining two being significant at the 0.05 level (two tailed test).

7.4.5: Items deleted as a result of item analyses

Nine items were considered for elimination as a result of these analyses. These are detailed in Table 7.7 together with the rationale for deletion or retention.

As noted previously, item elimination was approached with caution. Item wording was therefore reviewed and consideration given as to whether its removal would adversely affect coverage of the concept as described in Chapter 5, prior to a final decision being made as to whether the item should be deleted. As a result of this reflection, item F4: 'frequency of disagreement between healthcare professionals' was retained as it was felt to be reflective of a key aspect of coordination even if its occurrence was infrequent.

Five of the nine items considered for elimination were deleted at this stage. This resulted in 18 items being considered in model analysis.

Table 7.7: Items considered for deletion

Item	Rationale for deletion	Decision	Rationale for decision
B2	Missing responses 6.5%	Delete	Missing response rate >5%. Other conceptually similar items retained.
B6	Missing responses 5.2%	Delete	Missing response rate >5%. Other conceptually similar items retained.
B8	Correlation of >.75 with item B9.	Delete	Item B9 had fewer missing responses (1.3% v 2%) and a higher global item correlation (.427 v .412).
B9	Correlation of >.75 with item B8.	Retain	Item B9 had fewer missing responses (1.3% v 2%) and a higher global item correlation (.427 v .412).
D5	Missing responses 5.9%	Retain	Only item relating to healthcare provider initiated changes.
E2	Correlation of >.75 with item E3.	Retain	Item E2 had a higher correlation with the global item (.266 v .252).
E3	Correlation of >.75 with item E2.	Delete	Item E2 had a higher correlation with the global item (.266 v .252).
F3	Maximum endorsement frequency >80%.	Delete	Conceptually may be more reflective of unprofessional behaviour than coordination .
F4	Maximum endorsement frequency >80%.	Retain	Considered conceptually important, if rare.

7.5: Model analysis

Analyses in this section were conducted upon a sub-set of the sample who reported receiving care from more than one care provider and for whom there was a complete dataset (n=126).

7.5.1: Causal model analysis using structural equation modelling (SEM)

I first tested the *a priori* two-level causal model that hypothesised three sub-areas of coordination: care planning, care delivery and observations of healthcare professionals' behaviour which then combined into a single overall measure. Items were assigned to these sub-areas as detailed in Table 7.8. The path diagram for this model was given in Figure 6.2.

This model hypothesises that:

- Responses to the CCQ generate three first order factors (labelled care planning, care delivery and professional behaviours) which in turn generate one second order factor (coordination)
- Each item has a nonzero loading on the first order factor it is supposed to contribute to and zero loadings on the other first order factors
- Items are assumed to correlate freely
- Measurement error is captured at the first and second level factor level.

I likewise tested the alternative one-level causal model in which all 18 items contributed directly to a single latent measure of coordination.

Neither the two-level nor the alternative one-level causal model could be statistically identified in AMOS. Problems in achieving identification are a common problem in structural equation modelling of causal models (Diamantopoulos et al., 2008). A modification that can sometimes rectify this is to standardise the causally measured construct by fixing its variance to unity (Diamantopoulos et al., 2008). I implemented this in both the one- and two-level model specification but it did not resolve the problem. It was therefore not possible to obtain goodness of fit statistics for these models. This does not imply that the a-priori assumption of a causal model between items and latent variables is invalid in itself, but only that the properties of the dataset were such that AMOS was not able to successfully estimate such a model. Time constraints for completing the work also meant that I was not in a position to learn how to use, and then experiment with, other SEM software packages to determine if they could estimate the model. In view of this, and following advice from my supervisory team, I elected to proceed to exploratory factor analysis as described in Chapter 6 section 6.5.2.2. The implications of the implied change of direction, from a causal to an effect model of relationships, will be addressed in the discussion chapter.

Table 7.8: Item allocation for causal model

Sub-scale	Item detail
Planning of care	B1: frequency with which healthcare professionals explained how they planned to address your health problems.
	B3: frequency with which your preferences were taken into account when making decisions about your healthcare.
	B4: frequency with which your healthcare providers took notice of your views about how to manage your health problems.
	B5: frequency with which you were unsure about what each of your healthcare providers were there to do for you.
	B7: frequency with which you left an appointment unsure what was going to happen next in your care.
Delivery of care	B9: frequency with which you got the care that you healthcare professionals said that you would.
	B10: frequency with which you had to wait longer than expected before obtaining a service.
	B11: frequency with which you saw a different healthcare professional to the one you were expecting.
	B12: frequency with which your healthcare professionals were missing information necessary to make decisions about your treatment.
	B13: frequency with which you felt like complaining about the way your care was organised.
	B14: frequency with which you have had problems with the coordination of your care.
	D2: ease of making changes to the arrangements for your care.
	D3: frequency with which unsure who to contact to make changes to the arrangements for your care.
	D5: satisfaction with healthcare professional initiated changes to the organisation of your care.
	E2: frequency with which given an explanation of errors in the organisation of care.
Observations of provider interactions	F1: frequency with which one of your healthcare providers seemed unaware of what others were doing for you.
	F2: frequency with which one healthcare professional said one thing about your care and another said something quite different.
	F4: frequency with which your healthcare providers appeared to disagree with each other about the best care for you.

7.5.2: Exploratory factor analysis

Exploratory factor analysis was conducted using principal axis factoring with oblique rotation. This suggested five factors with Eigenvalues >1, which explained a total variance of 65.8%. One item loaded onto two potential factors and a further three items did not load onto any factor >0.4. Factor loadings and the factor correlation matrix for this solution are shown in Tables 7.9 and 7.10. Factor loadings >0.4 are highlighted in bold.

Table 7.9: Factor loadings for five factor solution

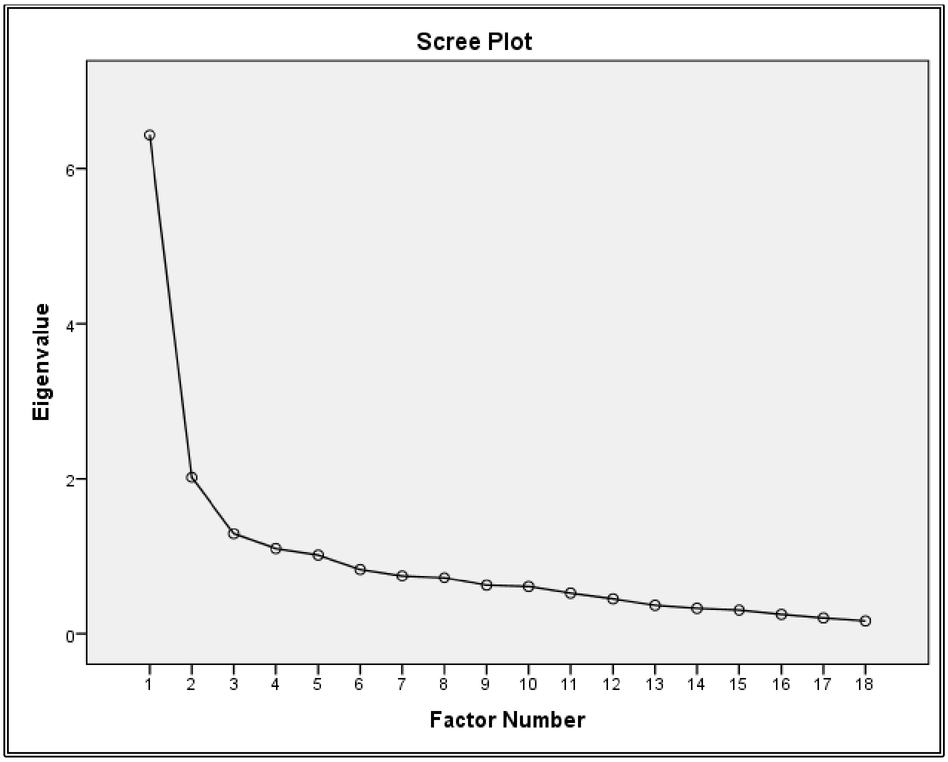
Item	Factor 1	Factor 2	Factor 3	Factor 4	Factor 5
B12: HCPs missing necessary information	**.446**	-.056	.015	-.055	-.199
B14: problems with the coordination of care	**.744**	.105	-.076	-.376	-.095
F1: one HCP unaware of what others are doing	**.784**	.116	-.058	.056	-.067
F2: HCP gave conflicting advice	**.643**	.105	-.081	.170	-.032
D2: ease of making changes to arrangements for care	.218	**.811**	-.041	-.020	.165
D3: unsure about who to contact to make changes to care	-.213	**.578**	.003	-.004	-.117
B1: HCP explained how intended to address problems	.134	.040	**-.499**	.065	-.219
B3: preferences taken into account when making decisions	-.042	-.013	**-.812**	.023	.025
B4: HCP took notice of views about how to manage health problems	.018	-.059	**-.929**	.008	.047
B5: unsure about what HCPs there to do	.228	.245	-.051	**.494**	**-.482**
B13: felt like complaining about the way care was organised	.352	.017	-.225	**-.433**	-.253
E2: how often given an explanation as to what went wrong with organisation of care	.023	.239	.078	**-.456**	-.162
B7: unsure of what was going to happen next in care	.168	-.059	-.110	.049	**-.690**
B10: waiting longer than expected for a service	-.089	.070	-.188	-.153	**-.590**
B11: saw a different HCP to the one you were expecting	.084	-.053	.010	-.039	**-.594**
B9: received care HCPs said you would	.112	.170	-.376	-.031	-.099
D5: satisfaction with HCP changes to organisation of care	-.096	.365	-.207	-.279	-.088
F4: HCPs appeared to disagree with each other	.379	-.114	-.061	.019	.009

Table 7.10: Factor correlations for five factor solution

Factor	1	2	3	4	5
1	1.000	.048	-.466	.042	-.489
2	.048	1.000	-.260	-.245	-.312
3	-.466	-.260	1.000	.110	.476
4	.042	-.245	.110	1.000	.176
5	-.489	-.312	.476	.176	1.000

However, the scree plot provided no clear disjunction in trend after five factors (see Figure 7.1). Factors 1, 3 and 5 were also correlated at -.466, -.489 and .476 indicating that a smaller number of factors may represent a better solution)

Figure 7.1: scree plot for initial principal axis factoring with oblique rotation



To allow for uncertainty around the use of an Eigenvalue >1 as the criteria for the number of factors, additional analyses were performed with fixed factor solutions of four and six. Again these were performed using principal axis factoring with oblique rotation.

The fixed four-factor solution explained 60.2% of variance with two items that cross loaded between factors and three items which failed to load to any factor >0.4. Each factor had a minimum of three items. A moderate correlation was observed between factors 1 and 3 (.556). Factor loadings and the factor correlation matrix are reproduced in Tables 7.11 and 7.12.

Table 7.11: Factor loadings fixed four factor solution

Item	Factor 1	Factor 2	Factor 3	Factor 4
B5: unsure about what HCPs there to do	**.603**	.334	-.041	**.463**
B7: unsure of what was going to happen next in care	**.622**	.126	-.133	-.007
B11: saw a different HCP to the one you were expecting	**.474**	.128	-.014	-.074
B12: HCPs missing necessary information	**.579**	-.077	.025	-.072
B13: felt like complaining about the way care was organised	**.489**	.041	-.227	**-.458**
B14: problems with the coordination of care	**.749**	.019	-.075	-.347
F1: one HCP unaware of what others are doing	**.802**	-.014	-.049	.053
F2: HCP giving conflicting advice	**.655**	-.023	-.070	.160
D2: ease of making changes to arrangements for care	.106	**.578**	-.050	-.023
D3: unsure about who to contact to make changes to care	**-.131**	.689	.012	.024
D5: satisfaction with HCP changes to organisation of care	-.062	**.424**	-.215	-.271
B1: HCP explained how intended to address problems	.284	.080	**-.501**	.054
B3: preferences taken into account when making decisions	-.075	-.025	**-.837**	.025
B4: HCP took notice of views about how to manage health problems	-.031	-.076	**-.935**	.017
E2: how often given an explanation as to what went wrong with organisation of care	.099	.311	.076	**-.458**
B9: received care HCPs said you would	.171	.186	-.374	-.025
B10: waiting longer than expected for a service	.306	.274	-.203	-.176
F4: HCPs appeared to disagree with each other	.370	-.193	-.051	.016

Table 7.12: Factor correlations for fixed four factor solution

Factor	1	2	3	4
1	1.000	.178	-.556	-.087
2	.178	1.000	-.278	-.253
3	-.556	-.278	1.000	.135
4	-.087	-.253	.135	1.000

The six-factor solution explained 70.5% of variance, eliminated cross loading of items between factors but resulted in a limited number of items loading onto some factors (less than three). No items loaded onto factor six >0.4. Correlations of .485 were observed between factors 1 and 3, .465 between factors 1 and 5 and .425 between factors 3 and 5. See Appendix 12 for details of factor loadings and the factor correlation matrix. This possible solution was not progressed further.

From comparison of the three sets of results the five-factor solution was selected as providing the best combination of statistical performance and interpretability of the factors and subjected to further evaluation in an SEM measurement model.

7.5.3: Model refinement using SEM

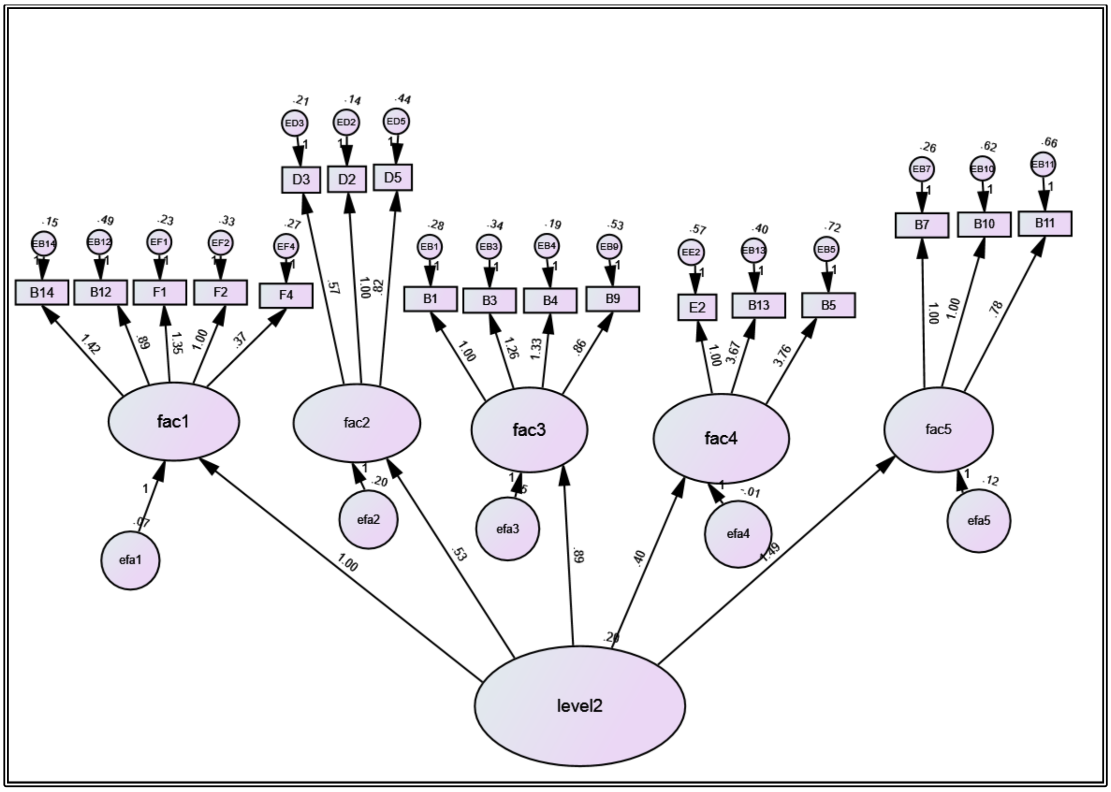
The five factor solution was explored. Items were allocated to factors on the basis of their highest loading (see Table 7.9). Where items had failed to load onto any factors >.4 (items B9, D5 and F4) they were allocated to the factor with which they had demonstrated the highest loading. In all cases this loading exceeded .3. This model was specified to include a second level factor of ‘overall coordination’ which was assumed to underlie all of the five individual first-level factors. This assumption was made as all five factors demonstrated some degree of inter-correlation during EFA (see Table 7.10).

This model is illustrated in Figure 7.2. This model of coordination of care hypothesises *a priori* that:

- Responses to the CCQ can be explained by five first order factors (labelled fac1, fac2, fac3, fac4 and fac5) and one second order factor (coordination)
- Each item has a non-zero loading on the first order factor it is supposed to measure and zero loadings on the other first order factors
- Error terms for each item are uncorrelated
- Covariance between the five first order factors is explained by their regression onto the second order factor.

This model demonstrated good fit indices (RMSEA = 0.076, CFI = 0.90) but estimated path coefficients between some factors and items were >1.0. This was resolved by moving item B5 from factor four to factor five. During EFA this item had a factor loading of .494 with factor four and -.482 with factor five making this move reasonable. This had little impact upon fit indices (RMSEA = 0.078, CFI = 0.89). However, this resulted in factor four only including two items: E2 and B13. This fourth factor also had a non-significant loading onto the second-order factor (regression weight =.464. p=.006). Inspection of the solution modification indices, item multiple correlations and factor loading indicated that item E2 did not fit well with the rest of the model. Deleting this item and loading item B13 onto factor one (its second highest factor loading) resulted in a new four factor model with improved goodness of fit (RMSEA = 0.074, CFI = 0.91).

Figure 7.2: Path diagram of five factor two level measurement model with path coefficients



Key:

⬭ Latent variable. The first level latent variables are labelled fac1, fac2, fac3, fac4 and fac5. The second level latent variable is labelled 'level2'. Error terms for all measured variables are also indicated by ellipses and are labelled as E(item number)

▭ Measured variable. These are labelled with the relevant item number.

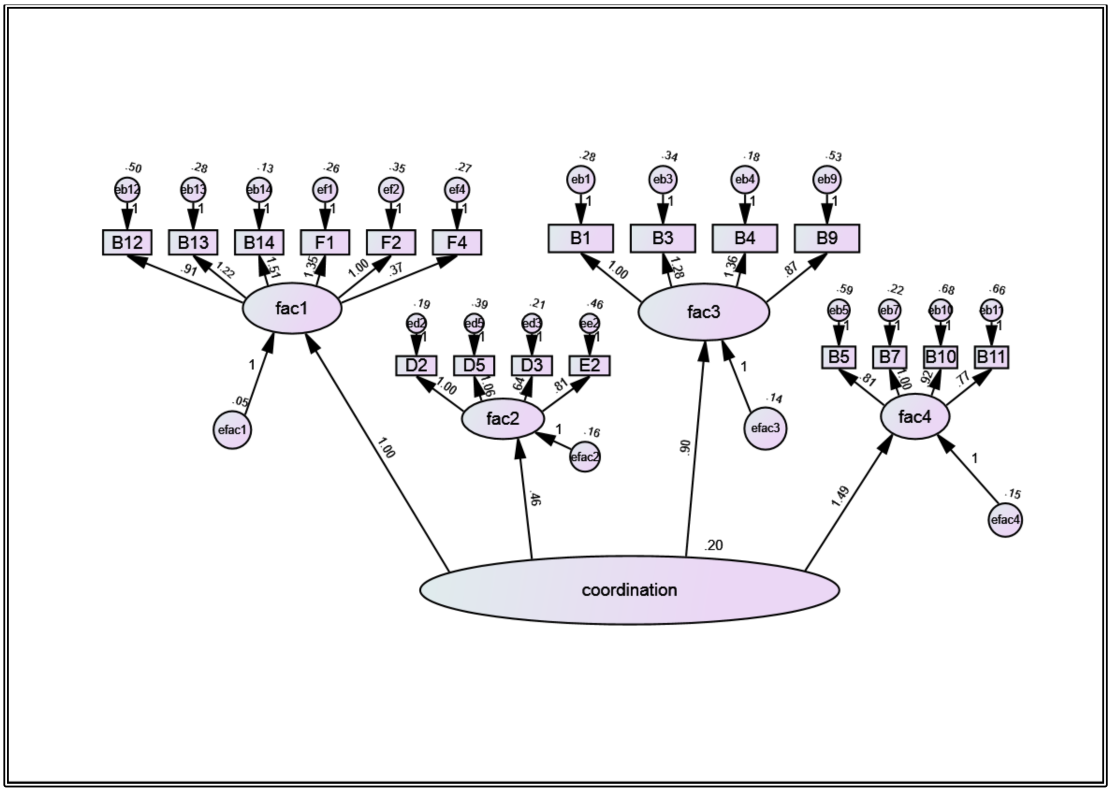
→ Direction of impact of one variable on another

↔ Correlated variables

However, item E2 was felt to be important conceptually as it related to provider responses to errors in the organisation of care. Conceptually this item was felt to be closest to factor two (items D2, D3 and D5). Therefore a further four-factor two-level model was developed with this item loading onto factor two. This modification resulted in a reasonable model fit (RMSEA = 0.076, CFI = 0.893) and is illustrated in Figure 7.3. All factor loadings between items and their nominated factors and first and second level factors were significant. Standardised regression weights are given in Table 7.13.

Regression weights, squared multiple correlations, error covariance and full model fit statistics are reproduced in Appendix 13. This solution was adopted as the final model and used to derive factor weights for computing an overall coordination score for a patient from their responses to each individual item.

Figure 7.3: Path diagram for final two level four factor measurement model with path coefficients



Key:

⬭ Latent variable. The first level latent variables are labelled fac1, fac2, fac3 and fac4. The second level latent variable is labelled ‘coordination’. Error terms for all measured variables are also indicated by ellipses and are labelled as E(item number)

▭ Measured variable. These are labelled with the relevant item number.

→ Direction of impact of one variable on another

↔ Correlated variables

Table 7.13: Standardised regression weights for final two level four factor measurement model

			Estimate
fac1	<---	coordination	.900
fac2	<---	coordination	.465
fac3	<---	coordination	.739
fac4	<---	coordination	.863
B12	<---	fac1	.539
B13	<---	fac1	.754
B14	<---	fac1	.903
F1	<---	fac1	.797
F2	<---	fac1	.643
F4	<---	fac1	.338
D2	<---	fac2	.714
D5	<---	fac2	.603
D3	<---	fac2	.527
E2	<---	fac2	.473
B1	<---	fac3	.715
B3	<---	fac3	.767
B4	<---	fac3	.868
B9	<---	fac3	.543
B5	<---	fac4	.629
B7	<---	fac4	.852
B10	<---	fac4	.651
B11	<---	fac4	.591

7.6: Final instrument structure

The final structure of the CCQ is a two-level model comprising of four factors, detailed in Figure 7.3. These factors broadly reflect some structural elements of the questionnaire, such as negatively worded items. Given this, and the lack of a strong theoretical basis from which to interpret the meaning of these groupings these factors have not been given descriptive labels but are referred to as factors A, B, C and D. Factor A comprises of six items, factor B four items, factor C four items and factor D four items. The items relating to each factor are shown in Table 7.14.

Given that these factors appear to represent elements of the questionnaire structure they were not pursued further as potential sub-scales.

Table 7.14: Final first level factor item groupings in the CCQ

Factor	Item detail
A	B12: frequency with which your healthcare professionals were missing information necessary to make decisions about your treatment.
	B13: frequency with which you felt like complaining about the way your care was organised.
	B14: frequency with which you have had problems with the coordination of your care.
	F1: frequency with which one of your healthcare providers seemed unaware of what others were doing for you.
	F2: frequency with which one healthcare professional said one thing about your care and another said something quite different.
	F4: frequency with which your healthcare providers appeared to disagree with each other about the best care for you.
B	D2: ease of making changes to the arrangements for your care.
	D3: frequency with which unsure who to contact to make changes to the arrangements for your care.
	D5: satisfaction with healthcare professional initiated changes to the organisation of your care.
	E2: frequency with which given an explanation of errors in the organisation of care.
C	B1: frequency with which healthcare professionals explained how they planned to address your health problems.
	B3: frequency with which your preferences were taken into account when making decisions about your healthcare.
	B4: frequency with which your healthcare providers took notice of your views about how to manage your health problems.
	B9: frequency with which you got the care that you healthcare professionals said that you would.
D	B5: frequency with which you were unsure about what each of your healthcare providers were there to do for you.
	B7: frequency with which you left an appointment unsure what was going to happen next in your care.
	B10: frequency with which you had to wait longer than expected before obtaining a service.
	B11: frequency with which you saw a different healthcare professional to the one you were expecting.

7.7: Scoring of the CCQ

Respondent scores were calculated using both methods described in Chapter 6, namely a simple summation of responses and a summation of responses weighted by the factor weights obtained through structural equation modelling. Mean differences between these methods were small for both the individual factors and the overall score, however examination of histograms identified a wide range of difference of up to 20 points. Examination of Bland Altman plots did not suggest any consistent relationship between these differences (see Appendix 14). Therefore, at this time I would recommend calculating an overall coordination score in which each item is weighted by its standardised second level factor weight. Details of the raw and standardised factor weights are given in Table 7.15.

Table 7.15: Raw and standardised second level factor weights used in scoring

Item	Raw factor weight	Standardised factor weight
B1	0.027	0.038
B3	0.029	0.041
B4	0.059	0.084
B5	0.030	0.042
B7	0.097	0.137
B9	0.013	0.018
B10	0.029	0.041
B11	0.026	0.037
B12	0.022	0.031
B13	0.053	0.075
B14	0.141	0.199
D2	0.028	0.040
D3	0.016	0.0323
D5	0.014	0.020
E2	0.009	0.013
F1	0.063	0.089
F2	0.034	0.048
F4	0.017	0.024

An overall score could be calculated for 230 respondents. The mean score in this sample was 87.37 (sd 13.70; minimum 32.78, maximum 100).

7.8: Tests of reliability

7.8.1: Temporal stability

Ninety-four respondents completed both an initial and retest questionnaire. Of these, 19 respondents (20.4%) reported a change in their health since completion of the original questionnaire and 15 respondents (16.1%) reported changes in their healthcare.

The ICC for the full sample of 94 respondents was .629 for patient-level scores (95% confidence interval .489 - .737) and .772 for scores across the patient sample (95% confidence interval .657 - .849).

Excluding those respondents who reported a change to either their health or healthcare (n=24) produced an ICC of .626 for single scores (95% confidence interval .460 - .750) and .770 for average scores (95% confidence interval .630 - .857). An ICC of ≥ is desirable to demonstrate stability (Terwee et al., 2007). Therefore the results above suggest that the CCQ has good reliability at the patient-group level in this sample, but not at the individual patient level.

7.9: Tests of validity

7.9.1: Correlation with the single evaluation item

The correlation between the overall coordination score and the single evaluation item was .611 ($p<.000$, n=279) and was significant at the 0.01 level (one tailed test).

7.9.2: Correlation with the satisfaction items

A score was calculated from the five ‘satisfaction with coordination’ items in section C of the questionnaire. Item performance was evaluated through assessment of missing responses, maximum endorsement frequency and the identification of potential redundancy. Missing items and maximum endorsement frequencies were acceptable and are detailed in Table 7.16, but all five items inter-correlated with at least one other item >0.75. As a result of this the two items with the greatest number of inter-correlations were deleted as detailed in Table 7.17. A satisfaction score was then created using the responses to the remaining items.

The correlation between the overall coordination score and the satisfaction score was .635 ($p<.000$, $n=279$) and was significant at the 0.01 level (two tailed test).

Table 7.16: Item analyses Section C: missing responses, maximum endorsement frequency and correlation with global item

Item	Percentage missing responses	Maximum endorsement frequency >80%	Correlation with global coordination rating
C1	2.0	No	0.482
C2	0	No	0.31
C3	2.0	No	0.489
C4	2.0	No	0.386
C5	2.0	No	0.565

Table 7.17: Items considered for deletion Section C

Item	Rationale for deletion	Decision	Rationale for decision
C1	Inter-correlates with other items in this section >.75.	Delete	Inter-correlates with three other items in this section >.75.
C2	Inter-correlates with other items in this section >.75.	Retain	Inter-correlation with only two other items in this section.
C3	Inter-correlates with other items in this section >.75.	Delete	Inter-correlates >.75 with all other items in this section
C4	Inter-correlates with other items in this section >.75.	Retain	Only two inter-correlations >.75 with items in this section, one of which is to be deleted.
C5	Inter-correlates with other items in this section >.75.	Retain	Correlation with item C2 <.75. Correlation with global item r=.565, the highest for this set of items.

7.9.3: Correlation with the CPCQ

All respondents completed the CPCQ. Missing responses were noted in relation to all items. Across the full sample these ranged from 2.6 to 14.4% (excluding missing responses as a result of turning over two pages at once). The highest missing response rate of 14.4% was observed in relation to an item enquiring about difficulties with transport which had previously been noted as ambiguously worded. Other items with missing response rates greater than 10% were items asking about carer involvement with decision making (10.3%), carer satisfaction with care (11.7%) and frequency with which GP seemed to be communicating with other providers (11%). Missing responses for the remaining items ranged from 2.6 to 8.7%. Missing responses by item are reproduced in Appendix 15.

Scores on the CPCQ were calculated for 187 respondents as described in Chapter 6 section 6.5.4. CPCQ scores and CCQ scores were available for 176 respondents. The resulting correlation between these scores was .677 (p<.000) which was significant at the 0.01 level (two tailed test) suggesting that they are measuring similar constructs.

7.9.4: Construct validity

Two *a priori* hypotheses were tested. Firstly, that coordination scores would decrease with an increase in the number of providers and secondly, that coordination scores would decrease with an increase in the number of long-term conditions reported.

7.9.4.1: Relationship between coordination scores and numbers of providers

The *a priori* hypothesis was upheld.

Respondents with a single care provider reported higher coordination scores than those with two providers (U = 5174.00, z = -4.202) and this difference was significant (p<.000). An effect size was calculated as r = .268 suggesting a small to medium effect of an increase from one to two providers on overall coordination.

Likewise, respondents with a single care provider reported higher coordination scores than those with three or more providers (U = 1093.50, z = -2.731, p=0.006). An effect size was calculated as r = .223 again indicating a small to medium effect of an increase from one to three or more providers on overall coordination.

7.9.4.2: Relationship between coordination score and numbers of long term conditions

Again, the *a priori* hypothesis was upheld with the correlation between these variables calculated as -.212 (p<.000) which was significant at the 0.01 level (one tailed test).

7.10: Summary

The CCQ is a measure of coordination comprising of 18 items that group into four first-level factors. These four factors further combine into a single second-level overall measure of coordination. The four separate factors were not pursued as discrete sub-scales. An overall score for the CCQ was calculated by summing the result obtained by multiplying each item response by its standardised second-level factor weight. These scores were then used in subsequent evaluations of reliability and validity.

In this sample the CCQ has demonstrated good test-retest reliability at the patient-group level, but not at the level of individual patients. It has also shown reasonable concurrent and construct validity. Correlations between CCQ scores and both the global evaluation item and the satisfaction items were positive and significant. Likewise it performed well in comparison to the CPCQ, an existing measure of coordination. The two *a priori* hypotheses were upheld, although the effect size of an increase in providers was small.

7.11: Recommendations for modification/ development of the CCQ

7.11.1: Minor modifications

A number of minor modifications are suggested for the presentation and layout of the CCQ as a result of these analyses. Firstly, I would caution against the use of gloss finish paper as it appears to have resulted in a systematic loss of information.

Secondly, consideration needs to be given to the position of the skip items on the page of the questionnaire. Whilst these were generally followed correctly and I would not recommend their removal at this stage the location of one item to be skipped at the top of a page may have resulted in some confusion.

Thirdly, consideration could be given to redrafting Section A so that instead of asking respondents to mark the providers seen they are asked to select individual healthcare professionals. Limiting the response options in this section may have led to an underestimate of the need for coordination as it does not allow intra-provider coordination needs to be identified.

Fourthly, the response numbering included on the questionnaire could be changed to a scale of 0-4, with 0 indicating the poorest response. This would allow responses and scores to be standardised without requiring recoding of the original entry, thus reducing the potential for error.

Finally, the items in the CCQ were presented in a logical order which followed the patient pathway. This may have had an impact upon the way people responded. Future work could evaluate the impact of presenting items in a more random order. Future work should also explore the potential for a simplification of the scoring process.

7.11.2: Potential areas for further development

Further development work to address the two key limitations of this study is recommended before the CCQ is put to widespread use. These potential limitations arise from firstly, issues with the study sample and secondly, possible issues with the selected response options.

7.11.2.1: Issues with the study sample

There are three potential issues arising from the study sample which require further exploration. Firstly, the response rate to the questionnaire of 30.5% was lower than had been estimated during sample size calculation. This did not impact upon the analysis of the correlation of responses between the CCQ and CPCQ as the actual correlation was stronger than that used to calculate the required sample size. However, it does raise the question of non-response bias (Edwards et al., 2002), which has not been assessed in this study.

Secondly, the total sample size is relatively small. Model analysis was performed on the sub-set of respondents who reported receiving care from two or more providers (n=126). Whilst this was an adequate number for exploratory factor analysis using the criteria proposed by Terwee et al. (2007), there are different views as to the minimum sample required (Field, 2009). Additionally, much larger samples have been recommended for performing structural equation modelling, where a typical sample size is about 200 cases, although the adequacy of this is dependent upon the complexity of the model (Kline, 2011). An adequate sample size is necessary to enhance the reliability of the results. The implication of the small sample size used to model the CCQ is that the second-level factor weights used to combine the items may not be reproducible and therefore require further exploration.

Thirdly, the respondents in this sample were predominantly older in age and described their ethnic group as white. As explored in Chapter 3, the antecedents of coordination are multiple, interdependent healthcare providers, the need for which is determined by patient morbidity and healthcare organisation not demographic characteristics. Respondents to this study did not adequately reflect the age and ethnicity characteristics of the wider population in which it could reasonably be expected to be used. Its performance characteristics in these groups is unknown. This is important as different age groups are known to rate their satisfaction with health services differently, with older patients generally being more positive in their responses even when experiences are similar (Campbell et al., 2001). The majority of the sample is also either retired, unable to work or otherwise unemployed (due in the main to the older average age). The self-reported experiences of coordination in this group may differ from that of younger or employed patients as, for example, they may have more time available to accommodate changes in their healthcare delivery and contribute to the coordination of their care.

Differences in responses are also seen in patients from different ethnic groups. Patients from non-white ethnic groups tend to record lower levels of satisfaction even when their experience has been similar to that of white patients (Lyratzopoulos et al., 2012). The reasons for this are unclear, and may be due to differences in expectations, differences in services or differences in the interpretation of the questionnaire items (Mead and Roland, 2009).

7.11.2.2: Issues with the response options

There are some potential limitations arising from the selected response options. Mean coordination scores in this sample were skewed towards the more positive end of the scale. This is a common feature of instruments which seek to measure aspects of healthcare, especially those related to the measurement of satisfaction (Collins and O'Cathain, 2003), but it results in a potential limitation on the discriminative ability of the instrument. If response options are never, or rarely, endorsed then this effectively reduces the number of response options and the information gained (Streiner and Norman, 2009). This raises the question of whether a different set of response options would improve the performance of the CCQ in differentiating between people with generally positive experiences.

One approach could be to expand the number of response options. It has been suggested that the optimal number of response options is between five and nine (Streiner and Norman, 2009). As piloted, the CCQ used a five point balanced response scale so there is scope for this to be expanded without introducing a disproportionate effect upon respondent burden. Alternatively, a packed response scale could be developed in which the 'average' is not the mid-point and there are a greater number of positive than negative response options (Streiner and Norman, 2009). Previous research suggests that a five point packed scale resulted in better discrimination than a five point balanced scale (in which the mid-point is the 'average'), although it was outperformed by a balanced scale with a greater number of response points (Hancock and Klockars, 1991). One challenge to expanding the number of response options would be the development of adjectival labels for each point which are meaningful to respondents. Future work could explore whether changing the response options improves the discriminative properties of the CCQ.

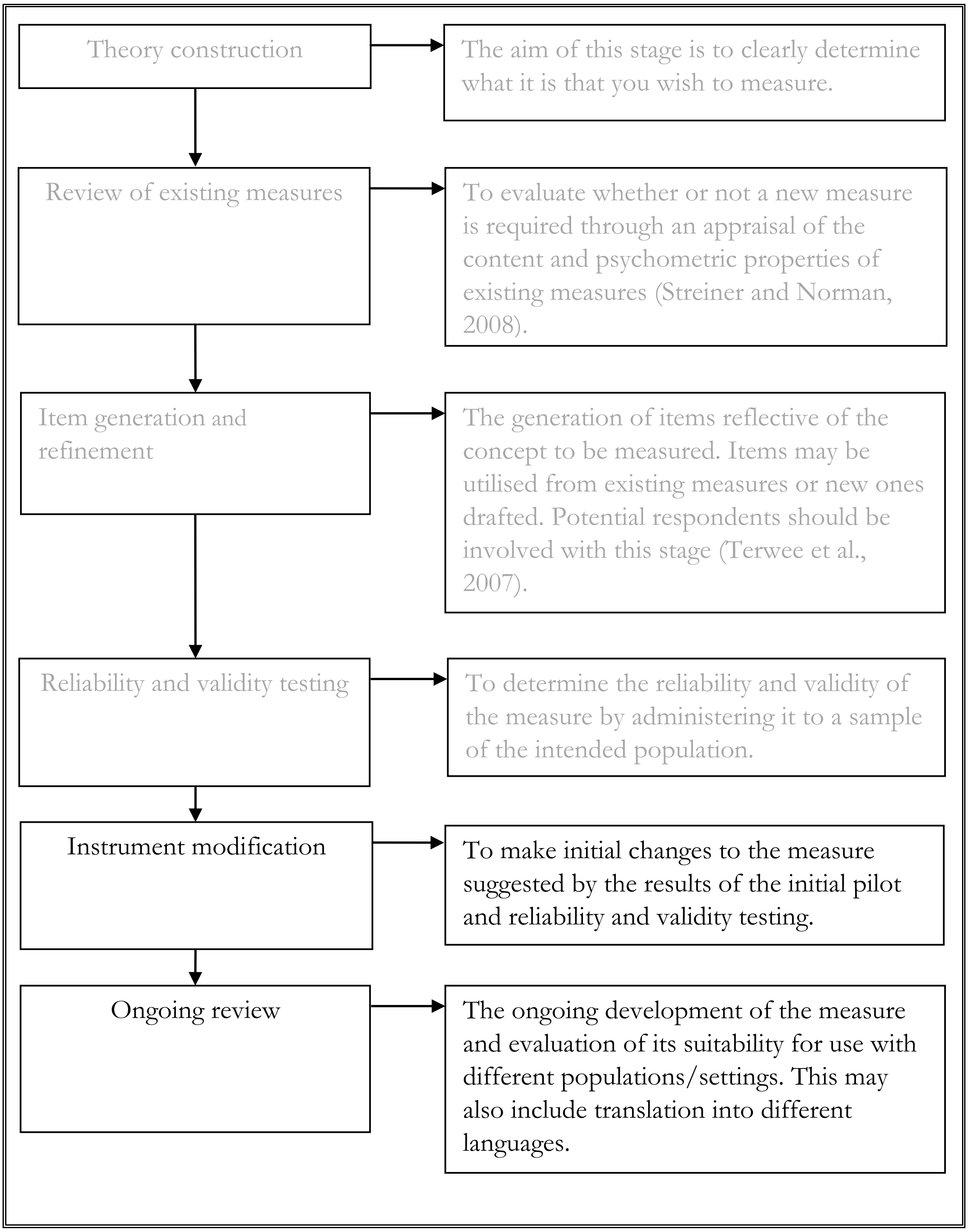
Chapter 8: Discussion

8.1: Introduction

Coordination of care is widely held to be a critical issue for many health systems (Bodenheimer, 2008). It is thought that poor coordination impacts negatively on patient experience of care (Allen et al., 2004), whilst well-coordinated care has the potential to reduce adverse events, improve patient outcomes and result in greater health system efficiencies (McDonald et al., 2007). However, coordination is frequently a poorly articulated concept in the context of healthcare. This results in a conceptual muddling with related phenomena such as patient centred care, integration and continuity. This presents challenges for both the development and evaluation of approaches to improve coordination. How can we seek to improve what we cannot describe? Similarly, how can we evaluate the impact of any change?

The overarching aim of this thesis was to contribute to improved understanding of the definition and measurement of coordination of healthcare with a focus on the patient perspective. This chapter begins by revisiting the stated aims and objectives, reflecting upon the extent to which these were met and summarising the key findings. It addresses the final stage of instrument development: modification and ongoing review (see Figure 8.1). This is followed by a critical reflection of the key limitations of each part of the research. The chapter concludes with proposals for future work and consideration of the implications for policy and practice.

Figure 8.1: Stages in Measure Development



Theory construction

The aim of this stage is to clearly determine what it is that you wish to measure.

Review of existing measures

To evaluate whether or not a new measure is required through an appraisal of the content and psychometric properties of existing measures (Streiner and Norman, 2008).

Item generation and refinement

The generation of items reflective of the concept to be measured. Items may be utilised from existing measures or new ones drafted. Potential respondents should be involved with this stage (Terwee et al., 2007).

Reliability and validity testing

To determine the reliability and validity of the measure by administering it to a sample of the intended population.

Instrument modification

To make initial changes to the measure suggested by the results of the initial pilot and reliability and validity testing.

Ongoing review

The ongoing development of the measure and evaluation of its suitability for use with different populations/settings. This may also include translation into different languages.

8.2: Objectives and main findings

Four discrete objectives were identified in order to support the development of a patient reported measure of coordination of care. These were (1) the development of a conceptual definition of coordination, (2) an appraisal of existing measures, (3) the refinement or development of a revised measure and finally (4) the piloting and initial assessment of the psychometric characteristics of the measure.

8.2.1: Summary of results of the concept analysis

The purpose of the concept analysis was to develop a definition of coordination of care and an understanding of its antecedents, attributes and consequences. This would then be used to guide measure development through the identification of the empirical referents from the patient perspective.

Coordination was defined as a process for the organisation of patient care activities which involve multiple professionals or provider organisations. Its aim is to manage the interdependencies inherent in situations involving multiple participants. These interdependencies are antecedent to the need for coordination. Four characteristics of coordination were identified:

- It being a purposeful activity;
- It requiring communication and information exchange between participants;
- These participants have an awareness of their roles and the roles of others and are able to access the necessary resources to deliver care; and finally
- Participants are able to respond to changes arising in relation to both the patient's health and the care environment.

Consequences of coordination were anticipated to include improvements in patient outcomes, increased patient satisfaction with care, reductions in waste and healthcare costs, although the evidence to support this is mixed. In part this is due to the lack of tools available to measure coordination.

This definition supported the identification of the boundaries of the concept and helped to delineate it from other concepts, specifically continuity of care, integration of care and patient centred care.

8.2.2: Summary of results from the systematic review

The primary purpose of the systematic review was to determine whether development of a new instrument was necessary. This determination was based primarily upon a content analysis of the items in existing measures of coordination which were mapped onto the attributes of coordination described above.

Five measures of coordination were identified with a further 10 measures reporting a coordination sub-scale. Analysis of the item content of these measures identified that they did not seem to fully encompass the conceptual definition. Additionally, many included items reflective of concepts other than coordination, with the associated risk of introducing measurement error (Streiner and Norman, 2009). Psychometric properties of the instruments and the quality of the reporting studies were then critically appraised (see Tables 4.6-4.9). These were generally reasonable although were limited in relation to assessments of temporal stability.

The Client Perceptions of Coordination Questionnaire (CPCQ) (McGuiness and Sibthorpe, 2003) was the closest to what was desired in terms of an instrument that could be used in primary care, was reflective of the conceptual definition and had demonstrated promising psychometric properties on initial piloting. However, closer examination of the item content identified potential issues with the use of jargon, ambiguous phrasing and asking respondents to simultaneously judge and report on their care which can contribute to bias and measurement error. This measure was also given a negative rating for internal consistency.

Given these potential issues I decided against adopting the unmodified CPCQ and elected to proceed with the development of a new measure.

8.2.3: Summary of results from instrument development and piloting

The process of instrument development was designed to address some of the problems with item comprehension identified in existing measures. In line with current best practice, it explicitly included incorporation of patient views through focus group discussions and cognitive testing of potential items. A small number of items were deleted from the item pool or reworded as a result of this work. The resulting questionnaire consisted of 28 items, each with a five point Likert-type response scale, arranged into five sections: experiences with healthcare, making changes to care, service responses to error or failure, observations of healthcare provider behaviours and an overall evaluation item.

During piloting items generally performed well with only two being deleted due to missing responses.

The *a priori* dimensions of coordination were not upheld during model analysis, and thus an exploratory factor analysis was carried out. Exploratory factor analysis and subsequent structural equation modelling suggested that the empirical data are best explained by a two level model of coordination comprising of four first level factors. These first level factors were not pursued as sub-scales. Instead, individual scores on the CCQ were calculated using standardised second level factor weights for each item.

The resulting measure demonstrated desirable test-retest reliability at the group, but not patient, level. Concurrent validity was demonstrated through the finding of positive correlations of overall CCQ score with: the single item of overall evaluation of coordination; the group of items assessing satisfaction with aspects of coordination; and with scores on the Client Perceptions of Coordination Questionnaire. Modest construct validity and discriminative ability was demonstrated through the upholding of *a priori* hypotheses relating to diminishing CCQ scores with increases in the numbers of providers and increases in the numbers of long term conditions.

8.3: Critique of the current study

8.3.1: Critique of the concept analysis

Understanding the concept to be measured and its relationship to related concepts is a critical first step in instrument development. The selected definition will inform the development of items and any subsequent assessment of content validity. A concept analysis methodology was used here to develop a definition of coordination of care. The strengths of concept analysis methods are that they allow for a detailed immersion in the meaning and use of a given concept. Drawing upon data sources from different fields can allow for new insights to be developed. However, they have a number of limitations. The main one of these is that it is a necessarily subjective process and alternative conceptualisations may be proposed depending upon the data sources used. As discussed in Chapter 3 there are two main competing conceptualisations of coordination of care. The definition and attributes proposed here represent a refinement of that proposed by McDonald et al. (2007), achieved primarily through greater recourse to the organisational literature. As such it builds upon an internationally developed definition.

Alternative approaches to developing an understanding of the concept include a narrative review of relevant publications or the derivation of core content from existing measures of the concept. Whilst these may have been more replicable than a concept analysis they bring their own weaknesses. Specifically, these relate to the contested nature of coordination in the healthcare literature and the subsequent limited coverage of existing measures.

8.3.2: Critique of the systematic review

The search strategy undertaken to identify measures utilised three electronic databases and reviewing the reference lists of identified studies. The MEDLINE and EMBASE databases are those most commonly used to identify health related studies (Centre for Reviews and Dissemination, 2009). The Health and Psychosocial Instruments database was also searched as this provides specific information about measurement instruments, including those developed in organisational behaviour studies. Despite this there is the possibility that some instruments may have been missed. The results may have been affected by publication bias (Centre for Reviews and Dissemination, 2009) as searching did not extend to unpublished work.

Another limitation of this study was the exclusion of studies published in languages other than English.

The search terms selected to identify studies were broadly defined and focused upon coordination and synonyms such as integration or transitional care together with terms suggesting an absence of coordination i.e. fragmentation. Studies were included in the review if the abstract stated that the reported instrument was intended to measure coordination or incorporated a coordination or integration sub-scale. It is possible that the search may have missed studies where this was not explicitly stated.

The initial review of identified study titles and abstracts was undertaken by a single reviewer which may have increased the possibility of error and bias in identification of relevant studies. The effect of this can be minimised by the use of two reviewers (Centre for Reviews and Dissemination, 2009) but this was not possible here due to resource limitations.

The criteria used to evaluate the psychometric properties of the instruments and the methodological quality of the studies are also subject to debate. The COSMIN Guidelines (Mokkink et al., 2010) used to evaluate methodological quality represent an attempt to bring some consistency to the evaluation of measurement instruments. The output of an international Delphi group of measurement experts, the developers recommend that it can be used both for the evaluation of existing measures and to guide the design and development of new instruments (Mokkink et al., 2010). However, the guidelines are limited in that firstly, while standards are proposed for methodological quality these do not include standards for the reported psychometric properties. This requires that an alternative standard is used for these aspects, which are also subject to debate (Terwee et al., 2007). Secondly, the rating system for methodological quality has been developed relatively recently (Terwee et al., 2012) and as such is still in development itself. The use of the 'worst score counts' to provide the overall score for a measurement attribute may result in an overly harsh judgement in some cases.

The final limitation relates to the decision to use the attributes of coordination, derived from the concept analysis described above, to evaluate the conceptual coverage of the item content of each measure. This is necessarily a subjective process (Fitzpatrick et al., 1998) and as noted in Chapter 4, items frequently did not reflect a single attribute and some items were unable to be categorised. This may have led to conceptual coverage being underestimated.

8.3.3: Critique of measure development

A major strength of instrument development was the explicit incorporation of pre-testing of potential items through cognitive interviewing. Whilst this study was small (n=10) it allowed for known problems with item wording and some of the key assumptions underpinning the instrument, such as whether respondents could make an evaluation across all their providers, to be explored. In line with current best practice, potential respondents were also engaged in the development of items. Whilst beyond the scope of this study, both these aspects of this work could have been enhanced through the use of a larger more diverse sample of people in terms of age and ethnicity. This would help to increase confidence that the resulting instrument was suitable for use in the wider population for which it was intended.

Another limitation arises from the need to operationalise the concept and to identify the empirical referents of coordination from a patient perspective (see Chapter 3 section 3.5). The three factor structure proposed here was derived from the concept analysis and subsequently found not to be supported by the empirical data. It is possible more extensive fieldwork to test the putative empirical referents prior to their incorporation into the instrument would have provided better data to support this aspect of the work (Schwartz-Barcott and Kim, 2000). However, the resources needed to conduct such research extended beyond those available.

8.3.4: Critique of the pilot study

The strengths and limitations of the pilot study will be considered in relation to the study design, the sampling strategy, the resulting sample size and the implications of this for the interpretation of the both exploratory factor analysis and SEM. I will then consider the implications of moving from a causal measurement model to the final effect model.

8.3.4.1: Study design

The main limitation of a cross-sectional postal survey is that conclusions cannot be drawn as to the causal nature of any relationships which are observed.

The response rate of 30.5% was lower than that which had been estimated when determining sample size and lower than reported responses to national questionnaires about GP services (Campbell et al., 2009). This raises questions about the potential impact of any non-response bias. Non-response bias can be problematic if there are systematic differences between those who respond to a survey and those who do not (Campbell et al., 2009). Demographic data and information about health status and numbers of long-term conditions was only collected from those people who responded to the survey so an assessment of the impact of non-response bias was not possible.

However, the demographic characteristics reported in Chapter 7 suggest a relatively homogenous sample in terms of ethnicity, age and employment status. Given there are known differences in response between people of different ages and ethnicities (Campbell et al., 2001, Lyratzopoulos et al., 2012), the homogeneity of the study group raises the possibility that there may be an issue with non-response bias. Further work is required to understand the performance of the CCQ in a more heterogeneous sample.

8.3.4.2: Sample selection

The sampling strategy detailed in section 6.4.2 was developed in an attempt to maximise the numbers of respondents with multiple providers and complexity of care needs.

Respondents were asked to indicate the number of providers from whom they had received care in the preceding 6 months. This may have underestimated the coordination requirements of respondents as it did not capture coordination within the GP practice i.e. between the GP and practice nurses. Most long-term conditions where care is incentivised through the Quality and Outcomes Framework in the UK incorporate an element of nurse led care (McDonald et al., 2009) with concomitant intra-practice coordination requirements.

General practice may also not have been the right venue to recruit patients with rarer but potentially complex conditions due to the low prevalence at a practice level. Recruitment might have been more successful and resulted in a more diverse sample if patients had also been recruited from secondary care outpatient departments. This mixed recruitment method was used successfully by Baker et al (1999).

8.3.4.3: Sample size

Sample size was calculated by estimating the numbers of responses required to detect a correlation of 0.15 at 80% power and at the 5% significance level between the CCQ and the CPCQ. This sample size was not achieved. As the actual correlation with the CPCQ was greater than estimated this did not have an adverse effect upon this calculation. However, the sample size used to estimate model fit and perform factor analysis (n=126) was small. An adequate sample size is necessary to enhance the reliability and trustworthiness of the results. Larger samples have greater statistical power which in turn increases the probability of identifying a reasonably correct model (Kline, 2011).

The general advice is that structural equation modelling requires large samples (Kline, 2011). There is debate as to what constitutes 'large' as sample size estimates are affected by the number of parameters, the distribution of the data and the type of estimation algorithm used (Kline, 2011). Suggestions have been made for both 'rules of thumb' for calculating sample size and recommended absolute numbers (Kline, 2011). A commonly cited rule of thumb calculation for models using maximum likelihood estimates is based upon a ratio of the number of cases to the numbers of estimated parameters, with a ratio of 20:1 being suggested as ideal (Jackson, 2003). When considering absolute numbers, 200 cases can be viewed as a typical minimum (Kline, 2011).

The final two level four factor model reported here comprises of 40 estimated parameters. Using Jackson's (2003) ideal ratio the recommended sample size would be 800 cases. The achieved sample size of 126 cases represents a ratio of 3:1 which falls well below both the ideal ratio of 20:1 and the less ideal ratio of 10:1.

A similar debate exists with regard to the sample size required for exploratory factor analysis (Field, 2009). Using the criteria suggested by Terwee et al (2007) and replicated in the COSMIN Guidelines (Mokkink et al., 2010) (seven times the number of items and >100 cases) the sample size reported here was just adequate.

The main implications of this small sample size are that the trustworthiness and reliability of the results may be compromised. As such, the model proposed here can only be viewed as a tentative solution which requires replication in a larger sample. It also means that the initial three factor model cannot be rejected with confidence. Retesting the structure with a larger population and thus an improved case to parameter ratio would give greater confidence in its stability and the resulting second-level factor weights used in scoring (Field, 2009).

It could be argued that the use of SEM in this study was premature given that this was the first administration of the items (Byrne, 2010) and that exploratory factor analysis alone would have been reasonable. However, given that items were developed to reflect the three *a priori* domains of coordination it was not unreasonable to evaluate the extent to which they were reflected in the empirical data.

Alternative methods of questionnaire development include item response theory (IRT). IRT is a family of statistical techniques which have been developed to address some of the perceive weaknesses of classical test theory (Streiner and Norman, 2009). Classical test theory focuses upon the performance of a set of items in a particular sample which means that reliability and validity is established in relation to that sample. It needs to be re-estimated if the test is used in a different sample. Classical test theory also assumes that each item contributes equally to the instrument score irrespective of the strength of its correlation with the underpinning construct (Streiner and Norman, 2009). In contrast to classical test theory which focuses upon the performance of a test, IRT methods focus upon the performance of individual items. Individual items can be evaluated according to their difficulty i.e the level of the construct of interest required to 'pass' an item and their discriminative ability i.e. identifying the degree to which responses can be classified as 'pass' or 'fail' (De Vellis, 2003). Typically, this information is represented graphically in an item response curve. IRT models are particularly useful firstly, where items can be formed into hierarchies and secondly, where there are differences in the way different groups respond to items (De Vellis, 2003).

IRT methods may offer some potential advantages in the further development of coordination of care instruments in that it may be possible to generate hierarchical items. Likewise it is possible that, in common with satisfaction measures, different groups of patients may respond differently to coordination measures. IRT could assist with determining whether these groups genuinely differ in terms of their experiences or if they have the same experience but are responding to items differently. However, IRT methods are derived from classical test theory and as such assume a reflective measurement model, which was not the approach originally envisaged for the measurement of coordination in this study.

8.3.4.4: Causal versus effect measurement models

Measure development began with coordination of care being identified as a causal model rather than an effect model (see Chapter 5 section 5.3). Two causal models were developed and described in Chapter 6 section 6.5.2.2. As described in Chapter 7 section 7.5 it was not possible to derive goodness of fit indices for these models as AMOS could not statistically identify the models. In the absence of alternative *a priori* causal models exploratory factor analysis was used to explore the empirical data and to identify plausible groupings of items to enable an overall 'score' to be generated. Exploratory factor analysis and the subsequent SEM models used to test goodness of fit assume an effect measurement model.

This raises the question of whether coordination should be considered within a causal or effect model. Existing measures of coordination have all been developed within effect measurement models with little or no consideration as to whether this the optimal approach to the construct of coordination. Causal (also called formative) models have been used more widely in the management literature, although its use in published studies is still scarce (Diamantopoulos et al., 2008). In part this is due to the fact that development methods for reflective measures are more widely established (Diamantopoulos et al., 2008).

Model choice should be theoretically justifiable (Jarvis et al., 2003). The theoretical grounds for using a formative model approach was detailed in Chapter 5, section 5.3. Despite the problems encountered during causal model estimation it is likely that the theoretical rational is reasonable. Logically, it appears more reasonable that it is the indicators which determine the construct of coordination rather than the alternative which is that these indicators are a reflection of coordination as an underlying latent construct. However, there is also debate within the literature as to which measurement model is the most realistic, with some arguing that constructs are neither inherently causal nor effect making both measurement options plausible (Wilcox et al., 2008). However, model misspecification has also been shown to over-estimate the impact of the latent variable of interest on other variables in a structural model (Diamantopoulos et al., 2008). Incorrect model specification can also result in the inappropriate use of statistical methods of item selection such as internal consistency checks (Diamantopoulos et al., 2008).

Item selection in this study followed the procedures recommended for causal models with item deletion requiring justification on theoretical rather than purely statistical grounds. Failure to do this can result in items being inappropriately deleted, which in a causal model is akin to missing part of the construct (Diamantopoulos and Winklhofer, 2001). The move to EFA (which assumes an effect model) occurred after item selection and was a pragmatic rather than a theoretically driven decision in order to determine a reasonable grouping of items to generate an overall coordination score. This became necessary due to the problems encountered with the statistical specification of the causal models in AMOS. Given these practical issues it would be premature to reject the causal model at this stage, although alternative estimation models such as the approach used here are required to create a usable measure. The utility of a causal model could be addressed in future work where the measure of coordination developed here is evaluated within a wider structural model which incorporates its consequences (Diamantopoulos et al., 2008).

8.4: Findings in the context of previous literature

In many respects the measurement of coordination is in its infancy. Only five measures were identified prior to 2011 which purported to measure this concept (McGuiness and Sibthorpe, 2003, Baker et al., 1999, Parchman et al., 2005, Coleman et al., 2005, Grimmer and Moss, 2001). Two of these focused upon the quality of care transition between acute and primary care (Grimmer and Moss, 2001, Coleman et al., 2005), one upon the complete patient pathway through primary to secondary care and back again (Baker et al., 1999), one upon experiences of problems resulting from poor coordination (Parchman et al., 2005) and one in a primary care population identified as needing a care coordination intervention (McGuiness and Sibthorpe, 2003). Two further measures of coordination have been published since this review was completed: one focused upon the coordination of cancer care (Young et al., 2011) and one upon perceptions of coordination in patients with multiple long-term conditions recruited via primary care clinics (Singer et al., 2013).

The relative performance of the CCQ will be considered first in the light of the two most similar measures; the CPCQ (McGuiness and Sibthorpe, 2003) and a more recently published measure; the Patient Perceptions of Integrated Care Survey (PPIC) (Singer et al., 2013). Both of these instruments are intended for use with a primary care sample with either multiple long-term conditions or an identified requirement for care coordination and are at a similar stage of development as the work reported here.

As noted in Chapter 4, the CPCQ (McGuiness and Sibthorpe, 2003) identified six empirical domains of coordination: identification of need, access to care, patient participation, patient provider communication, inter-provider communication and a global assessment of care. The PPIC (Singer et al., 2013) was developed from a conceptual framework which identified seven domains: coordination within the care team, coordination across care teams, coordination between care teams and community resources, familiarity with the patient over time, proactive and responsive action between visits, patient centeredness and shared responsibility. Exploratory factor analysis supported five domains of coordination and one of patient centeredness.

Whilst there are a number of similarities between the items in these measures and those in the CCQ the main differences arise in relation to items which relate firstly, to specific care providers and secondly, to specific care activities or care structures. For example, both the CPCQ and PPIC include items relating to coordination activities in primary care and separate but similar items relating to specialist care. These measures also include items relating to specific care activities such as having blood tests or other investigations and the process for receiving the results of these. The PPIC also includes standards within these items, for example 'when you received the test results how often did you get them within two weeks after the test?' This instrument also includes items more specific to the US health system, for example, those related to the affordability of specialist care. These instruments therefore are more closely linked to both discrete care activities which the individual respondents may have experienced, the structures through which they are delivered and the cultural standards surrounding their delivery e.g. waiting times, than the CCQ. Instruments with these features are potentially limited in later use. For example, they cannot be used to evaluate the impact on coordination where changes have been made to the structure of care. Similarly, they may have potential limited applicability in international comparisons of interventions where there are differences in the way services are structured.

One of the aims of this work was to develop an instrument that would be able to provide a measure of coordination irrespective of the philosophy underpinning care and the structures used to deliver it. Implicitly, therefore the CCQ is a measure of coordination at the system level. A potential limitation of this approach is that there is a loss of detail about the experiences of coordination at the provider level. Advocates of the use of multiple items related to individual providers argue that this enables comparison of the coordination activities of individual providers and that this is a better reflection of the way in which care is experienced (McGuiness, 2001). However, an implicit assumption of this approach is that patients are able to correctly attribute coordination failings to individual providers. Whilst this may be the case in some instances, it is by no means certain that patients are able to do this consistently, especially when a coordination failure on the part of one provider only becomes apparent during an encounter with another provider. Professional behaviour may dictate that patients are not told of another provider's apparent failings which may result in patients attributing the coordination problem to the provider who identified it rather than to the provider where it occurred.

A second potential limitation of measuring coordination at the system level is that patients may find it difficult to make an overall assessment. This was considered during instrument development through cognitive testing of items which suggested that respondents were able to make an overall judgement.

The impact of making an overall judgement of the care experience versus reporting on individual providers in relation to the overall functioning and utility of a measure of coordination is unknown and requires further investigation. However, it can be partially explored in this data set by examining the performance of the CPCQ in relation to the two construct validation tests reported in Chapter 7 for the CCQ. The *a priori* hypotheses were that firstly, respondents with a single care provider would report higher coordination scores than those with two providers and those with three or more providers; and secondly that coordination scores would decrease as the number of long term conditions respondents reported increased. The CPCQ demonstrated a similar ability to the CCQ to differentiate between respondents with different numbers of providers. Those with a single care provider reported higher scores on the CPCQ than those with two providers (U = 5425.00, z = -4.427, p < .000) with an effect size of r = .278. Similarly, those with a single provider reported higher scores on the CPCQ than those with three or more providers (U = 987.00, z = -3.485, p = 0.001), with an effect size of r = .279. This similarity in performance was also observed in relation to the correlation between the CPCQ and numbers of long-term conditions (-.197, p = 0.001).

These results do not suggest a significant advantage to the inclusion of provider specific items in the measurement of coordination in differentiating between the experiences of these patient groups. However, the majority of items in the CPCQ (n=15) relate to overall evaluations of care with only 10 items relating to individual providers which may account for the similarities in performance with the CCQ.

Other instruments, such as the Patient Career Diary (Baker et al., 1999) are more context specific than the CCQ. This instrument comprises of seven individual sets of items which relate to a particular point on a typical NHS patient care pathway transitioning primary and secondary care. As such it offers the potential to pinpoint where on the pathway coordination problems were experienced. System wide measures such as the CCQ lack this ability to determine where problems were experienced but the comparative performance of these instruments is untested. There is no *a priori* theoretical reason as to why a context specific instrument would demonstrate better discriminative validity but this should be explored in future work. If context specific instruments do not demonstrate better discriminative validity, then a potential advantage of measures such as the CCQ, which are not aligned to health system structures, is that they can be used to compare experiences both within and between health systems.

Questions have also been raised as to whether coordination is a binary state i.e. care is coordinated or not, or whether there are different levels of coordination. The CCQ with its five category response options assumes that coordination runs on a continuum from poor (or no coordination) through to excellent (or fully coordinated care). This approach is shared with all the other measures of coordination identified as part of the systematic review. The PPIC incorporated both binary and ordinal response options and concluded that the items with dichotomous response options should be reworded to a four point response set to test if that resulted in increased variation (Singer et al., 2013).

Conceptually, if coordination is a process for the organisation of patient care activities which involve multiple professionals or provider organisations it seems logical that this process may be delivered in part as well as in whole or not at all. Some support for this can be drawn from the endorsement of all response options to the overall evaluation of coordination item in the CCQ. However, this question requires further qualitative and quantitative exploration with different stakeholders before conclusions can be drawn.

As noted explicitly in this thesis, and less directly in other attempts to measure coordination, the measurement of coordination from the patient perspective is necessarily partial as some aspects of inter-professional and inter-organisational coordination are not visible to the patient. During the development of the CCQ, the patient experience of coordination was viewed as resulting from production failure on the part of healthcare providers; an approach also taken by others (Haggerty et al., 2013). It is therefore an indirect observation of healthcare provider activities.

Other potentially indirect measures of provider activities include the Patient Assessment of Chronic Illness Care (PACIC) (Glasgow et al., 2005). PACIC is a 20 item instrument which aims to measure the extent to which patient care is experienced as being aligned to the Chronic Care Model (CCM). A parallel measure, the Assessment of Chronic Illness Care (ACIC), exists for providers to assess their adherence to the CCM (Bonomi et al., 2003). Reasons for the development of these parallel measures include providing convergent evidence for delivery of the CCM and to counterbalance potential over-reporting of providers in the extent of their adherence to the CCM (Glasgow et al., 2005).

It could be argued that the CCQ performs a similar function to PACIC. However, whilst the PACIC and the ACIC could be described as evaluating two sides of the same coin (adherence to the CCM), measuring coordination may be more complex. As noted above, the patient perspective is necessarily partial and indirect with the resulting ‘blind spots’ limiting the potential conceptual coverage when measuring the phenomenon. This makes the original ambition of developing a comprehensive measure of coordination within a single instrument both undesirable and unlikely. Different, but complimentary, measures are required to evaluate the extent of healthcare provider coordination activities (Haggerty et al., 2012). However, unlike the relationship between the PACIC and ACIC where each provides convergent validity for the other, it is by no means clear that provider and patient measures of coordination would achieve this. One would only expect this relationship to be observed if interventions to promote better coordination between providers also impacted directly upon the patient experience. For example, access to electronic health records which are shared across organisational boundaries should improve provider efficiency but may not necessarily result in an improved patient experience. This was observed in the evaluation of the Integrated Care Pilots where professional perceptions of improved working were not reflected in the patient experience (RAND Europe and Ernst and Young, 2012).

In common with other measures of coordination (for example the patient career diary) the CCQ included four items related to patient observations and subsequent interpretations of the behaviours of healthcare professionals involved in their care (items F1-F4). These items effectively relate to inter-provider coordination activities, which were noted above as being poorly observable by patients and are therefore qualitatively different to those items which ask about the patient's direct experience. This raises two questions. Firstly, to what extent are they necessary to a measure of coordination from the patient perspective in that their inclusion results in improved psychometric and discriminative properties and secondly, if they are necessary, are there other aspects of health professional activity that patients can observe and report on?

The initial model of coordination tested here proposed that these items would be distinct from, and represent a different domain, to those asking about direct experiences of care. This was not upheld with this sample and the items grouped together with other items relating to different aspects of care, such as healthcare professionals missing necessary information. Two of these items (F3 and F4) also performed poorly in terms of maximum endorsement, with only one being retained as it was felt to represent a conceptually important aspect of care. They also suffered from a higher than desirable missing response rates (5.1%-6.4%). Given the proportion of the sample who reported a single care provider these items may benefit from the addition of a 'not applicable' response option. Further work is needed to evaluate whether the inclusion of these items aids the discriminative ability of the CCQ.

Other aspects of provider behaviours which have been included in existing measures of coordination relate to perceptions of healthcare provider teamwork and communication (Kautz et al., 2007, Singer et al., 2013). These were deliberately excluded from this questionnaire during development on the grounds that patients would not be able to observe these activities and would be required to make a guess at an answer, which is unsatisfactory from a psychometric perspective (Nunnally and Bernstein, 1994). Haggerty et al. (2013) note that for many patients the default position is that care will be coordinated and therefore, unless they experience poor coordination, they are likely to feel that their care providers communicate and work well together. It is possible therefore, that responses to items such as these are more reflective of a patient's sense of security and trust in the system (Haggerty et al., 2013) than being a report of healthcare provider behaviours. Their utility may be limited by the extent to which individual responses to them are influenced by factors unrelated to coordination which influence patients' perceptions of trust and security.

Two such items are included in the CPCQ relating to how often GPs and other providers seemed to be communicating with others. In this sample, these items suffered from higher than desirable missing response rates (11% with regard to GP led communication and 8.7% with regard to other provider led communication), suggesting that the decision to exclude them from the CCQ was reasonable and that more specific questioning in relation to observable behaviours may be the better approach. However, this requires further exploration.

Having noted the relative infancy of patient reported measures of coordination the critical question of their utility remains, and specifically how can they be used to improve the patient experience. There is limited evidence with which to address this as most work to date has focussed upon instrument development rather than construct validation. Given this, only one coordination measure, the Patient Career Diary (Baker et al., 1999), has been used to make a comparative evaluation of patient's experiences.

This has demonstrated an ability to differentiate between patients following different care pathways (Julian et al., 2007) suggesting a potential utility in evaluating different care pathways.

Efforts to address coordination of care and evaluate the impact of different coordination mechanisms could reasonably fit the description of a complex intervention (Medical Research Council, 2008). Critical to the evaluation of such complex interventions is a theoretical understanding of the concept of coordination of care, how the intervention being adopted intends to address coordination problems and where the benefits of this intervention are expected to manifest themselves. As was discussed in both the introduction and concept development chapter, whilst the call for improved coordination as a solution for fragmented care has an intuitive appeal what different stakeholders mean by this, the identification of coordination problems and how different coordination mechanisms could be employed to address them is less well defined. In the absence of this, evaluations of coordination initiatives have demonstrated conflicting results (Powell Davies et al., 2008, McDonald et al., 2007, Brown et al., 2008, RAND Europe and Ernst and Young, 2012). The impact upon the patient experience is a legitimate, but not exclusive, outcome of such interventions with outcomes likely to vary with the nature of the intervention. Instruments such as the CCQ allow for an estimation of the patient's experience of coordination of care rather than using proxy measures such as continuity and satisfaction with services. They also support a more detailed understanding of the components of coordinated care and the impact of any intervention on these than measures incorporating an integration/ coordination sub-scale (Singer et al., 2013).

8.5: Recommendations for future work

The recommendations for future work made here seek to address some of the technical limitations of this study which mean that whilst the CCQ has demonstrated some potential in the measurement of coordination further work is required before it is used in an evaluative context. Consideration is also given to potential future work in relation to construct validation.

8.5.1: Addressing the technical limitations of this study

The generalisability of the results of this study is limited due to the small sample size which impacted upon the assessment of the structure of the CCQ and the relative homogeneity of the sample in terms of age, ethnicity and employment status. Retesting in a larger, more heterogeneous sample is therefore recommended. This should incorporate the minor modifications proposed at the end of Chapter 7 and include the avoidance of gloss paper, more careful consideration of the position on the page of items to be skipped, the renumbering of response options to reduce the potential for error during data transformation and consideration of a more random presentation of the items.

Retesting could also incorporate a revised response set to evaluate the respondent's need for coordination. In this study respondents were asked to indicate the provider organisations from which they had received care in the previous 6 months. Therefore, whilst this captured potential inter-provider interdependencies it failed to identify intra-provider coordination requirements. This may have underestimated the total coordination requirements of respondents, especially where they receive care from multiple professionals within primary or secondary care.

The primary rationale for retesting would be to address the outstanding questions regarding the structure of the CCQ. This could include further exploration of whether coordination can be explained by a causal rather than an effect measurement model but as a minimum should seek to evaluate the plausibility of the four factor two-level SEM solution presented here and confirm or otherwise the appropriateness of the factor weights used in scoring. Using the case to variable ratio rule of thumb for calculating sample size a minimum of 800 usable cases would be necessary for this (Jackson, 2003). A revised sampling framework which recruits potential respondents from both primary and secondary care may also be required in order to maximise the numbers of respondents with coordination requirements.

Subsequent retesting could also evaluate the utility of a revised response set as discussed in Chapter 7.

8.5.2: Construct validation

Construct validation is an ongoing process and two future studies are suggested to explore the performance of the retested CCQ. These relate to firstly, understanding the relative performance of the CCQ against a context specific instrument and secondly, exploring the ability of the CCQ to differentiate between patients experiences of different care delivery contexts.

8.5.2.1: Relative performance against a context specific measure

As noted earlier in this chapter there is a potential trade-off between context independent instruments such as the CCQ and context specific instruments such as the Patient Career Diary (Baker et al., 1999) in terms of the granularity at which the respondent experience is measured. This potentially has implications for the subsequent use of the instruments. However, as both these instruments purport to be measuring the same thing some correlation between the resulting scores would be expected, although potentially at a modest level. It is proposed therefore that retesting of the CCQ could also incorporate concurrent administration of relevant sections of the patient career diary with the aim of evaluating their relative performance in making an overall evaluation of the respondent's experience of coordination of care. Should this performance prove comparable, the CCQ has some potential advantages over the Patient Career Diary when used in an evaluative context in terms of respondent burden in that it can be completed in a single administration and comprises of fewer items. The fact that it is not linked to the structure of any health service may also some advantages in that it can potentially be used in any health system.

Similar studies will be required in order to evaluate the performance of the CCQ in international settings. These will firstly, enable evaluation of the performance of the CCQ against local context specific measures and secondly, determine whether there are cultural differences in the way in which patients evaluate coordination of care.

8.5.2.2: Discriminating between different care contexts

In order to be used in an evaluative context the CCQ needs to demonstrate discriminative validity and differentiate between respondents with different experiences. In this study the CCQ demonstrated a modest ability to differentiate between firstly, people with one and more than one care providers and secondly, between people with increasing numbers of long-term conditions. It has yet to demonstrate a discriminative ability in relation to experiences with different care delivery contexts. This is necessary before it can be used to evaluate the impact of different coordination mechanisms/interventions.

It is therefore proposed that the CCQ be administered to patients receiving care in different care contexts. The NHS in England has invested significant amounts in integrated care pilots (Department of Health, 2009, National Collaboration for Integrated Care and Support, 2013) which seek to strengthen coordination of care for particular patient groups in new and novel ways. The effectiveness of the CCQ in comparing these different models of service delivery against existing usual care could be evaluated in a study in which the sample size is calculated to detect differences in terms of patient reported coordination scores between these two groups.

The CCQ could also be used to compare coordination experiences in countries with different health system structures. Perhaps the most obvious of these would be to compare coordination experiences of patients in a primary-care centred health system structure such as the NHS with a more specialist care centred health system structure such as that seen in the US. Any study to explore differences in experiences between these health systems could also be expanded to include patients in the US with a 'medical home'. As noted in Chapter 1, medical homes are more primary care focused and incorporate a focus upon coordination of care. Given this it would not be unreasonable to hypothesise that the experiences of these patients would be different to those of people receiving usual care in the US health system and perhaps more similar to those of patients within a primary care based system.

8.6: Implications for policy and practice

Following further development work, the CCQ could be useful in future health services research by incorporating the patient perspective into evaluations of interventions to improve coordination of care. As noted by Malone and Crowston (1994), coordination mechanisms may be interchangeable and further research is required to identify the optimal solutions for specified coordination problems. Evaluation in a patient-centred health system should incorporate seeking the patient perspective of the impact of any change alongside other outcome measures and the CCQ provides a mechanism to do this. It also appears to measure the construct of interest rather than having to rely upon proxy measures such as satisfaction. As discussed earlier in this chapter, not all coordination mechanisms will have a positive impact upon the patient experience but as a minimum they should not have a deleterious effect.

This work could also encompass a furthering of our empirical and theoretical understanding of the relationships between coordination and other key constructs such as relational continuity, patient centred care and empowerment or patient activation.

It may also be useful for provider organisations and professionals to understand the impact of any local initiative to improve coordination. Improving the patient experience of integrated care is a key objective for the NHS in England with measurement against this being reported from 2015/16 through the NHS Outcomes Framework (Department of Health, 2013). Findings from this study, and other initiatives internationally, suggest that the concept of coordination is amenable to measurement from the patient perspective. However, instruments are in the early stages of development and questions remain regarding which patient groups to target, how to interpret 'scores' resulting from single cross-sectional administrations and any subsequent changes in these scores. These questions are critical given the intention to use these measures to evaluate NHS performance (Department of Health, 2013). Further refinement of the CCQ may enable identification of key items predictive of the experience of coordination of care which could be incorporated into broader surveys of patient experiences of the quality of their care.

8.7: Summary

This study developed and tested a patient reported instrument to measure coordination of care and made a preliminary evaluation of tis reliability and validity. The resulting instrument comprises of four factors which combine to create a single coordination score. In these preliminary evaluations the instrument has demonstrated good reliability at the group level, good concurrent validity when compared to the CPCQ. Initial construct validation studies were also positive, although the effect sizes were modest.

Some key questions remain regarding the structure of the instrument including whether coordination should be considered within a causal or effect measurement model and the structure proposed here requires further validation in a bigger, more heterogeneous sample. However, following this further development work the instrument has the potential to be of practical use as a research tool in the evaluation of different coordination mechanisms for defined coordination problems.

Chapter 9: Conclusion

Coordination is an increasingly important attribute of quality health care. The measurement and evaluation of coordination is therefore of relevance for many health systems. This thesis has described the development and initial validation of a patient experience measure of coordination of care, the CCQ (Care Coordination Questionnaire). The development of this measure necessitated consideration and explication of the meaning of coordination both as an abstract concept and how it is experienced by patients. In doing this I drew upon literature in the spheres of both healthcare and management and organisational science. The resulting definition shares similarities with those published elsewhere although its key differentiating feature relates to the role played by the patient. Within the definition presented here, patients may play an active role in the coordination of their care, but this is not essential.

The CCQ is an 18 item measure which includes items related to the planning and delivery of healthcare, together with items relating to patient observations of provider behaviour. During initial testing it demonstrated moderate to good psychometric properties in relation to item responses, group-level reliability, and concurrent and construct validity. However, further development work is required before it is recommended for widespread use. In the first instance this should focus upon understanding the performance of the measure in a larger, more diverse sample so as to address the limitations of this study with regard to firstly, the model analysis and subsequent weighting of responses and secondly, understanding any differences in responses between different age and ethnic groups. Recommendations have also been made for potential modifications to response options to improve the discriminative properties of the measure.

Should the CCQ demonstrate adequate performance characteristics across a more diverse sample of respondents then it may have the potential to be used in making comparisons between the coordination of care experienced by patients whose care is organised in different models of service delivery. There is also the potential for the CCQ to be used to make international comparisons of the patient experience of coordination of care.

References

ACOCK, A. C. 2008. *A gentle introduction to Stata,* Texas, Stata Press.

ALIOTTA, S. 2003. Coordination of care: the Council for Case Management Accountability's third state of the science paper. *Case Manager,* 14**,** 49-52.

ALLEN, D., GRIFFITHS, L. & LYNE, P. 2004. Understanding complex trajectories in health and social care provision. *Sociology of health and illness,* 26**,** 1008-1030.

ALLRED, C. A., ARFORD, P. H. & MICHEL, Y. 1995. Coordination as a critical element of managed care. *Journal of Nursing Administration,* 25**,** 21-28.

AMERICAN ACADEMY OF PEDIATRICS 1999. Care coordination: integrating health and related systems of care for children with special health needs. *Pediatrics,* 104**,** 978-981.

ANTONELLI, R. C. & ANTONELLI, D. M. 2004. Providing a medical home: the cost of care coordination services in a community-based, general pediatric practice. *Pediatrics,* 113**,** 1522-1528.

ANTONELLI, R. C., STILLE, C. J. & ANTONELLI, D. M. 2008. Care coordination for children and youth with special healthcare needs: a descriptive, multisite study of activities, personnel costs and outcomes. *Pediatrics,* 122**,** e209-e216.

AUSTRALIAN GOVERNMENT DEPARTMENT OF HEALTH AND AGING 2007. Australian Coordinated Care Trials 2007: Part 1 - Executive Summary - Coordination of Care and Efficiency of Healthcare: Lessons from the Second Round of Australian Coordinated Care Trials. *In:* AGING, D. O. H. A. (ed.). Commonwealth of Australia.

AYANIAN, J. Z., ZASLAVSKY, A. M., GUADAGNOLI, E., FUCHS, C. S., YOST, K. J., CREECH, C. M., CRESS, R. D., O'CONNOR, L. C., WEST, D. W. & WRIGHT, W. E. 2005. Patients' perceptions of quality of care for colorectal cancer by race, ethnicity and language. *Journal of Clinical Oncology,* 23**,** 6576-6586.

BAKER, R., PRESTON, C., CHEATER, F. & HEARNSHAW, H. 1999. Measuring patient's attitudes to care across the primary/ secondary care interface: the development of the patient career diary. *Quality in Health Care,* 8**,** 154-160.

BATESON, J. 2002. Are your customers good enough for your service business? *The Academy of Management Executive,* 16**,** 110-120.

BAYLISS, E. A., STEINER, S. F., FERNALD, D. H., CRANE, L. & MAIN, D. S. 2003. Descriptions of barriers to self care by persons with co-morbid chronic disease. *Annals of family medicine,* 1**,** 15-21.

BEATTY, P. C. & WILLIS, G. B. 2007. Research synthesis: the practice of cognitive interviewing. *Public Opinion Quarterly,* 71**,** 287-311.

BEAUDIN, C. L., LAMMERS, J. C. & PEDROJA, A. T. 1999. Patient perceptions of coordinated care: the importance of organized communication in hospitals. *Journal for Healthcare Quality,* 21**,** 18-23.

BENNET, P. J., FOSBINDER, D. & WILLIAMS, M. 1997. Care coordination in an academic medical centre. *Nursing Case Management,* 2**,** 75-82.

BERINGER, A. J. 2005. *People and processes: a structuration approach to the coordination of children's inpatient health care.* PhD, London South Bank University.

BINDMAN, A. B., BLUM, J. D. & KRONICK, R. 2013. Medicare's Translational Care Payment - A Step toward the Medical Home. *New England Journal of Medicine,* 368**,** 692-694.

BODENHEIMER, T. 2008. Coordinating care - a perilous journey through the health care system. *New England Journal of Medicine,* 358**,** 1064-1071.

BOLLEN, K. & LENNOX, R. 1991. Conventional wisdom on measurement: a structural equation perspective. *Psychological Bulletin,* 110**,** 305-314.

BONOMI, A. E., WAGNER, E. H., GLASGOW, R. E. & VONKORFF, M. 2003. Assessment of chronic illness care (ACIC): a practical tool to measure quality improvement. *Health Services Research,* 37**,** 791-820.

BRITISH MEDICAL ASSOCIATION 2013. Understanding the reforms: Choice and any qualified provider. London: British Medical Association.

BROWN, R., PEIKES, D., CHEN, A. & SCHORE, J. 2008. 15-site randomized trial of coordinated care in Medicare FFS. *Health Care Financing and Review,* 30**,** 5-25.

BRUCE, G., WISTOW, G. & KRAMER, R. 2011. Connected care re-visited: Hartlepool and beyond. *Journal of integrated care,* 19**,** 13-21.

BYNUM, J. P. W. & ROSS, J. S. 2012. A measure of care coordination? *Journal of General Internal Medicine,* 28**,** 336-338.

BYRNE, B. M. 2010. *Structural equation modeling with AMOS: basic concepts, applications and programming,* New York, Routledge.

CAMPBELL, J., SMITH, P., NISSEN, S., BOWER, P., ELLIOTT, M. & ROLAND, M. 2009. The GP patient surey for use in primary care in the National Health Service in the UK - development and psychometric characteristics. *BMC Family Practice,* 10**,** 57.

CAMPBELL, J. L., RAMSAY, J. & GREEN, J. 2001. Age, gender, socioeconomic, and ethnic differences in patients' assessments of primary health care. *Qual Health Care,* 10**,** 90-95.

CAMPBELL, S. & ROLAND, M. 2003. Improving the quality of health care through clinical governance. *In:* DOWLING, B. & GLENDINNING, C. (eds.) *The new primary care: modern, dependable, successful?* London: Open University Press.

CASSADY, C. E., STARFIELD, B., HURTADO, M. P., BERK, R. A., NANDA, J. P. & FRIEDENBERG, L. A. 2000. Measuring consumer experiences with primary care. *Pediatrics,* 105**,** 998-1003.

CENTRE FOR REVIEWS AND DISSEMINATION 2009. *Systematic reviews: CRD's guidance for undertaking reviews in health care,* York, CRD, University of York.

CHEN, A., BROWN, R., ARCHIBALD, N., ALIOTTA, S. & FOX, P. 2000. Best practices in coordinated care. Princeton,,NJ: Mathematica Policy Research.

CHOI, B. C. K. & PAK, A. W. P. 2005. A catalog of biases in questionnaires. *Preventing chronic disease [serial online],* 2**,** 1-13.

CLAIBORNE, N. 2006. Effectiveness of a care coordination model for stroke survivors: a randomized study. *Health and Social Work,* 31**,** 87-96.

CLARK, C., SCOTT YOUNG, M., JACKSON, E., GRAEBER, C., MAZELIS, R., KAMMERER, N. & HUNTINGTON, N. 2008. Consumer perceptions of integrated trauma-informed services among women with co-occurring disorders. *Journal of Behavioural Health Services and Research,* 35**,** 71-90.

COCKERILL, R., JAGAL, S., CHARLES, L. L., CHAMBERS, L., BRAZIL, K. & COHEN, C. 2006. Components of coordinated care: a new instrument to assess caregivers' and care recipients' experiences with networks of dementia care. *Dementia,* 5**,** 51-66.

COLEMAN, E. A., MAHONEY, E. & PARRY, C. 2005. Assessing the quality of preparation for posthospital care from the patient's perspective: the Care Transitions Measure. *Medical Care,* 43**,** 246-255.

COLEMAN, E. A., SMITH, J. D., FRANK, J. C., EILERTSEN, T. B., THIARE, J. N. & KRAMER, A. M. 2002. Development and testing of a measure designed to assess the quality of care transitions. *International Journal of Integrated Care,* 2**,** 1-9.

COLLINS, D. 2003. Pretesting survey instruments: an overview of cognitive methods. *Quality of Life Research,* 12**,** 229-238.

COLLINS, K. & O'CATHAIN, A. 2003. The continuum of patient satisfaction - from satisfied to vary satisfied. *Social Science and Medicine,* 57**,** 2465-2470.

COUNCIL ON CHILDREN WITH DISABILITIES & MEDICAL HOME IMPLEMENTATION PROJECT ADVISORY COMMITTEE 2014. Patient and family centred care coordinaiton: a framework for integrating care for children and youth across multiple systems. *Pediatrics,* 133**,** e1451.

CRONBACH, L. J. & MEEHL, P. E. 1955. Construct validity in psychological tests. *Psychological Bulletin,* 52**,** 281-302.

DE VELLIS, R. 2003. *Scale development: theory and applications,* California, Sage Publications.

DEFOSSEZ, G., MATHOULIN-PELISSIER, S., INGRAND, I., GASQUET, I., SIFER-RIVIERE, L., INGRAND, P., SALAMON, R. & MIGEOT, V. 2007. Satisfaction with care among patients with non-metastatic breast cancer: development and first steps of validation of the REPERES-60 questionnaire. *BMC Cancer,* 7.

DEPARTMENT OF HEALTH 2000. The NHS plan: a plan for investment, a plan for reform. London: The stationary office.

DEPARTMENT OF HEALTH 2006. Our health, our care, our say: a new direction for community services. London.

DEPARTMENT OF HEALTH 2008a. High quality care for all: NHS next stage review final report. London: The Stationary Office.

DEPARTMENT OF HEALTH 2008b. Integrated care pilot programme: prospectus for potential pilots. London: The Stationary Office.

DEPARTMENT OF HEALTH 2008c. Raising the profile of long term conditions care: a compendium of information. London: Department of Health.

DEPARTMENT OF HEALTH 2009. Integrated care pilots: an introductory guide. London: Department of Health.

DEPARTMENT OF HEALTH 2010a. Equity and excellence: liberating the NHS. London.

DEPARTMENT OF HEALTH 2010b. Liberating the NHS: transparency in outcomes - a framework for the NHS. London: Department of Health.

DEPARTMENT OF HEALTH 2012. Improving integration of services - The Health and Social Care Act 2012. London: Department of Health.

DEPARTMENT OF HEALTH 2013. The NHS outcomes framework 2013/14. London: Department of Health.

DIAMANTOPOULOS, A., RIEFLER, P. & ROTH, K. P. 2008. Advancing formative measurement models. *Journal of Business Research,* 61**,** 1203-1218.

DIAMANTOPOULOS, A. & SIGUAW, J. A. 2006. Formative versus reflective indicators in organizational measure development: a comparison and empirical illustration. *British Journal of Management,* 17**,** 263-282.

DIAMANTOPOULOS, A. & WINKLHOFER, H. M. 2001. Index construction with formative indicators: an alternative to scale development. *Journal of Marketing Research,* 38**,** 269-277.

DRENNAN, J. 2003. Cognitive interviewing: verbal data in the design and pretesting of questionnaires. *Journal of Advanced Nursing,* 42**,** 57-63.

EDMONDS, P., VIVAT, B., BURMAN, R., SILBER, E. & HIGGINSON, I. J. 2007. 'Fighting for everything': service experiences of people severely affected by multiple sclerosis. *Multiple Sclerosis,* 13**,** 660-667.

EDWARDS, P., ROBERTS, I., CLARKE, M., DI GUISEPPI, C., PRATAP, S., WENTZ, R. & KWAN, I. 2002. Increasing response rates to postal questionnaires: systematic review. *British Medical Journal,* 324**,** 1183-1192.

EHRLICH, C., KENDALL, E., MUENCHBERGER, H. & ARMSTRONG, K. 2009. Coordinated care: what does that really mean? *Health and Social Care in the Community,* 17**,** 619-627.

EPSTEIN, R. M., FISCELLA, K., LESSER, C. S. & STANGE, K. C. 2010. Why the nation needs a policy push on patient centered health care. *Health Affairs,* 29**,** 1489-1495.

EPSTEIN, R. M. & STREET, R. L. 2011. The values and value of patient-centered care. *Annals of family medicine,* 9**,** 100-103.

FABRIGAR, L. R., WEGENER, D. T., MACCALLUM, R. C. & STRAHAN, E. J. 1999. Evaluating the use of exploratory factor analysis in psychological research. *Psychological Methods,* 4**,** 272-299.

FARAJ, S. & XIAO, Y. 2006. Coordination in fast-response organizations. *Management Science,* 52**,** 1155-1169.

FERN, E. 2001. *Advanced focus group research,* California, Sage Publications Inc.

FIELD, A. 2009. *Discovering statistics using SPSS,* London, Sage Publications.

FIELD, S. 2012. NHS Future Forum: summary report - second phase. London: Department of Health.

FINCH, H. & LEWIS, J. 2010. Focus groups. *In:* RITCHIE, J. & LEWIS, J. (eds.) *Qualitative research practice: a guide for social science students and researchers.* London: Sage.

FITZPATRICK, R., DAVEY, C., BUXTON, M. & JONES, D. 1998. Evaluating patient-based outcome measures for use in clinical trials. *Health Technology Assessment,* 2**,** 1-76.

FLETCHER, R. H., O'MALLEY, M. S., FLETCHER, S. W., EARP, J. A. L. & ALEXANDER, J. P. 1984. Measuring the continuity and coordination of medical care in a system involving multiple providers. *Medical Care,* 22**,** 403-411.

FLOCKE, S. A. 1997. Measuring attributes of primary care: development of a new instrument. *The Journal of Family Practice,* 45**,** 64-74.

FLOYD, F. & WIDAMAN, K. 1995. Factor analysis in the developemnt and refinement of clinical assessment instruments. *Psychological Assessment,* 7**,** 286-299.

FREEMAN, G. K. & HUGHES, J. 2010. Continuity of care and the patient experience. London: The Kings Fund.

FREEMAN, G. K., SHEPPERD, S., ROBINSON, I., EHRICH, K. & RICHARDS, S. 2000. Continuity of care: report of a scoping exercise for the National Coordinating Centre for NHS Service Delivery and Organisation R&D (NCCSDO). London: NCCSDO.

FREEMAN, G. K., WOLOSHYNOWCH, M., BAKER, R., BOLTON, M., GUTHRIE, B., CAR, J., HAGGERTY, J. L. & TARRANT, C. 2007. Continuity of care 2006: what have we learnt since 2000 and what are the policy imperatives now? London: NCCSDO.

FROST, M., REEVE, B., LIEPA, A., STAUFFER, J. & HAYS, R. 2007. What is sufficient evidence for the reliability and validity of patient-reported outcome measures *Value in Health,* 10**,** S94-S105.

FULOP, N., MOWLEM, A. & EDWARDS, N. 2005. Building integrated care: lessons from the UK and elsewhere. London: NHS Confederation.

GEMMEL, I., CAMPBELL, S., HANN, M. & SIBBALD, B. 2009. Assessing workload in general practice in England before and after the introduction of the pay-for-performance contract. *Journal of Advanced Nursing,* 65**,** 509-515.

GERTEIS, M., EDGMAN-LEVITAN, S., DALEY, J. & DELBANCO, T. L. 1993. *Through the patients' eyes: understanding and promoting patient-centered care,* San Franciso, CA, Jossey-Bass.

GILBERT, M. & COUNSELL, C. M. 1995. Coordinated care for the SCI patient. *SCI Nurse,* 12**,** 87-89.

GITTELL, J. H. 2002. Relationships between service providers and their impact on customers. *Journal of Service Research,* 4**,** 299-311.

GITTELL, J. H. 2009. Relational coordination: guidelines for theory, measurement and analysis. Waltham: Brandeis University.

GLASGOW, R. E., WAGNER, E. H., SCHAEFER, J., MAHONEY, L. D., REID, R. J. & GREENE, S. M. 2005. Development and validation of the Patient Assessment of Chronic Illness Care (PACIC). *Medical Care,* 43**,** 436-444.

GRIMMER, K. & MOSS, J. 2001. The development, validation and application of a new instrument to assess the quality of discharge planning activities from the community perspective. *International Journal for Quality in Health Care,* 13**,** 109-116.

GROB, R. 2013. The heart of patient-centered care. *Journal of Health Politics, Policy and Law,* 38**,** 457-465.

HAGGERTY, J. L., REID, R. J., FREEMAN, G., STARFIELD, B., ADAIR, C. E. & MCKENDRY, R. 2003. Continuity of care: a multidisciplinary review. *British Medical Journal,* 327**,** 1219-1221.

HAGGERTY, J. L., ROBERGE, D., FREEMAN, G. K. & BEAULIEU, C. 2013. Experienced continuity of care when patients see multiple clinicians: a qualitative metasummary. *Annals of family medicine,* 11**,** 262-271.

HAGGERTY, J. L., ROBERGE, D., FREEMAN, G. K., BEAULIEU, C. & BRETON, M. 2012. Validation of a generic measure of continuity of care: when patients encounter several clinicians. *Annals of family medicine,* 10**,** 443-451.

HANCOCK, G. R. & KLOCKARS, A. J. 1991. The effect of scale manipulations on validity: targetting frequency rating scales for anticipated performance levels. *Applied Ergonomics,* 22**,** 147-154.

HARKNESS, E., BOWER, P., GASK, L. & SIBBALD, B. 2005. Improving primary care mental health: survey evaluation of an innovative workforce development in ENgland. *Primary Care Mental Health,* 34**,** 253-260.

HARRISON, A. & VERHOEF, M. 2002. Understanding coordination from the consumer's perspective in a regional health system. *Health Services Research,* 37**,** 1031-1054.

HAVENS, D. S., VASEY, J., GITTELL, J. H. & LIN, W. T. 2010. Relational coordination among nurses and other providers: impact on the quality of patient care. *Journal of Nursing Management,* 18**,** 926-937.

HAWLEY, S. T., JANZ, N. K., LILLIE, S. E., FRIESE, C. R., GRIGGS, J. J., GRAFF, J. J., HAMILTON, A. S., JAIN, S. & KATZ, S. J. 2010. Perceptions of coordination in a population-based sample of diverse breast cancer patients. *Patient Education and Counselling,* 81S**,** S34.

HIPPISLEY-COX, J. & PRINGLE, M. 2007. Comorbidity of disease in the new general medical services contract for general practitioners: analysis of QRESEARCH data. Nottingham.

HOMER, C. J., KLATKA, K., ROMM, D., KUHLTHAU, K., BLOOM, S., NEWACHECK, P., VAN CLEAVE, J. & PERRIN, J. M. 2008. A review of the evidence for the medical home for children with special health care needs. *Pediatrics,* 122**,** e922-937.

HORROCKS, S., ANDERSON, E. & SALISBURY, C. 2002. Systematic review of whether nurse practitioners working in primary care can provide equivalent care to doctors. *British Medical Journal,* 324**,** 819-823.

HU, L. & BENTLER, P. M. 1999. Cutoff criteria for fit indexes in covariance structure analysis: conventional criteria versus new alternatives. *Structural equation modeling,* 6**,** 1-55.

HUDON, C., FORTIN, M., HAGGERTY, J. L. & LOIGNON, C. 2012. Patient-centered care in chronic disease management: a thematic analysis of the literature in family medicine. *Patient Education and Counselling,* 88**,** 170-176.

IBM CORP 2012. SPSS statistics for windows. 21.0 ed. Armonk, New York: IBM Corp.

INSTITUTE OF MEDICINE 2001. Crossing the quality chasm: a new health system for the 21st century. Washington (DC).

JACKSON, D. L. 2003. Revisiting sample size and number of parameter estimates: some support for the N:q hypothesis. *Structural equation modeling,* 10**,** 128-141.

JARVIS, C., MACKENZIE, S. & PODSAKOFF, P. A. 2003. Critical review of construct indicators and measurement model misspecification in marketing and consumer research. *Journal of Consumer Research,* 30**,** 199-218.

JORESKOG, K. G. 1993. Testing structural equation models. *In:* BOLLEN, K. A. & LANG, J. S. (eds.) *Testing structural equation models.* California: Sage Publications.

JULIAN, S., NAFTALIN, N. J., CLARK, M., SZCZEPURA, A., RASHID, A., BAKER, R., TAUB, N. & HABIBA, M. 2007. An integrated care pathway for menorrhagia across the primary-secondary interface: patients' experience, clinical outcomes and service utilisation. *Quality and Safety in Health Care,* 16**,** 110-115.

JUNIPER, E. F., GUYATT, G. H. & KING, D. R. 1994. Comparison of methods for selecting items for a disease-specific Quality of Life questionnaire: importance versus factor analysis. *Quality of Life Research,* 3**,** 52-53.

KAUTZ, C. M., GITTELL, J. H., WEINBERG, D. B., LUSENHOP, R. W. & WRIGHT, J. 2007. Patient benefits from participating in an integrated delivery system: impact on coordination of care. *Health Care Management Review,* 32**,** 284-294.

KIBBE, D. 2002. Care coordination. Helping physicians improve care for the chronically ill. *Mgma Connexion/ Medical Group Management Association,* 2**,** 44-47.

KITSON, A., MARSHALL, A., BASSETT, K. & ZEITZ, K. 2012. What are the core elements of patient-centred care? A narrative review and synthesis of the literature from health policy, medicine and nursing. *Journal of Advanced Nursing,* 69**,** 4-15.

KLINE, P. 1994. *An easy guide to factor analysis,* London, Routledge.

KLINE, R. B. 2011. *Principles and practice of structural equation modeling,* New York, The Guilford Press.

KNAFL, K. A. & DEATRICK, J. A. 2000. Knowledge synthesis and concept development in nursing. *In:* RODGERS, B. L. & KNAFL, K. A. (eds.) *Concept development in nursing: foundations, techniques and applications.* Second ed. Philadelphia: Saunders.

KNUDSON, E. G. 1968. The functional importance of co-ordination. *International journal of nursing studies,* 5**,** 5-9.

KODNER, D. & SPREEUWENBERG, C. 2002. Integrated care: meaning, logic, applications and implications - a discussion paper. *International Journal of Integrated Care,* 2**,** 1-6.

KROGSTAD, U., HOFOSS, D. & HJORTDAHL, P. 2002. Continuity of hospital care: beyond the question of personal contact. *British Medical Journal,* 324**,** 36-38.

KROLL, T. & NERI, M. 2003. Experiences with care coordination among people with cerebral palsy, multiple sclerosis or spinal cord injury. *Disability and Rehabilitation,* 25**,** 1106-1114.

LARSSON, R. & BOWEN, D. E. 1989. Organization and customer: managing design and coordination of services. *Academy of Management Review,* 14**,** 213-233.

LAURANT, M., REEVES, D., HERMENS, R., BRASPENNING, J., GROL, R. & SIBBALD, B. 2004. Substitution of doctors by nurses in primary care. *The Cochrane Database of Systematic Reviews*.

LEE, J. H., CHOI, Y. J., SUNG, N. K., KIM, S. Y., CHUNG, S. H., KIM, J., JEON, T. H. & PARK, H. K. 2009. Development of the Korean primary care assessment tool - measuring user experience: tests of data quality and measurement performance. *International Journal for Quality in Health Care,* 21**,** 103-111.

LEUTZ, W. N. 1999. Five laws for itegrating medical and social services: lessons from the United States and the United Kingdom. *Milbank Quarterly,* 77**,** 77-110.

LEWIS, R., ROSEN, R., GOODWIN, N. & DIXON, J. 2010. Where next for integrated care orgnaisations in the English NHS? London: The Nuffield Trust.

LIU, C. W., EINSTADTER, D. & CEBUL, R. D. 2010. Care fragmentation and emergency department use among complex patients with diabetes. *American Journal of Managed Care,* 16**,** 413-420.

LONGEST, J. B. B. & KLINGENSMITH, J. M. 1994. Coordination and communication. *In:* SHORTELL, S. M. & KALUZNY, A. D. (eds.) *Healthcare management: organisation design and behaviour.* New York: Delmar Publishers Inc.

LYRATZOPOULOS, G., ELLIOTT, M., BARBIERE, J. M., HENDERSON, A., STAETSKY, L., PADDISON, C., CAMPBELL, J. & ROLAND, M. 2012. Understanding ethnic and other socio-demographic differences in patient experience of primary care: evidence from the English General Practice Patient Survey. *BMJ Quality and Safety,* 21**,** 21-29.

MACPHAIL, L. H., NEUWIRTH, E. B. & BELLOWS, J. 2009. Coordination of diabetes care in four delivery models using an electronic health record. *Medical Care,* 47**,** 993-999.

MALONE, T. W. & CROWSTON, K. 1991. Toward an interdisciplinary theory of coordination.

MALONE, T. W. & CROWSTON, K. 1994. The interdisciplinary study of coordination. *ACM Computing Surveys,* 26**,** 87-119.

MANSER, T., HOWARD, S. K. & GABA, D. M. 2008. Adaptive coordination in cardiac anaesthesia: a study of situational changes in coordination patterns using a new observation system. *Ergonomics,* 51**,** 1153-1178.

MARCH, J. G. & SIMON, H. A. 1958. *Organizations,* New York, Wiley and Sons.

MARES, A., GREENBERG, G. & ROSENHECK, R. 2008. Client level measures of service integration among chronically homeless adults. *Community mental health journal,* 44**,** 367-376.

MATHERS, C. & LONCAR, D. 2007. Predictions of global mortailty and burden of disease from 2002 to 2032. *PLOS medicine,* 3.

MCCANN, J. E. & FERRY, D. L. 1979. An approach for assessing and managing inter-unit interdependence. *The Academy of Management Review,* 4**,** 113-119.

MCCOLL, E., JACOBY, A., THOMAS, L., SOUTTER, J., BAMFORD, C., STEEN, N., THOMAS, R., HARVEY, E., GARRATT, A. & BOND, J. 2001. Design and use of questionnaires: a review of best practice applicable to surveys of health service staff and patients. *Health Technology Assessment,* 5.

MCDONALD, K. M., SUNDARAM, V., BRAVATA, D. M., LEWIS, R., LIN, N., KRAFT, S., MCKINNON, M., PAGUNTALAN, H. & OWENS, D. K. 2007. Care Coordination. *In:* SHOJANIA, K. G., MCDONALD, K. M., WATCHER, R. M. & OWENS, D. K. (eds.) *Closing the care gap: a critical analysis of quality improvement strategies.* Rockville, MD: Agency for Healthcare Research and Quality,.

MCDONALD, R., CAMPBELL, S. & LESTER, H. 2009. Practice nurses and the effects of the new general practitioner contract in the English National Health Service: The extension of a professional project? *Social Science and Medicine,* 68**,** 1206-1212.

MCGUINESS, C. 2001. *Client perceptions: a useful measure of coordination of health care.* PhD, Australian National University.

MCGUINESS, C. & SIBTHORPE, B. 2003. Development and initial validation of a measure of coordination of health care *International Journal for Quality in Health Care,* 15**,** 309-318.

MCKENNA, H. P. & CUTCLIFFE, J. R. 2005. An introduction to concepts and their analyses. *In:* CUTCLIFFE, J. R. & MCKENNA, H. P. (eds.) *The essential concepts of nursing.* Edinburgh: Elsevier Churchill Livingstone.

MEAD, N. & ROLAND, M. 2009. Understanding why some ethnic minority patients evaluate medical care more negatively than white patients: a cross sectional analysis of a routine patient survey in English general practices. *British Medical Journal,* 339**,** b3450.

MEANS, B., NIGAM, A., ZARROW, M., LOFTUS, E. & DONALDSON, M. 1989. Vital and health statistics: autobiographical memory for health related events. Maryland: National Center for Health Statistics.

MEDICAL RESEARCH COUNCIL. 2008. *Developing and evaluating complex interventions: new guidance* [Online]. Medical Research Council. Available: www.mrc.ac.uk/complexinterventionsguidance.

MEIJER, W. J. & VERMEIJ, D. G. B. 1997. A comprehensive model of cooperation between caregivers related to quality of care. *International Journal for Quality in Health Care,* 9**,** 23-33.

MICHIE, S., MILES, J. & WEINMAN, J. 2003. Patient-centredness in chronic illness: what is it and does it matter? *Patient Education and Counselling,* 51**,** 197-206.

MOKKINK, L. B., TERWEE, C. B., PATRICK, D. L., ALONSO, J., STRATFORD, P. W., KNOL, D. L., BOULTER, L. M. & DE VET, H. C. W. 2010. The COSMIN checklist for assessing the methodological quality of studies on measurement properties: a clarification of its content. *BMC Medical Research Methodology,* 10**,** 22.

MORSE, J. M., HUPCEY, J., MITCHAM, C. & LENZ, E. 1996. Concept analysis in nursing research: a critical appraisal. *Scholarly Inquiry for Nursing Practice,* 10**,** 253-277.

NATIONAL COLLABORATION FOR INTEGRATED CARE AND SUPPORT 2013. Integrated care and support: our shared commitment. London: Department of Health.

NATIONAL QUALITY FORUM (NQF) 2006. NQF-endorsed definition and framework for measuring and reporting care coordination. Washington DC: NQF.

NATIONAL VOICES 2012. Integrated care: what do patients, service users and carers want? London: National Voices.

NATIONAL VOICES 2013. A narrative for person-centred coordinated care. London: Department of Health.

NHS CONFEDERATION 2003. Investing in General Practice: the new General Medical Services Contract. London: NHS Confederation.

NHS FUTURE FORUM 2012. Integration: a report from the NHS Future Forum. London: Department of Health.

NHS INSTITUTE. 2013. *Supporting integrated care and integrated commissioning* [Online]. [Accessed 20/09/13 2013].

NIGHTINGALE, F. 1898. *Notes on nursing: what it is, and what it is not,* New York, D Appleton and Company.

NOLTE, E. & MCKEE, M. 2008. Integration and chronic care: a review. *In:* NOLTE, E. & MCKEE, M. (eds.) *Caring for people with chronic conditions: a health system perspective.* Maidenhead: Open University Press.

NUNNALLY, J. & BERNSTEIN, I. 1994. *Psychometric theory,* New York, McGraw-Hill.

OFFICE FOR NATIONAL STATISTICS 2013a. Estimates for the very old (including centenarians), 2002-2011, England and Wales.

OFFICE FOR NATIONAL STATISTICS 2013b. General Lifestyle Survey Overview - a report on the 2011 General Lifestyle Survey.

OFFICE FOR NATIONAL STATISTICS 2013c. Life expectancy at birth and age 65 for local areas in ENgland and Wales, 2009-11.

OKHUYSEN, G. A. & BECHKY, B. A. 2009. Coordination in organisations: an integrative perspective. *The Academy of Management Annals,* 3**,** 463-502.

OVRETVEIT, J. 2011. Does clinical coordination improve quality and save money? London: Health Foundation.

OXFORD DICTIONARIES. 2014. *Oxford Dictionaries English Dictionary* [Online]. Oxford: Oxford Univeristies Press. Available: http://www.oxforddictionaries.com/definition/english/coordination?q=coordination [Accessed 20/07/2014 2014].

PALFREY, J. S., SOFIS, L. A., DAVIDSON, E. J., LIU, J., FREEMAN, L. & GANZ, M. L. 2004. The pediatric alliance for coordinated care: evaluation of a medical home model. *Pediatrics,* 113**,** 1507-1516.

PALSBO, S. E. & HO, P. S. 2007. Consumer evaluation of a disability care coordination organisation. *Journal of health care for the poor and underserved,* 18**,** 887-901.

PALSBO, S. E., MASTAL, M. F. & O'DONNELL, L. T. 2006. Disability care coordination organizations: improving health and function in people with disabilities. *Lippincott's Case Management,* 11**,** 255-264.

PARCHMAN, M. L., NOEL, P. H. & LEE, S. 2005. Primary care attributes, health care system hassles, and chronic illness. *Medical Care,* 43**,** 1123-1129.

PHAM, H., O'MALLEY, A., BACH, P., SALONTZ-MARTINEZ, C. & SCHRAG, D. 2009. Primary care physicians links to other physicians through medicare patients: the scope of care coordination. *Annals of internal medicine,* 150**,** 236-242.

PHAM, H., SCHRAG, D., O'MALLEY, A., WU, B. & BACH, P. 2007. Care patterns in medicare and their implications for pay for performance. *The New England journal of medicine,* 356**,** 1130-1139.

POWELL DAVIES, G., HARRIS, M., PERKINS, D., ROLAND, M., WILLIAMS, A., LARSEN, K. & MCDONALD, J. 2006. Coordination of care within primary health care and other sectors: a systematic review. UNSW: Research Centre for Primary Health Care and Equity,.

POWELL DAVIES, G., WILLIAMS, A. M., LARSEN, K., PERKINS, D., ROLAND, M. & HARRIS, M. F. 2008. Coordinating primary health care: an analysis of the outcomes of a systematic review. *Medical Journal of Australia,* 188**,** S65-S68.

RAND EUROPE & ERNST AND YOUNG 2012. National evaluation of the Department of Health's integrated care pilots: summary report. Cambridge: RAND Europe.

RATHNAM, S., MAHAJAN, V. & WHINSTON, A. B. 1995. Facilitating coordination in customer support teams: a framework and its implications for the design of information technology. *Management Science,* 41**,** 1900-1921.

REID, R. J., HAGGERTY, J. L. & MCKENDRY, R. 2002. Defusing the confusion: concepts and measures of continuity of healthcare.

RITCHIE, J. & LEWIS, J. 2003. *Qualitative research practice: a guide for social science students and researchers,* London, Sage Publications.

ROE, L. & NORMAND, C. 2013. An examination of care coordination mechanisms in integrated care interventions for community dwelling frail older people. *The World Conference on Integrated Care.* Singapore.

ROSENTHAL, G. & SHANNON, S. 1997. The use of patient perceptions in the evaluation of health care delivery systems. *Medical Care,* 35**,** NS58-68.

SAFRAN, D. G., KARP, M., COLTIN, K., CHANG, H., LI, A., OGREN, J. & ROGERS, W. H. 2005. Measuring patients experiences with individual primary care physicians: results of a statewide demonstration project. *Journal of General Internal Medicine,* 21**,** 13-21.

SAFRAN, D. G., KOSINSKI, M., TARLOV, A., ROSGERS, W., TAIRA, D., LIEBERMAN, N. & WARE, J. 1998. The primary care assessment survey: tests of data quality and measurement performance. *Medical Care,* 36**,** 728-739.

SALISBURY, C., SAMPSON, F., RIDD, M. & MONTGOMERY, A. 2009. How should continuity of care in primary health care be assessed? *British Journal of General Practice,* 59**,** 276-282.

SCHOENBERG, N., LEACH, C. & EDWARDS, W. 2009. "It's a toss up between my hearing, my heart and my hip": prioritizing and accomodating multiple morbidities by vulnerable older adults. *Journal of health care for the poor and underserved,* 20**,** 134-151.

SCHOLLE, S. H., WEISMAN, C. S., ANDERSON, R. T. & CAMACHO, F. 2004. The development and validation of the primary care satisfaction survey for women. *Women's Health Issues,* 14**,** 35-50.

SCHWARTZ-BARCOTT, D. & KIM, H. S. 2000. An expansion and elaboration of the hybrid model of concept development. *In:* RODGERS, B. L. & KNAFL, K. A. (eds.) *Concept development in nursing: foundations, techniques and applications.* Second ed. Philadelphia: Saunders.

SEGAL, L., DUNT, D. & DAY, S. E. 2004a. Introducing coordinated care (2): evaluation of design features and implemnetation processes implications for a preferred health system reform model. *Health Policy,* 69**,** 215-228.

SEGAL, L., DUNT, D., DAY, S. E., DAY, N. A., ROBERTSON, I. & HAWTHORNE, G. 2004b. Introducing co-ordinated care (1): a randomised trial assessing client and cost outcomes. *Health Policy,* 69**,** 201-213.

SIEHL, C., BOWEN, D. E. & PEARSON, C. M. 1992. Service encounters as rites of integration: an information processing model. *Organization Science,* 3**,** 537-555.

SINGER, S. J., BURGERS, J., FREIDBERG, M., ROSENTHAL, M. B., LEAPE, L. & SCHNEIDER, E. 2011. Defining and measuring integrated patient care: promoting the next frontier in health care delivery. *Medical Care Research and Review,* 68**,** 112-127.

SINGER, S. J., FREIDBERG, M. W., KIANG, M. V., DUNN, T. & KUHN, D. M. 2013. Development and preliminary validation of the patient perceptions of integrated care survey. *Medical Care Research and Review,* 70**,** 143-164.

SINGH, D. & HAM, C. 2006. Improving care for people with long-term conditions: a review of UK and international frameworks. Birmingham: University of Birmingham

NHS Institute.

SOFAER, S. & FIRMINGER, K. 2004. Patient perceptions of the quality of health services. *Annual Review of Public Health,* 26**,** 513-559.

SOFAER, S., KRELING, B. & CARMEL, M. 2000. Coordination of care for persons with disabilities enrolled in medicaid managed care: a conceptual framework to guide development of measures. Baruch College School of Public Affairs.

STARFIELD, B., LEMKE, K. W., BERNHARDT, T., FOLDES, S., FORREST, C. B. & WEINER, J. P. 2003. Comorbidity: implications for the importance of primary care in 'case' management. *Annals of family medicine,* 1**,** 8-14.

STARFIELD, B. H., SIMBORG, D. W., HORN, S. D. & YOURTEE, S. A. 1976. Continuity and coordination in primary care: their achievement and utility. *Medical Care,* 14**,** 625-36.

STILLE, C. J., JERRANT, A., BELL, D., MELTZER, D. & ELMORE, J. G. 2005. Coordinating care across diseases, settings and clinicians: a key role for the generalist in practice. *Annals of internal medicine,* 142**,** 700-708.

STOTT, N. C. 1995. Personal care and teamwork: implications for the general practice based primary health care team. *Journal of interprofessional care,* 9**,** 95-99.

STREINER, D. 2003. Being inconsistent about consistency: when coefficient alpha does and doesn't matter. *Journal of Personality Assessment,* 80**,** 217-222.

STREINER, D. & NORMAN, G. 2009. *Health measurement scales: a practical guide to their development,* Oxford, Oxford University Press.

SULLIVAN, M. 2003. The new subjective medicine: taking the patient's point of view on health care and health. *Social Science and Medicine,* 56**,** 1595-1604.

SUTER, P., HENNESSEY, B., HARRISON, G., FAGAN, M., NORMAN, B. & SUTER, W. N. 2008. Home-based chronic care: an expanded integrative model for home health professionals. *Home Healthcare Nurse,* 26**,** 222-229.

TERWEE, C. B., BOT, S. D. M., BOER, M. R., VAN DE WINDT, D., KNOL, D., DEKKER, J., BOUTER, L. & DE VET, H. 2007. Quality criteria were proposed for measurement properties of health status questionnaires. *Journal of Clinical Epidemiology,* 60**,** 34-42.

TERWEE, C. B., MOKKINK, L. B., KNOL, D., OSTELO, R. W. J. G., BOUTER, L. & DE VET, H. 2012. Rating the methodological quality in systematic reviews of studies on measurement properties: a scoring system for the COSMIN checklist. *Quality of Life Research,* 21**,** 651-657.

THOMPSON, J. 1967. *Organizations in action: social science basis of adminstrative theory,* New York, McGraw Hill.

TOURANGEAU, R. 1984. Cognitive Science and survey methods: a cognitive perspective. *In:* JABINE, T., STRAF, M., TANUR, J. & TOURANGEAU, R. (eds.) *Cognitive aspects of* *survey design: building a bridge between disciplines.* Washington DC: National Academy Press.

UIJEN, A., HEINST, C., SCHELLEVIS, F., VAN DEN BOSCH, W., VAN DE LAAR, F., TERWEE, C. B. & SCHERS, H. 2012. Measurement properties of questionnaires measuring continuity of care: a systematic review. *PLos One,* 7**,** e42256.

VALDERAS, J. M., STARFIELD, B., SIBBALD, B., SALISBURY, C. & ROLAND, M. 2009. Defining comorbidity: Implications for understanding health and health services. *Annals of family medicine,* 7**,** 357-363.

VAN ACHTERBERG, T., STEVENS, F. J., CREBOLDER, H. F., DE WITT, L. P. & PHILIPSEN, H. 1996. Coordination of care: effects on the continuity and quality of care. *International Journal of Nursing Studies,* 33**,** 638-650.

VAN DE VEN, A. H., DELBECQ, A. L. & KOENIG, R. 1976. Determinants of coordination modes within organisations. *American Sociological Review,* 41**,** 322-338.

VOGT, D. S., KING, D. W. & KING, L. A. 2004. Focus groups in psychological assessment: enhancing content validity by consulting members of the target population. *Psychological Assessment,* 16**,** 231-243.

WALKER, L. O. & AVANT, K. C. 2005. *Strategies for theory construction in nursing,* New Jersey, Pearson Education.

WALSH, J., YOUNG, J. M., HARRISON, J. D., BUTOW, P. N., SOLOMON, M. J., MASYA, L. & WHITE, K. 2010. What is important in cancer care coordination? A qualitative investigation. *European Journal of Cancer Care,* 20**,** 220-227.

WILCOX, J. B., HOWELL, R. D. & BREIVIK, E. 2008. Questions about formative measurement. *Journal of Business Research,* 61**,** 1219-1228.

WILLIS, G. B. 2005. *Cognitive interviewing: a tool for improving questionnaire design,* California, Sage Publications.

YATES, P. 2004. Cancer care coordinators: realising the potential for improving the patient journey. *Cancer Forum,* 28**,** 128-132.

YOUNG, G. J., CHARNS, M. P., DALEY, J., FORBES, M. G., HENDERSON, W. & KHURI, S. F. 1997. Best practices for managing surgical services: the role of coordination. *Health Care Management Review,* 22**,** 72-81.

YOUNG, J. M., WALSH, J., BUTOW, P. N., SOLOMON, M. J. & SHAW, J. 2011. Measuring cancer care coordination: development and validation of a questionnaire for patients. *BMC Cancer,* 11**,** 298.

Appendix 1: Search terms used in concept development

1. “care coordination”.ti, tw
2. “coordinat* care”.ti, tw
3. “uncoordinat* care”,ti, tw
4. “fragment* care”.ti, tw
5. “transitional care”.ti, tw
6. “integrated care”.ti, tw
7. *Continuity of Patient Care/og
8. *Delivery of Patient Care, Integrated/mt, og
9. *Patient Care Planning/og
10. *Health Services Accessibility/og, st
11. * Patient Care Management/og
12. *Patient-Centred Care/og
13. *Cooperative Behavior/
14. *Patient Satisfaction/sn
15. “service co?ordination”.ti, tw

Appendix 2: Search terms used in measure identification

1. (care adj3 (coordinat* or integrat* or fragment* or transition* or shared or collaborat*)).mp.
2. primary secondary interface.mp. [mp=ti, ab, sh, de, md, sd, hw, tn, ot, dm, mf, ac, ip, vo, pg, ar, bs, bt, cf, dp, jn, ja, yr, so, pb, nm, an, ui]
3. *Delivery of Health Care/st
4. *Delivery of Health Care, Integrated/og, st
5. *Primary Health Care/og, st, sn
6. *Continuity of Patient Care/og
7. *Patient Satisfaction/sn
8. *Patient Discharge/st
9. or/1-8
10. (item or items).mp. [mp=ti, ab, sh, de, md, sd, hw, tn, ot, dm, mf, ac, ip, vo, pg, ar, bs, bt, cf, dp, jn, ja, yr, so, pb, nm, an, ui]
11. (instrument or instruments).mp. [mp=ti, ab, sh, de, md, sd, hw, tn, ot, dm, mf, ac, ip, vo, pg, ar, bs, bt, cf, dp, jn, ja, yr, so, pb, nm, an, ui]
12. (survey or surveyed).mp. [mp=ti, ab, sh, de, md, sd, hw, tn, ot, dm, mf, ac, ip, vo, pg, ar, bs, bt, cf, dp, jn, ja, yr, so, pb, nm, an, ui]
13. ((questionnaire or questionnaires) adj5 development).mp. [mp=ti, ab, sh, de, md, sd, hw, tn, ot, dm, mf, ac, ip, vo, pg, ar, bs, bt, cf, dp, jn, ja, yr, so, pb, nm, an, ui]
14. rating scale.mp. [mp=ti, ab, sh, de, md, sd, hw, tn, ot, dm, mf, ac, ip, vo, pg, ar, bs, bt, cf, dp, jn, ja, yr, so, pb, nm, an, ui]
15. test development.mp. [mp=ti, ab, sh, de, md, sd, hw, tn, ot, dm, mf, ac, ip, vo, pg, ar, bs, bt, cf, dp, jn, ja, yr, so, pb, nm, an, ui]
16. ((valid or validity or validation) and reliability).mp. [mp=ti, ab, sh, de, md, sd, hw, tn, ot, dm, mf, ac, ip, vo, pg, ar, bs, bt, cf, dp, jn, ja, yr, so, pb, nm, an, ui]
17. (measure or measures or measurement).mp. [mp=ti, ab, sh, de, md, sd, hw, tn, ot, dm, mf, ac, ip, vo, pg, ar, bs, bt, cf, dp, jn, ja, yr, so, pb, nm, an, ui]
18. *Psychometrics/
19. *Sociometric techniques/
20. *Health Care Surveys/mt, st, sn
21. *Outcome Assessment, Health Care/st, sn
22. or/10-21
23. 9 and 22
24. limit 23 to english language
25. limit 24 to human

Appendix 3: Focus group participant information sheet

MANCHESTER 1824
The University of Manchester

NHS
National Institute for Health Research

School for Primary Care Research

Increasing the evidence base for

primary care practice

Participant Information Sheet

Developing a coordination of care questionnaire

Focus group discussions

Version 1.8 23/03/2010

We would like to invite you to take part in our research study. Before you decide to take part we would like you to understand why the research is being done and what it would involve for you.

Please take the time to read this and ask us if there is anything that is not clear.

What is the purpose of the study?

Some patients experience problems with the coordination of their care, especially when they receive care from a number of different people e.g. GPs, district nurses, home carers etc. This can result in people not receiving the best care. A number of different ways are being considered in order to improve care coordination but new ways / methods are needed to help decide if these changes are working. The purpose of this study is to develop a questionnaire for patients to complete which will measure their views of how coordinated their care is.

We would like you to help us in the development of the questionnaire.

Why have I been invited?

You have been sent this information sheet because you replied to our advertisement for volunteers to take part in the study.

Do I have to take part?

No. It is up to you to decide if you would like to take part in the study. We will describe the study and go through this information sheet with you. If you agree to take part, we will ask you to sign a consent form. You can change your mind about taking part at any time, without giving a reason. If you do decide to withdraw at any time, this will not affect the standard of care you receive.

What will happen to me if I take part?

If you decide to take part you will be invited to a discussion group with approximately seven other people. This discussion group will last for about one and a half hours. It will be held in Central Manchester. During this meeting we will ask the group members to talk about how their health care is coordinated and how they decide if it is well coordinated or not. This discussion will be tape-recorded. We will also take written notes during the discussion. After the discussion group has finished then we will type up the recording. You will not be identified by name in this transcript.

We will also ask you to give us some information about yourself such as your age, gender, the types of health problems you have and the number of people involved in your care.

After the discussion group you will be asked if you would like to take part in any other work to develop the questions. If you agree to this we will keep your contact details so that we may get back in touch with you.

You do not have to do anything else. We will not be making any changes to your medical treatment and you will not have to attend any extra appointments.

Expenses and payments

We will refund your travel expenses. It is important that you keep any receipts if you wish to claim for your travel.

We will also give you £20 in recognition of the time you have contributed to the study. This will not affect any benefits you may receive.

What are the possible advantages and disadvantages of taking part?

Although we cannot promise that the study will help you personally, the information you provide might help improve the way services are provided to NHS patients in the future.

What support is available to me after taking part in the focus group?

If you wish to discuss any aspects of the focus group you will be able to contact a member of the research team (see contact details below). In addition, you are advised to discuss any concerns in relation to your care with your GP or practice nurse should you wish to. We can support you to do this if you would like us to.

Will my taking part in the study be kept confidential?

We will ask that all those taking part in the focus group respect the privacy of other people in the group, and do not discuss any of their personal details outside of the group. We will not discuss anything you tell us with your healthcare provider.

All papers and notes will be kept in a locked filing cabinet or stored on a password protected computer within a locked office at the University of Manchester. Notes and computer files will not be played or shown to anyone outside the research team. We will keep information relating to the study for either 5 years after the last publication of the study or for 10 years, whichever is longer.

What will happen to the results of the research study?

We will use the results of the discussion groups to help us develop questions to be used in the questionnaire. This process will be written up for academic journals. When we write up the results all personal details will be removed so that no-one will know who you are. We may use direct quotes from the focus group discussion but no real names will be used.

If you would like a copy of the study findings please let a member of the research team know and we will send you a short summary of the research findings once the study is completed.

Who is organising and funding the research?

This study is being organised and funded by the NIHR School of Primary Care Research, University of Manchester.

Who has reviewed the study?

All research involving people is looked at by an independent group of people, called a Research Ethics Committee. This study has been reviewed and given a favourable opinion by the University of Manchester Committee on the Ethics of Research on Human Beings.

What if there is a problem?

If you have any complaints about the way you have been dealt with during the study please contact the study coordinator (see contact details below). If you are not satisfied with the study coordinator's response, or if you do not wish to raise your complaint with the study coordinator, you can contact the Head of the Research Office, Christie Building, University of Manchester, Oxford Road, Manchester, M13 9PL.

Further information and contact details

The study coordinator is:

Rachel Foskett-Tharby, Research Training Fellow

NIHR School of Primary Care Research

5th Floor,

Williamson Building

University of Manchester

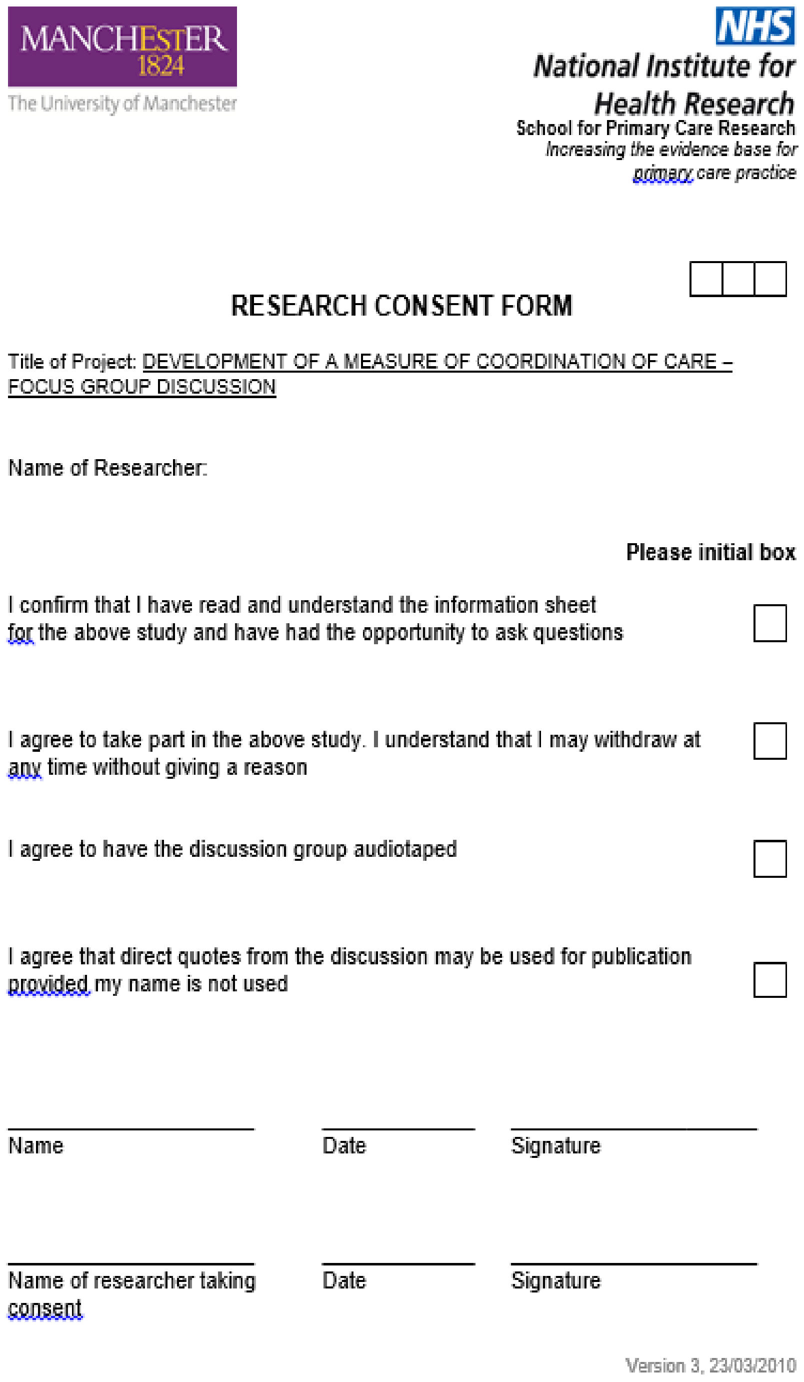
Oxford Road

M13 9PL

Tel: 0161 275 7633

Email: rachel.foskett-tharby@postgrad.manchester.ac.uk

Appendix 4: Focus group participant consent form



MANCHESTER
1824
The University of Manchester

NHS
National Institute for Health Research
School for Primary Care Research
Increasing the evidence base for primary care practice

☐☐☐

RESEARCH CONSENT FORM

Title of Project: DEVELOPMENT OF A MEASURE OF COORDINATION OF CARE – FOCUS GROUP DISCUSSION

Name of Researcher:

Please initial box

I confirm that I have read and understand the information sheet for the above study and have had the opportunity to ask questions ☐

I agree to take part in the above study. I understand that I may withdraw at any time without giving a reason ☐

I agree to have the discussion group audiotaped ☐

I agree that direct quotes from the discussion may be used for publication provided my name is not used ☐

Name ______________ Date ________ Signature ______________

Name of researcher taking consent ______________ Date ________ Signature ______________

Version 3, 23/03/2010

Appendix 5: Focus group topic guide

1. We think that coordinated care starts with a plan of care which acknowledges each of your problems. This care is then delivered in the way you expected. Thinking about the care you currently receive:
    a. Is there at least one person who you can go to in order to discuss your health and social care?
    b. Were you involved in agreeing what the most important aspects of your care are for you?
    c. Are you satisfied that the people involved in your care understand your needs?
    d. Have some of your needs been ignored by one or all of the professionals involved in your care? How often does this happen?
2. We also think that in order for care to be described as coordinated then it needs to be delivered according to this plan. Thinking about the care you currently receive:
    a. Have you been told which person would deliver each aspect of your care? If not, how often does this happen?
    b. Have you been given information about when/how long it would take for your care to be delivered?
    c. Did you get the care you expected to?
    d. Did this happen in the time you expected it to?
    e. Have you been told who to contact if something goes wrong with the arrangements for your care?
    f. When you do not receive the care you expected in the time expected were you given an explanation as to why this happened?

3. Coordinated well organised care is able to respond to any changes in your health or social circumstances:
    a. Have you been given information about who to contact if your health gets worse?
    b. When your health gets worse do the people involved in your care make changes to what they do in order to meet any new problems?
    c. How easy is it for you to make the changes to the organisation of your care?
    d. How often does this happen?
4. We are also interested in how much patients can see of the way in which the professionals involved in their care work together.
    a. Have you been given conflicting information by different people?
    b. Have you been given information which was incorrect?
    c. Do the people involved in your care tell you that another professional has not done something they were supposed to do?
    d. How often do the people involved in your care tell you that they are missing some information about your care e.g. test results, missing records.
    e. Do the people involved in your care tell you that they don't know what the others are doing for you?

Appendix 6: Cognitive interview participant information sheet

MANCHESTER
1824
The University of Manchester

NHS
National Institute for Health Research

School for Primary Care Research

Increasing the evidence base for

primary care practice

Participant Information Sheet

Developing a coordination of care questionnaire

Question testing

Version 1.8 23/03/2010

We would like to invite you to take part in our research study. Before you decide to take part we would like you to understand why the research is being done and what it would involve for you.

Please take the time to read this and ask us if there is anything that is not clear.

What is the purpose of the study?

Some patients experience problems with the coordination of their care, especially when they receive care from a number of different people e.g. GPs, district nurses, home carers etc. This can result in people not receiving the best care. A number of different ways are being considered in order to improve care coordination but new ways / methods are needed to help decide if these changes are working. The purpose of this study is to develop a questionnaire for patients to complete which will measure their views of how coordinated their care is.

We would like you to help us test the questions we have developed for our survey.

Why have I been invited?

You have been sent this information sheet because you replied to our advertisement for volunteers to take part in the study.

Do I have to take part?

No. It is up to you to decide if you would like to take part in the study. We will describe the study and go through this information sheet with you. If you agree to take part, we will ask you to sign a consent form. You can change your mind about taking part at any time, without giving a reason. If you do decide to withdraw at any time, this will not affect the standard of care you receive.

What will happen to me if I take part?

We have developed a number of questions to be used in a patient questionnaire which we would like to test with you. If you decide to take part you will be invited to an interview with one of the research team. This interview will take approximately an hour and will be held at the University of Manchester. During the interview we will read each question to you and ask you to answer it. We are interested in what you think about as you decide how to answer the question, so we will ask you to try to think aloud. We will also ask you what you think the questions mean and how they could be improved. The purpose of this is to find out if there are any problems with the way we have worded the questions.

With your consent the interview will be tape-recorded. We will also take written notes during the discussion. You will not be identified by name in this transcript.

We will also ask you to give us some information about yourself such as your age, gender, the types of health problems and the number of people involved in your care.

You do not need to do anything else. We will not be making any changes to your medical treatment and you will not have to attend extra appointments.

Expenses and payments

We will refund your travel expenses. It is important that you keep any receipts if you wish to claim for your travel.

We will also give you £20 in recognition of the time you have contributed to the study. This will not affect any benefits you may receive.

What are the possible advantages and disadvantages of taking part?

Although we cannot promise that the study will help you personally, the information you provide might help improve the way services are provided to NHS patients in the future.

What support is available to me after taking part?

If you wish to discuss any aspects of the interview you will be able to contact a member of the research team (see contact details below). In addition, you are advised to discuss any concerns in relation to your care with your GP or practice nurse should you wish to. We can support you to do this if you would like us to.

Will my taking part in the study be kept confidential?

Everything you tell us during the interview is completely confidential. We will not discuss anything you tell us with your healthcare provider.

All papers and notes will be kept in a locked filing cabinet or stored on a password protected computer within a locked office at the University of Manchester. Notes and computer files will not be played or shown to anyone outside the research team. We have to keep these files for either 5 years after the last publication of the study or for 10 years, whichever is longer.

What will happen to the results of the research study?

We will use the results of these interviews to improve the quality of the questions to be used in the questionnaire we are developing. This process will be written up for academic journals. When we write up the results all personal details will be removed so that no-one will know who you are. We may use direct quotes from the interview but no real names will be used.

If you would like a copy of the study findings please let a member of the research team know and we will send you a short summary of the research findings once the study is completed.

Who is organising and funding the research?

This study is being organised and funded by the NIHR School of Primary Care, University of Manchester.

Who has reviewed the study?

All research involving people is looked at by an independent group of people, called a Research Ethics Committee. This study has been reviewed and given a favourable opinion by the University of Manchester Committee on the Ethics of Research on Human Beings.

What if there is a problem?

If you have any complaints about the way you have been treated during the study please contact the study coordinator (see contact details below). If you are not satisfied with the study coordinator’s response, or if you do not wish to raise your complaint with the study coordinator, you can contact the Head of the Research Office, Christie Building, University of Manchester, Oxford Road, Manchester, M13 9PL.

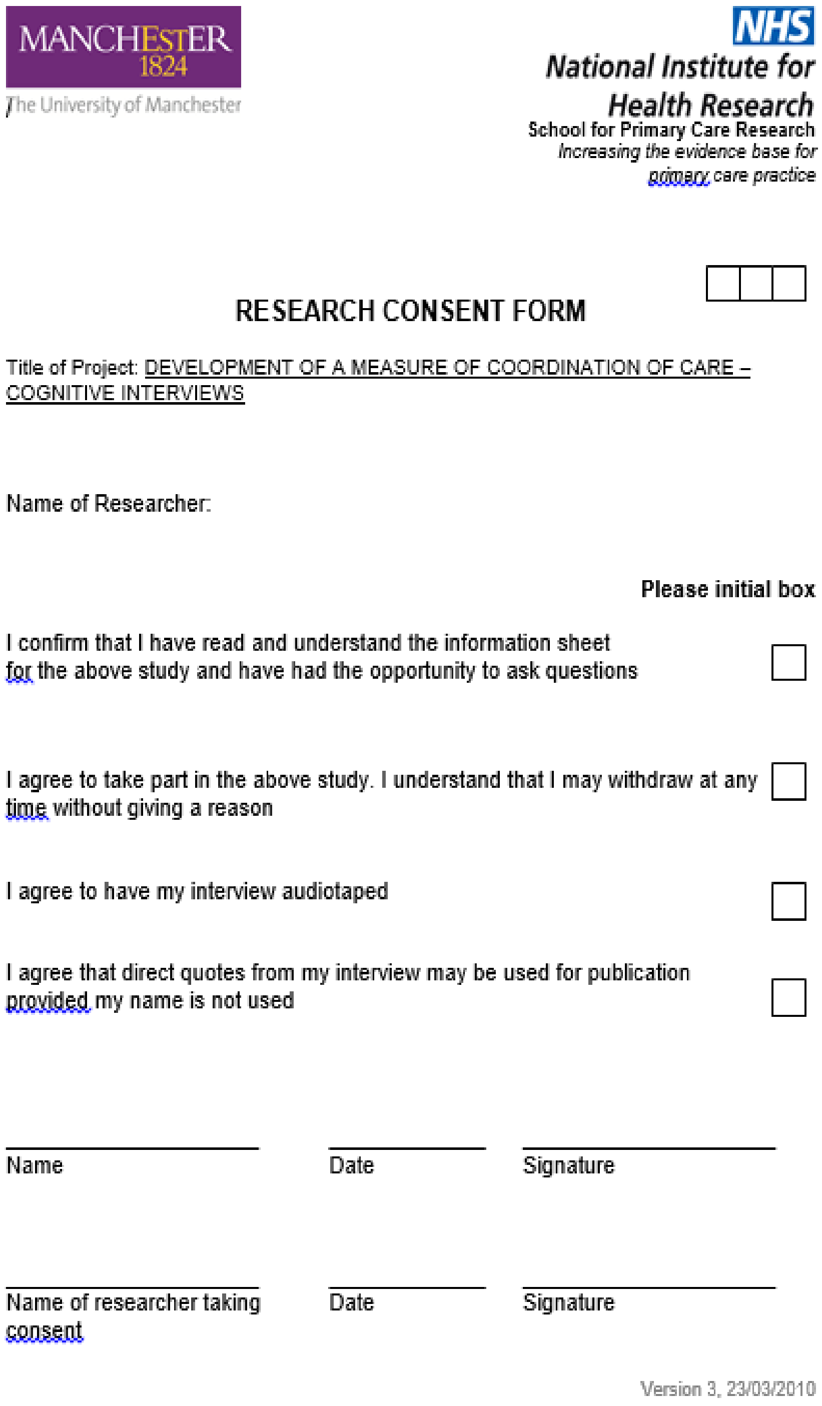
Further information and contact details

The study coordinator is:

Rachel Foskett-Tharby

Research Training Fellow
NIHR School of Primary Care Research
5th Floor, Williamson Building
University of Manchester
Oxford Road
M13 9PL
Tel: 0161 275 7633
Email: rachel.foskett-tharby@postgrad.manchester.ac.uk

Appendix 7: Cognitive interview participant consent form



MANCHESTER
1824
The University of Manchester

NHS
National Institute for
Health Research
School for Primary Care Research
Increasing the evidence base for
primary care practice

☐☐☐

RESEARCH CONSENT FORM

Title of Project: DEVELOPMENT OF A MEASURE OF COORDINATION OF CARE – COGNITIVE INTERVIEWS

Name of Researcher:

Please initial box

I confirm that I have read and understand the information sheet for the above study and have had the opportunity to ask questions ☐

I agree to take part in the above study. I understand that I may withdraw at any time without giving a reason ☐

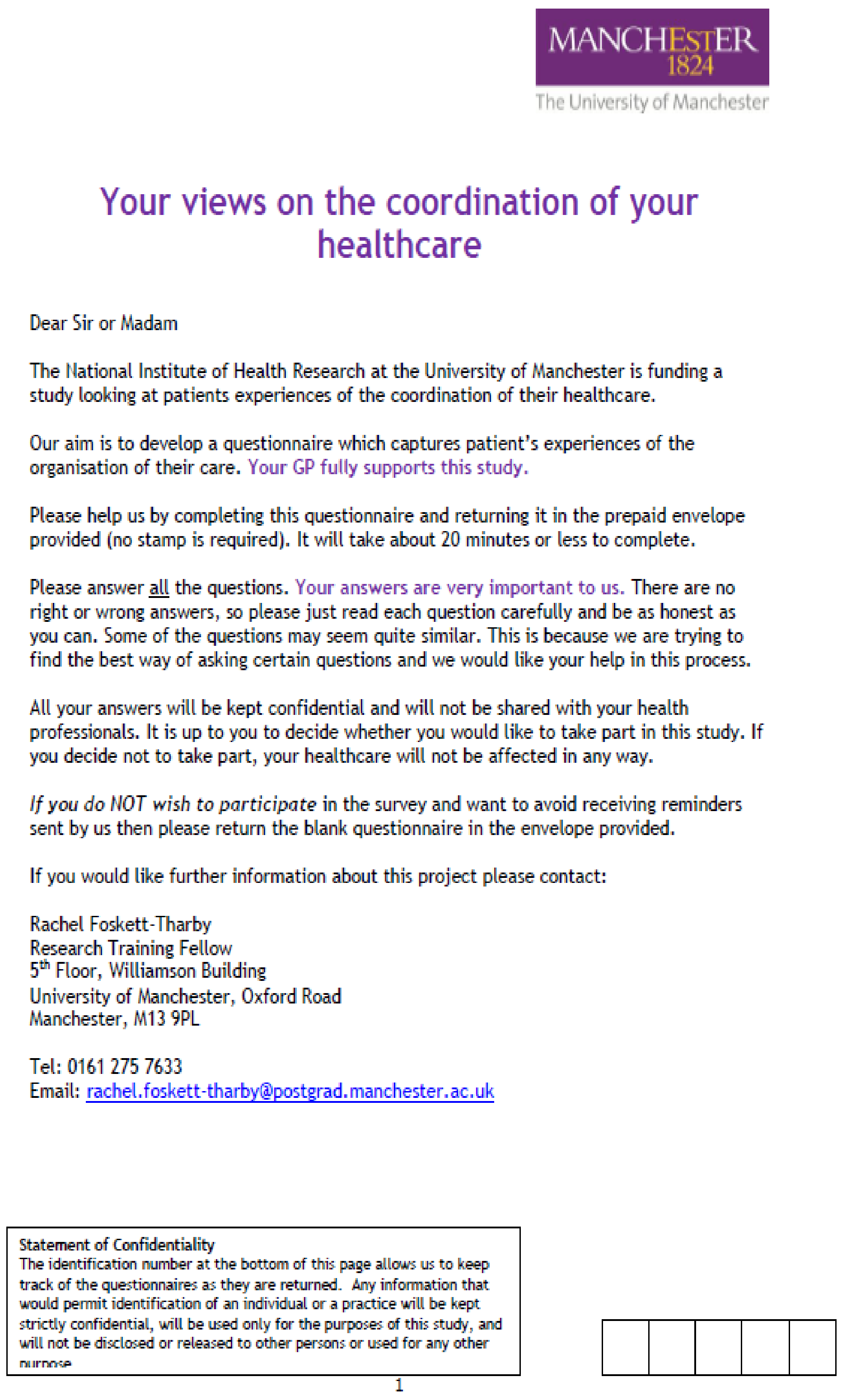
I agree to have my interview audiotaped ☐

I agree that direct quotes from my interview may be used for publication provided my name is not used ☐

Name	Date	Signature
Name of researcher taking consent	Date	Signature

Version 3, 23/03/2010

Appendix 8: Pilot version of Care Coordination Questionnaire (CCQ)



MANCHESTER
1824
The University of Manchester

Your views on the coordination of your healthcare

Dear Sir or Madam

The National Institute of Health Research at the University of Manchester is funding a study looking at patients experiences of the coordination of their healthcare.

Our aim is to develop a questionnaire which captures patient's experiences of the organisation of their care. Your GP fully supports this study.

Please help us by completing this questionnaire and returning it in the prepaid envelope provided (no stamp is required). It will take about 20 minutes or less to complete.

Please answer all the questions. Your answers are very important to us. There are no right or wrong answers, so please just read each question carefully and be as honest as you can. Some of the questions may seem quite similar. This is because we are trying to find the best way of asking certain questions and we would like your help in this process.

All your answers will be kept confidential and will not be shared with your health professionals. It is up to you to decide whether you would like to take part in this study. If you decide not to take part, your healthcare will not be affected in any way.

If you do NOT wish to participate in the survey and want to avoid receiving reminders sent by us then please return the blank questionnaire in the envelope provided.

If you would like further information about this project please contact:

Rachel Foskett-Tharby
Research Training Fellow
5th Floor, Williamson Building
University of Manchester, Oxford Road
Manchester, M13 9PL

Tel: 0161 275 7633
Email: rachel.foskett-tharby@postgrad.manchester.ac.uk

Statement of Confidentiality
The identification number at the bottom of this page allows us to keep track of the questionnaires as they are returned. Any information that would permit identification of an individual or a practice will be kept strictly confidential, will be used only for the purposes of this study, and will not be disclosed or released to other persons or used for any other purpose

1

A. About where you get your healthcare from …

1. In the last 6 months where did you get your healthcare from? (Please tick all the places that apply to you)	General Practice	☐1
	Hospital	☐2
	Community Health Service	☐3
	Other Health Service	☐4
	Social Care Service	☐5
	Other	☐6

Please think about all the professionals you have seen from these places when you are deciding how to answer the following questions. We are interested in your views of the care you have received overall from these places.

B. About your healthcare …

Please indicate how often the following happened to you in the last 6 months …

	Always	Mostly	Sometimes	Rarely	Never
1. Your healthcare professionals explained to you how they planned to address your health problems	☐1	☐2	☐3	☐4	☐5
2. Your healthcare professionals failed to understand your health problems	☐1	☐2	☐3	☐4	☐5
3. Your preferences were taken into account when decisions were made about your healthcare	☐1	☐2	☐3	☐4	☐5
4. Your healthcare professionals took notice of your views about how to manage your health problems	☐1	☐2	☐3	☐4	☐5

Please indicate how <u>often</u> the following happened to you in the last 6 months …

	Always	Mostly	Sometimes	Rarely	Never
5. You were unsure about what each of your healthcare professionals were there to do for you	☐1	☐2	☐3	☐4	☐5
6. Your healthcare professionals failed to deliver the care they said they would	☐1	☐2	☐3	☐4	☐5
7. You left an appointment unsure about what was going to happen next in your care	☐1	☐2	☐3	☐4	☐5
8. Your healthcare professionals did the things that they said they would	☐1	☐2	☐3	☐4	☐5
9. You got the care that your healthcare professionals said that you would	☐1	☐2	☐3	☐4	☐5
10. You had to wait longer than you expected before obtaining a service	☐1	☐2	☐3	☐4	☐5
11. You saw a different healthcare professional from the one you were expecting	☐1	☐2	☐3	☐4	☐5
12. One of your healthcare professionals told you they were missing information they needed, such as test results, to make decisions about your treatment	☐1	☐2	☐3	☐4	☐5
13. You felt like complaining about the way your care was organised	☐1	☐2	☐3	☐4	☐5
14. You have had problems with the coordination of your care	☐1	☐2	☐3	☐4	☐5

C. *How satisfied are you with the organisation of your care ..*

Please indicate how <u>satisfied</u> you were with the following in the last 6 months

	1=Very satisfied				5=Very Dissatisfied
1. Your preferences were taken into account when decisions were made about your care	☐1	☐2	☐3	☐4	☐5
2. Your healthcare professionals explained to you how they planned to address your health problems	☐1	☐2	☐3	☐4	☐5
3. Your healthcare professionals made arrangements for your care which were specific to you	☐1	☐2	☐3	☐4	☐5
4. The care you received took account of any special needs you had	☐1	☐2	☐3	☐4	☐5
5. The way the health service responded to any changes in your health or circumstances	☐1	☐2	☐3	☐4	☐5

D. *Making changes to your care ...*

1. Have you needed to make any changes to the arrangements for your care in the last 6 months?	Yes ☐1 No ☐2

If **'No'** then please go straight to question 4 on the following page.

2. How easy was it to make these changes?	Very easy ☐1 Easy ☐2 Not too much trouble ☐3 Difficult ☐4 Very Difficult ☐5

3. How often were you unsure about who to contact to make these changes?	Always ☐1 Mostly ☐2 Rarely ☐3 Sometimes ☐4 Never ☐5

4. Have your healthcare professionals made any changes to the organisation of your care in the last 6 months?	Yes ☐1 No ☐2

If **'No'** then please go straight to Section ***E***.

5. How satisfied were you with these changes?	Very satisfied ☐1 Satisfied ☐2 Neutral ☐3 Dissatisfied ☐4 Very dissatisfied ☐5

E. When things go wrong …

1. Did anything go wrong with the organisation of your care in the last 6 months?	Yes ☐1 No ☐2

If **'No'** then please go to Section ***F***.

2. When this happened how often were you given an explanation about what had happened?	Always ☐1 Mostly ☐2 Rarely ☐3 Sometimes ☐4 Never ☐5
3. How satisfied were you with these explanations?	Very satisfied ☐1 Satisfied ☐2 Neutral ☐3 Dissatisfied ☐4 Very dissatisfied ☐5

F. About your healthcare professionals …

How often have the following happened to you in the last 6 months …

	Always	Mostly	Sometimes	Rarely	Never
1. One of your healthcare professionals seemed unaware of what others were doing for you	☐1	☐2	☐3	☐4	☐5
2. One healthcare professional told you one thing about your care and another said something quite different	☐1	☐2	☐3	☐4	☐5
3. One of your healthcare professionals was critical of the care given to you by another professional	☐1	☐2	☐3	☐4	☐5
4. Your healthcare professionals appeared to disagree with each other about the best care for you	☐1	☐2	☐3	☐4	☐5

G. Overall view on the organisation of your care …

1. Overall, how would you rate the coordination of your care over the last 6 months?	Excellent ☐1 Good ☐2 Acceptable ☐3 Poor ☐4 Very poor ☐5

H. Your care overall …

Please think about your care over the **last 6 months** when deciding how to answer these questions

	Always	Mostly	Sometimes	Rarely	Never	Not applicable
1. How often did you get the services you thought you needed?	☐1	☐2	☐3	☐4	☐5	
2. How often did you have to wait too long to obtain a service/ appointment?	☐1	☐2	☐3	☐4	☐5	
3. How often was it difficult to get transport to services?	☐1	☐2	☐3	☐4	☐5	
4. In the past 6 months, how often did you seem to receive the medicines you thought you needed?	☐1	☐2	☐3	☐4	☐5	☐6
5. How often did providers seem to be unnecessarily repeating tests or assessments?	☐1	☐2	☐3	☐4	☐5	☐6
6. How often were the results of tests or assessments discussed with you, eg blood tests?	☐1	☐2	☐3	☐4	☐5	☐6
7. In the past 6 months, how often did you feel the care you received was well coordinated?	☐1	☐2	☐3	☐4	☐5	
8. How often were you happy with the quality of care you received?	☐1	☐2	☐3	☐4	☐5	
9. How often were you confused about the roles of different service providers?	☐1	☐2	☐3	☐4	☐5	☐6
10. In the past 6 months, how often have service providers responded appropriately to changes in your needs?	☐1	☐2	☐3	☐4	☐5	☐6
11. How often did you seem to be getting conflicting advice from service providers?	☐1	☐2	☐3	☐4	☐5	☐6
12. In the past 6 months, how often have you felt like complaining about any of your care?	☐1	☐2	☐3	☐4	☐5	

	Very	Fairly	Not at all
13. How well do you feel you understand your conditions?	☐1	☐2	☐3
14. How well do you feel you can cope with life?	☐1	☐2	☐3

15. Overall, how satisfied are you with the care you have received in the past 6 months?	Very satisfied ☐1 Satisfied ☐2 Neutral ☐3 Dissatisfied ☐4 Very dissatisfied ☐5

I. You and your GP

Please think about your care over the **last 6 months** when deciding how to answer these questions

	Always	Mostly	Sometimes	Rarely	Never	Not applicable
1. How often did you and your GP agree about your care needs?	☐1	☐2	☐3	☐4	☐5	
2. How often did your GP seem to be communicating with your other providers?	☐1	☐2	☐3	☐4	☐5	
3. How often did your GP involve you when making decisions about your care?	☐1	☐2	☐3	☐4	☐5	☐6
4. How often does your GP talk with you about your future care?	☐1	☐2	☐3	☐4	☐5	

5. How important is it to you to be involved in decisions with your GP about your care?	Not at all ☐1 Somewhat important ☐2 Very important ☐3

J. You and other professionals …

1. Do you currently have a 'case manager'? A case manager is a person who is employed specifically to help you organise your care	Yes ☐1 No ☐2

If 'yes' please go to question 4 below

2. Is your GP the only service provider you have seen in the past 6 months?	Yes ☐1 No ☐2

If 'yes' please go to Section *K* below

3. Please nominate one service provider, other than your GP, whom you have seen in the past 6 months	Specialist ☐1 Nurse ☐2 Home care worker ☐3 Social worker ☐4 Other ☐5

Please think about the service provider you nominated in question 3 when deciding how to answer the following questions

	Always	Mostly	Sometimes	Rarely	Never	Not applicable
4. How often did you and that service provider agree about your care needs?	☐1	☐2	☐3	☐4	☐5	
5. How often did that service provider seem to be communicating with your other providers?	☐1	☐2	☐3	☐4	☐5	
6. How often did that service provider involve you when making decisions about your care?	☐1	☐2	☐3	☐4	☐5	☐6
7. How often does that service provider talk with you about your future care?	☐1	☐2	☐3	☐4	☐5	

8. How important is it to you to be involved in decisions with that service provider about your care?	Not at all ☐1 Somewhat important ☐2 Very important ☐3

K. Your carers …

1. Who are your carers? A carer is someone you rely on to help with daily life but is not paid to do so i.e. a relative or friend	None ☐1 Spouse or partner ☐2 Parent ☐3 Son or daughter ☐4 Other family member ☐5 Friend ☐6 Other ☐7

If you answered **'none'** please go to Section *L*

	Always	Mostly	Sometimes	Rarely	Never
2. In the past 6 months, how often do you think your main carer was involved in making decisions about your care?	☐1	☐2	☐3	☐4	☐5
3. In the past 6 months, how often do you think your main carer was satisfied with the care you received?	☐1	☐2	☐3	☐4	☐5

L. Completing this form …

1. Who completed this form?	I did ☐1 I did with help ☐2 My carer ☐3

M. About you …

Please tick the appropriate box or write in the space provided.

1. Are you?	Male ☐1 Female ☐2

2. How old are you?	________years

3. What ethnic group do you belong to? *(Please tick one box only)*					
White	☐1	Black or Black British	☐2	Asian or Asian British	☐3
Chinese	☐4	Mixed ethnicity	☐5		
Other	☐6	Please specify			

4. Which of these qualifications do you have? *(Please tick all that apply)*	
1 or more O levels/ CSE/ GCSEs (any grade)	☐1
1 or more A levels or AS levels	☐2
Degree	☐3
NVQ	☐4
Other trade qualification	☐5
A professional qualification	☐6
No qualifications	☐7

5. Which of these best describes your current work situation? *(Please tick all that apply)*	
In paid work (full or part time including self employed)	☐1
Unemployed	☐2
Retired from paid work	☐3
Unable to work because of long term disability or ill-health	☐4
Looking after the family or home	☐5
In full-time education or training	☐6
Voluntary work	☐7
Other	☐8

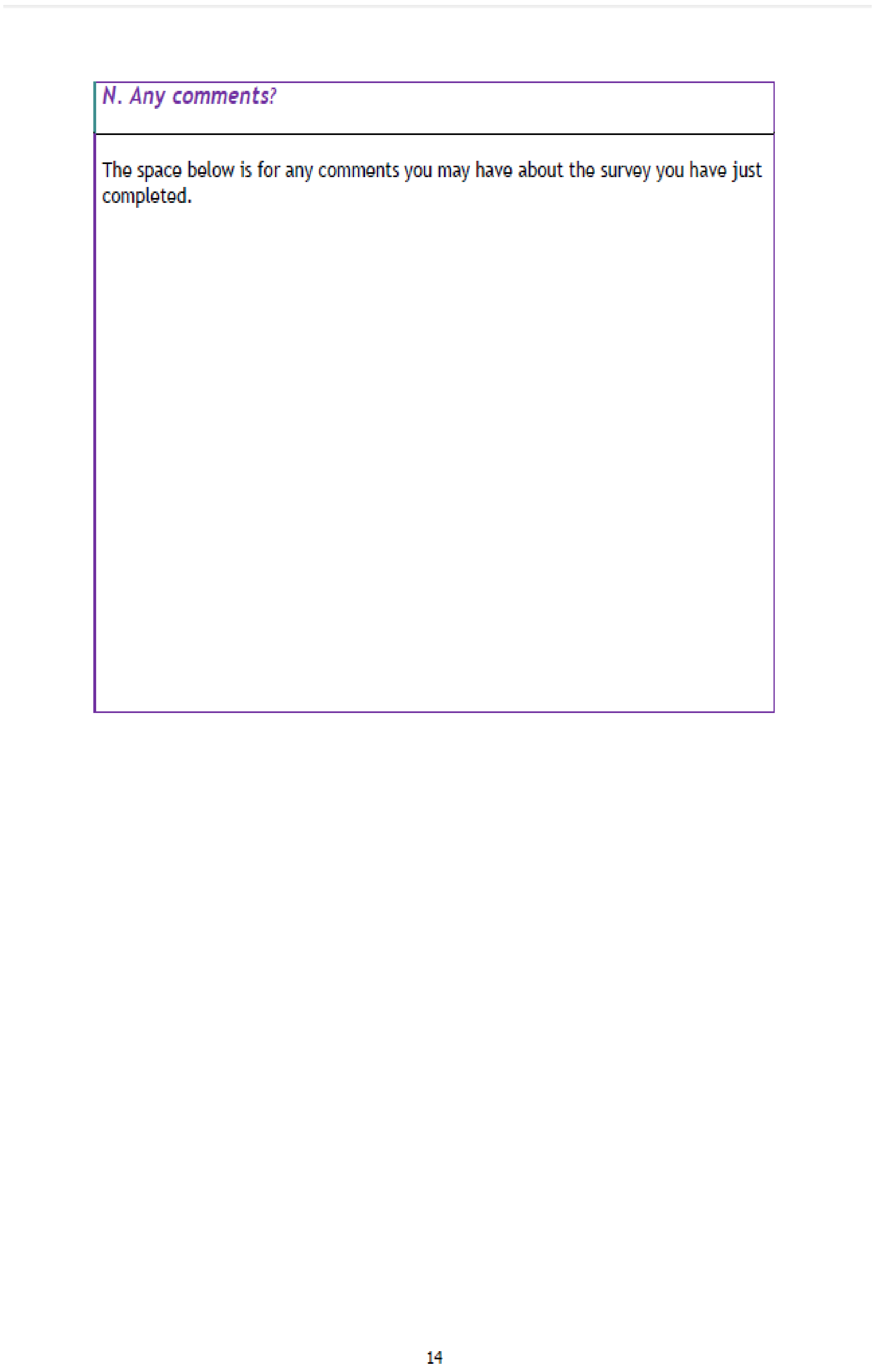
If other please describe:

6. Is your accommodation: *(Please tick one box only)*	
Owner-occupied/ mortgaged	☐1
Rented from local authority/ housing association	☐2
Rented from a private landlord	☐3
Other arrangements	☐4

If other please describe:

7. In general, how would you rate your health over the last 6 months?	
Excellent	☐1
Very good	☐2
Good	☐3
Fair	☐4
Poor	☐5

8. Which of the following conditions do you have? *(Please tick all that apply)*	
Diabetes	☐1
Chronic obstructive pulmonary disease (COPD)	☐2
Rheumatoid arthritis	☐3
Multiple sclerosis	☐4
Systemic lupus erythematosus	☐5
Sickle cell disease or thalassaemia	☐6
Haemophilia, haemochromatosis or other blood disorder	☐7
Coronary heart disease	☐8
Irritable bowel syndrome (IBS) or abdominal (tummy) problems	☐9
Other arthritis or painful joints, back trouble, osteoporosis	☐10
Heart problems or high blood pressure	☐11
Anxiety, depression or stress	☐12
Other conditions	☐13
If other, please give details	



N. Any comments?

The space below is for any comments you may have about the survey you have just completed.

14

O. Your contact details

This questionnaire has been sent to you directly by your GP. The research team does not have your contact details.

We are looking for volunteers to complete a second questionnaire for us. This would be sent to you in 2-4 weeks time. It will take about 10 minutes to complete and will ask similar questions to this one.

If you would be willing to complete a second questionnaire for us please write your contact details in the space below so that we can send you the questionnaire. Your contact details will be separated from the rest of the questionnaire and will not be given to any other person or used for any other purpose.

Name: ....

Address: ....

....

....

....

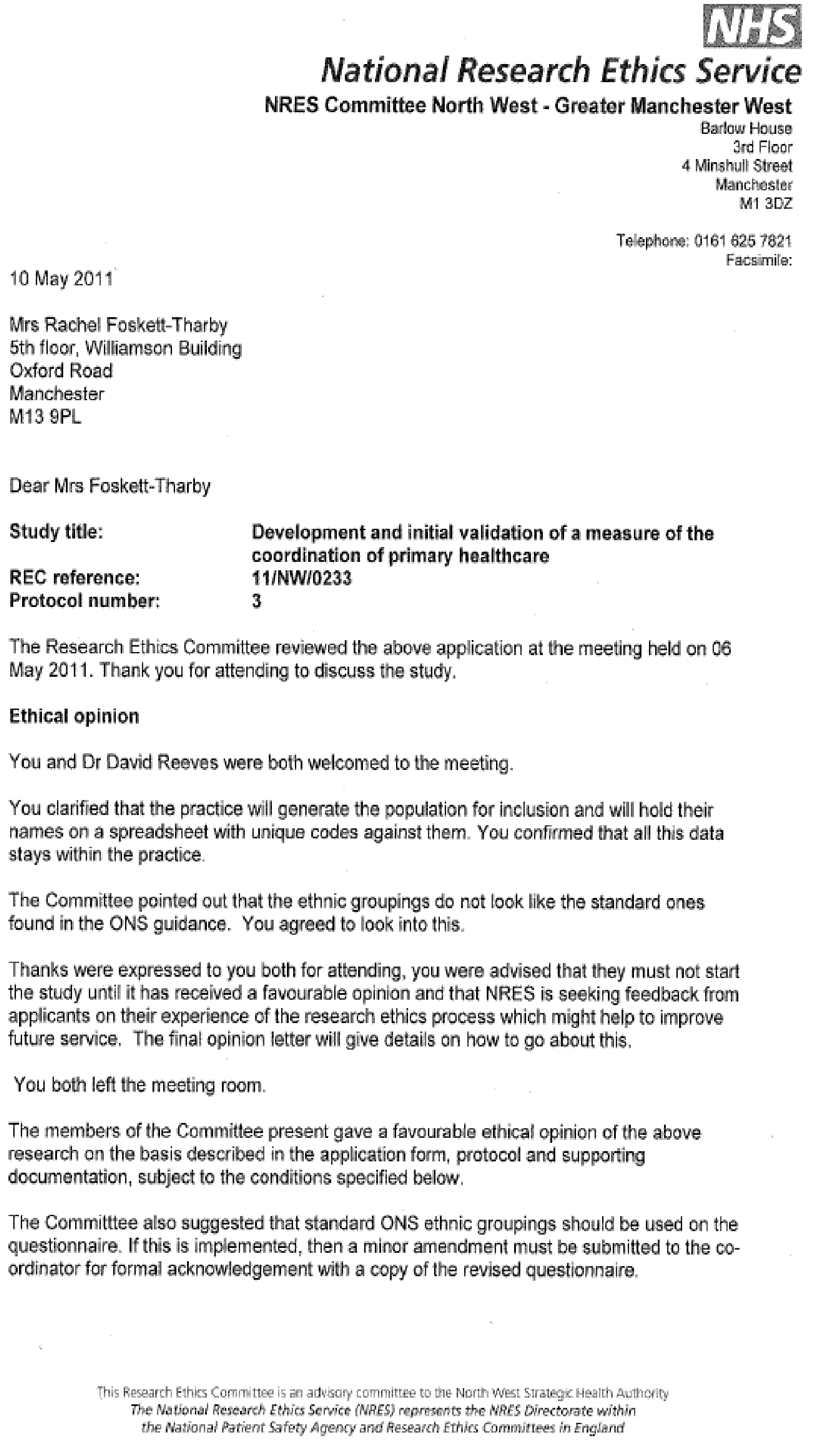
Please return your questionnaire in the enclosed prepaid envelope

(no stamp is required)

Thank you very much for taking part

Sections H - L of this questionnaire have been taken from the Client Perceptions of Coordination Questionnaire developed by McGuiness and Sibthorpe (2003). Sections A - G have been developed specifically for this research.

Appendix 9: Ethics Committee approval letter



NHS
National Research Ethics Service
NRES Committee North West - Greater Manchester West
Barlow House
3rd Floor
4 Minshull Street
Manchester
M1 3DZ

Telephone: 0161 625 7821
Facsimile:

10 May 2011

Mrs Rachel Foskett-Tharby
5th floor, Williamson Building
Oxford Road
Manchester
M13 9PL

Dear Mrs Foskett-Tharby

Study title: **Development and initial validation of a measure of the coordination of primary healthcare**
REC reference: **11/NW/0233**
Protocol number: **3**

The Research Ethics Committee reviewed the above application at the meeting held on 06 May 2011. Thank you for attending to discuss the study.

Ethical opinion

You and Dr David Reeves were both welcomed to the meeting.

You clarified that the practice will generate the population for inclusion and will hold their names on a spreadsheet with unique codes against them. You confirmed that all this data stays within the practice.

The Committee pointed out that the ethnic groupings do not look like the standard ones found in the ONS guidance. You agreed to look into this.

Thanks were expressed to you both for attending, you were advised that they must not start the study until it has received a favourable opinion and that NRES is seeking feedback from applicants on their experience of the research ethics process which might help to improve future service. The final opinion letter will give details on how to go about this.

You both left the meeting room.

The members of the Committee present gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below.

The Committtee also suggested that standard ONS ethnic groupings should be used on the questionnaire. If this is implemented, then a minor amendment must be submitted to the co-ordinator for formal acknowledgement with a copy of the revised questionnaire.

This Research Ethics Committee is an advisory committee to the North West Strategic Health Authority
The National Research Ethics Service (NRES) represents the NRES Directorate within the National Patient Safety Agency and Research Ethics Committees in England

Ethical review of research sites

NHS Sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at http://www.rdforum.nhs.uk.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations

It is responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Approved documents

The documents reviewed and approved at the meeting were:

Document	*Version*	*Date*
Protocol	3	25 February 2011
Investigator CV	Rachel Foskett-Tharby	31 March 2011
Investigator CV	Bonnie Sibbald	
Investigator CV	David Reeves	
Investigator CV	Elaine Harkness	
Questionnaire: Initial coordination questionnaire	5	15 March 2011
Evidence of insurance or indemnity	The University of Manchester	30 March 2011
Questionnaire: Second coordination questionnaire	1	15 March 2011
Covering Letter		31 March 2011
Letter from Sponsor	The University of Manchester	30 March 2011
REC application	3.1	31 March 2011

Membership of the Committee

The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Now that you have completed the application process please visit the National Research Ethics Service website > After Review

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

We would also like to inform you that we consult regularly with stakeholders to improve our service. If you would like to join our Reference Group please email referencegroup@nres.npsa.nhs.uk.

11/NW/0233	**Please quote this number on all correspondence**

With the Committee's best wishes for the success of this project

Yours sincerely

pp

Dr Lorraine Lighton
Chair

Email: Shehnaz.ishaq@northwest.nhs.uk

Enclosures:	List of names and professions of members who were present at the meeting and those who submitted written comments "After ethical review – guidance for researchers"

Appendix 10: Frequency of responses by item

Item B1: HCP explained how they intended to address problems

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	never	1	.7	.7	.7
	rarely	2	1.3	1.3	2.0
	sometimes	11	7.2	7.3	9.3
	mostly	50	32.7	33.1	42.4
	always	87	56.9	57.6	100.0
	Total	151	98.7	100.0	
Missing	99	2	1.3		
Total		153	100.0		

Item B2: HCP failed to understand problems

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	always	4	2.6	2.8	2.8
	mostly	6	3.9	4.2	7.0
	sometimes	19	12.4	13.3	20.3
	rarely	47	30.7	32.9	53.1
	never	67	43.8	46.9	100.0
	Total	143	93.5	100.0	
Missing	88	1	.7		
	99	9	5.9		
	Total	10	6.5		
Total		153	100.0		

Item B3: preferences taken into account when making decisions

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	never	2	1.3	1.4	1.4
	rarely	5	3.3	3.4	4.7
	sometimes	20	13.1	13.5	18.2
	mostly	52	34.0	35.1	53.4
	always	69	45.1	46.6	100.0
	Total	148	96.7	100.0	
Missing	99	5	3.3		
Total		153	100.0		

Item B4: HCP took notice of views about how to manage health problems

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	never	2	1.3	1.3	1.3
	rarely	4	2.6	2.7	4.0
	sometimes	16	10.5	10.7	14.8
	mostly	53	34.6	35.6	50.3
	always	74	48.4	49.7	100.0
	Total	149	97.4	100.0	
Missing	99	4	2.6		
Total		153	100.0		

Item B5: unsure about what HCPs there to do

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	always	7	4.6	4.7	4.7
	mostly	11	7.2	7.3	12.0
	sometimes	35	22.9	23.3	35.3
	rarely	31	20.3	20.7	56.0
	never	66	43.1	44.0	100.0
	Total	150	98.0	100.0	
Missing	99	3	2.0		
Total		153	100.0		

Item B6: HCPs failed to deliver care

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	always	2	1.3	1.4	1.4
	mostly	6	3.9	4.1	5.5
	sometimes	14	9.2	9.7	15.2
	rarely	39	25.5	26.9	42.1
	never	84	54.9	57.9	100.0
	Total	145	94.8	100.0	
Missing	99	8	5.2		
Total		153	100.0		

Item B7: unsure of what was going to happen next in care

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	always	1	.7	.7	.7
	mostly	5	3.3	3.3	4.0
	sometimes	25	16.3	16.6	20.5
	rarely	39	25.5	25.8	46.4
	never	81	52.9	53.6	100.0
	Total	151	98.7	100.0	
Missing	99	2	1.3		
Total		153	100.0		

Item B8: HCPs did things they said they would

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	never	5	3.3	3.3	3.3
	rarely	3	2.0	2.0	5.3
	sometimes	5	3.3	3.3	8.7
	mostly	51	33.3	34.0	42.7
	always	86	56.2	57.3	100.0
	Total	150	98.0	100.0	
Missing	99	3	2.0		
Total		153	100.0		

Item B9: received care HCPs said you would

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	never	4	2.6	2.6	2.6
	rarely	2	1.3	1.3	4.0
	sometimes	7	4.6	4.6	8.6
	mostly	47	30.7	31.1	39.7
	always	91	59.5	60.3	100.0
	Total	151	98.7	100.0	
Missing	99	2	1.3		
Total		153	100.0		

Item B10: waiting longer than expected for a service

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	always	9	5.9	6.0	6.0
	mostly	9	5.9	6.0	11.9
	sometimes	53	34.6	35.1	47.0
	rarely	45	29.4	29.8	76.8
	never	35	22.9	23.2	100.0
	Total	151	98.7	100.0	
Missing	88	1	.7		
	99	1	.7		
	Total	2	1.3		
Total		153	100.0		

Item B11: saw a different HCP to the one you were expecting

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	always	4	2.6	2.6	2.6
	mostly	8	5.2	5.3	7.9
	sometimes	55	35.9	36.4	44.4
	rarely	36	23.5	23.8	68.2
	never	48	31.4	31.8	100.0
	Total	151	98.7	100.0	
Missing	99	2	1.3		
Total		153	100.0		

Item B12: HCPs missing necessary information

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	always	1	.7	.7	.7
	mostly	4	2.6	2.6	3.3
	sometimes	25	16.3	16.6	19.9
	rarely	29	19.0	19.2	39.1
	never	92	60.1	60.9	100.0
	Total	151	98.7	100.0	
Missing	99	2	1.3		
Total		153	100.0		

Item B13: felt like complaining about way care was organised

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	mostly	3	2.0	2.0	2.0
	sometimes	22	14.4	14.7	16.7
	rarely	27	17.6	18.0	34.7
	never	98	64.1	65.3	100.0
	Total	150	98.0	100.0	
Missing	99	3	2.0		
Total		153	100.0		

Item B14: problems with the coordination of care

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	mostly	5	3.3	3.3	3.3
	sometimes	18	11.8	11.9	15.2
	rarely	28	18.3	18.5	33.8
	never	100	65.4	66.2	100.0
	Total	151	98.7	100.0	
Missing	99	2	1.3		
Total		153	100.0		

Item C1: satisfied preferences taken into account

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	very dissatisfied	3	2.0	2.0	2.0
	dissatisfied	2	1.3	1.4	3.4
	neutral	19	12.4	12.8	16.2
	satisfied	43	28.1	29.1	45.3
	very satisfied	81	52.9	54.7	100.0
	Total	148	96.7	100.0	
Missing	77	2	1.3		
	88	1	.7		
	99	2	1.3		
	Total	5	3.3		
Total		153	100.0		

Item C2: satisfied with explanation of plan to address health problems

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	very dissatisfied	3	2.0	2.0	2.0
	disatisfied	2	1.3	1.3	3.3
	neutral	10	6.5	6.6	9.9
	satisfied	47	30.7	31.1	41.1
	very satisfied	89	58.2	58.9	100.0
	Total	151	98.7	100.0	
Missing	77	2	1.3		
Total		153	100.0		

Item C3: satisfied care arrangements specific

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	very dissatisfied	3	2.0	2.0	2.0
	dissatisfied	4	2.6	2.7	4.7
	neutral	10	6.5	6.8	11.5
	satisfied	43	28.1	29.1	40.5
	very satisfied	88	57.5	59.5	100.0
	Total	148	96.7	100.0	
Missing	77	2	1.3		
	99	3	2.0		
	Total	5	3.3		
Total		153	100.0		

Item C4: satisfied care took account of special needs

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	very dissatisfied	5	3.3	3.4	3.4
	dissatisfied	5	3.3	3.4	6.8
	neutral	10	6.5	6.8	13.5
	satisfied	49	32.0	33.1	46.6
	very satisfied	79	51.6	53.4	100.0
	Total	148	96.7	100.0	
Missing	77	2	1.3		
	99	3	2.0		
	Total	5	3.3		
Total		153	100.0		

Item C5: satisfied with response to change in health or circumstances

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	very dissatisfied	3	2.0	2.0	2.0
	dissatisfied	6	3.9	4.1	6.1
	neutral	15	9.8	10.1	16.2
	satisfied	50	32.7	33.8	50.0
	very satisfied	74	48.4	50.0	100.0
	Total	148	96.7	100.0	
Missing	77	2	1.3		
	99	3	2.0		
	Total	5	3.3		
Total		153	100.0		

Item D1: needed to make changes to care

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	yes	32	20.9	21.3	21.3
	no	118	77.1	78.7	100.0
	Total	150	98.0	100.0	
Missing	77	2	1.3		
	99	1	.7		
	Total	3	2.0		
Total		153	100.0		

Item D2: ease of making changes

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	very difficult	1	.7	.7	.7
	difficult	1	.7	.7	1.3
	not too much trouble	9	5.9	6.0	7.4
	easy	12	7.8	8.1	15.4
	very easy or no change	126	82.4	84.6	100.0
	Total	149	97.4	100.0	
Missing	77	2	1.3		
	99	2	1.3		
	Total	4	2.6		
Total		153	100.0		

Item D3: unsure about who to contact to make changes

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	always	1	.7	.7	.7
	mostly	2	1.3	1.3	2.0
	sometimes	7	4.6	4.6	6.6
	rarely	11	7.2	7.3	13.9
	never or no changes	130	85.0	86.1	100.0
	Total	151	98.7	100.0	
Missing	77	2	1.3		
Total		153	100.0		

Item D4: HCPs made changes to care

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	yes	34	22.2	23.8	23.8
	no	109	71.2	76.2	100.0
	Total	143	93.5	100.0	
Missing	77	2	1.3		
	99	8	5.2		
	Total	10	6.5		
Total		153	100.0		

Item D5: satisfaction with these changes

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	very dissatisfied	1	.7	.7	.7
	dissatisfied	4	2.6	2.8	3.5
	neutral	6	3.9	4.2	7.7
	satisfied	14	9.2	9.9	17.6
	very satisfied or no changes	117	76.5	82.4	100.0
	Total	142	92.8	100.0	
Missing	77	2	1.3		
	99	9	5.9		
	Total	11	7.2		
Total		153	100.0		

Item E1: things going wrong with organisation of care

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	yes	15	9.8	10.1	10.1
	no	133	86.9	89.9	100.0
	Total	148	96.7	100.0	
Missing	77	2	1.3		
	99	3	2.0		
	Total	5	3.3		
Total		153	100.0		

Item E2: how often given an explanation as to what went wrong

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	never	4	2.6	2.7	2.7
	rarely	3	2.0	2.0	4.7
	sometimes	4	2.6	2.7	7.4
	mostly	3	2.0	2.0	9.5
	always or no error	134	87.6	90.5	100.0
	Total	148	96.7	100.0	
Missing	77	2	1.3		
	99	3	2.0		
	Total	5	3.3		
Total		153	100.0		

Item E3: how satisfied were you with explanations

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	very dissatisfied	3	2.0	2.0	2.0
	dissatisfied	4	2.6	2.7	4.7
	neutral	4	2.6	2.7	7.4
	satisfied	5	3.3	3.4	10.8
	very satisfied or no error	132	86.3	89.2	100.0
	Total	148	96.7	100.0	
Missing	77	2	1.3		
	99	3	2.0		
	Total	5	3.3		
Total		153	100.0		

Item F1: one HCP unaware of what others doing

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	mostly	5	3.3	3.4	3.4
	sometimes	20	13.1	13.6	17.0
	rarely	34	22.2	23.1	40.1
	never	88	57.5	59.9	100.0
	Total	147	96.1	100.0	
Missing	77	1	.7		
	88	1	.7		
	99	4	2.6		
	Total	6	3.9		
Total		153	100.0		

Item F2: HCP giving conflicting advice

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	mostly	4	2.6	2.7	2.7
	sometimes	20	13.1	13.6	16.3
	rarely	31	20.3	21.1	37.4
	never	92	60.1	62.6	100.0
	Total	147	96.1	100.0	
Missing	77	1	.7		
	99	5	3.3		
	Total	6	3.9		
Total		153	100.0		

Item F3: One HCP critical of another

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	mostly	1	.7	.7	.7
	sometimes	5	3.3	3.4	4.1
	rarely	17	11.1	11.6	15.6
	never	124	81.0	84.4	100.0
	Total	147	96.1	100.0	
Missing	77	1	.7		
	99	5	3.3		
	Total	6	3.9		
Total		153	100.0		

Item F4: HCPs appeared to disagree with each other

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	always	1	.7	.7	.7
	sometimes	4	2.6	2.7	3.4
	rarely	20	13.1	13.6	17.0
	never	122	79.7	83.0	100.0
	Total	147	96.1	100.0	
Missing	77	1	.7		
	99	5	3.3		
	Total	6	3.9		
Total		153	100.0		

Item G1: coordination rating in last 6 months

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	very poor	1	.7	.7	.7
	poor	2	1.3	1.3	2.0
	acceptable	16	10.5	10.7	12.7
	good	56	36.6	37.3	50.0
	excellent	75	49.0	50.0	100.0
	Total	150	98.0	100.0	
Missing	77	1	.7		
	99	2	1.3		
	Total	3	2.0		
Total		153	100.0		

Appendix 11: Inter-item correlations

Correlations

		B1	B2	B3	B4	B5	B6	B7	B8	B9	B10	B11	B12	B13	B14	D2	D3	D5	E2	E3	F1	F2	F3	F4	G1
B1: HCP explained how	Correlation Coefficient	1.000	.317**	.561**	.620**	.383**	.450**	.459**	.527**	.550**	.384**	.331**	.273**	.425**	.475**	.151	.154	.123	.204*	.167*	.422**	.357**	.310**	.306**	.492**
	Sig. (2-tailed)		.000	.000	.000	.000	.000	.000	.000	.000	.000	.000	.001	.000	.000	.067	.059	.143	.013	.042	.000	.000	.000	.000	.000
	N	151	142	146	147	148	143	149	148	149	149	149	149	148	149	149	151	142	148	148	145	145	145	145	148
B2: HCP failed to understand	Correlation Coefficient	.317**	1.000	.266**	.328**	.396**	.382**	.420**	.422**	.471**	.218**	.337**	.318**	.355**	.390**	.088	.035	.039	.048	.082	.563**	.480**	.350**	.394**	.322**
	Sig. (2-tailed)	.000		.001	.000	.000	.000	.000	.000	.000	.009	.000	.000	.000	.000	.301	.681	.657	.568	.335	.000	.000	.000	.000	.000
	N	142	143	141	141	141	138	143	141	141	142	143	142	142	143	141	143	135	141	141	138	139	139	139	140
B3: preferences taken into	Correlation Coefficient	.561**	.266**	1.000	.701**	.201*	.349**	.407**	.420**	.468**	.357**	.257**	.217**	.302**	.329**	.127	.090	.145	.076	.066	.370**	.332**	.203*	.212*	.299**
	Sig. (2-tailed)	.000	.001		.000	.015	.000	.000	.000	.000	.000	.002	.008	.000	.000	.127	.276	.087	.365	.431	.000	.000	.014	.011	.000
	N	146	141	148	147	146	141	147	146	146	147	147	147	146	147	146	148	140	146	146	143	145	145	145	146
B4: HCP took notice of views	Correlation Coefficient	.620**	.328**	.701**	1.000	.254**	.457**	.435**	.511**	.571**	.356**	.269**	.270**	.394**	.451**	.171*	.181*	.175*	.187*	.202*	.426**	.378**	.298**	.273**	.404**
	Sig. (2-tailed)	.000	.000	.000		.002	.000	.000	.000	.000	.000	.001	.001	.000	.000	.039	.027	.039	.024	.015	.000	.000	.000	.001	.000
	N	147	141	147	149	147	142	148	147	147	148	148	148	147	148	147	149	140	146	146	144	145	145	145	147
B5: unsure about what HCPs there	Correlation Coefficient	.383**	.396**	.201*	.254**	1.000	.351**	.489**	.259**	.291**	.283**	.395**	.272**	.265**	.277**	.108	.183*	.064	.082	.084	.430**	.380**	.269**	.273**	.329**
	Sig. (2-tailed)	.000	.000	.015	.002		.000	.000	.001	.000	.000	.000	.001	.001	.001	.190	.025	.450	.322	.309	.000	.000	.001	.001	.000
	N	148	141	146	147	150	144	149	148	148	149	149	149	148	149	148	150	141	147	147	144	145	145	145	147
B6: HCPs failed to deliver care	Correlation Coefficient	.450**	.382**	.349**	.457**	.351**	1.000	.459**	.485**	.573**	.316**	.283**	.273**	.571**	.463**	.199*	.042	.130	.257**	.261**	.387**	.362**	.394**	.365**	.439**
	Sig. (2-tailed)	.000	.000	.000	.000	.000		.000	.000	.000	.000	.001	.001	.000	.000	.017	.613	.131	.002	.002	.000	.000	.000	.000	.000
	N	143	138	141	142	144	145	145	144	144	144	145	144	145	145	143	145	136	142	142	140	141	141	142	142
B7: unsure of what was going to happen	Correlation Coefficient	.459**	.420**	.407**	.435**	.489**	.459**	1.000	.414**	.408**	.499**	.423**	.326**	.378**	.507**	.029	.126	.220**	.136	.166*	.416**	.410**	.310**	.272**	.459**
	Sig. (2-tailed)	.000	.000	.000	.000	.000	.000		.000	.000	.000	.000	.000	.000	.000	.722	.123	.008	.099	.044	.000	.000	.000	.001	.000
	N	149	143	147	148	149	145	151	149	149	150	151	150	150	151	149	151	142	148	148	146	147	147	147	148
B8: HCPs did things	Correlation Coefficient	.527**	.422**	.420**	.511**	.259**	.485**	.414**	1.000	.758**	.239**	.248**	.372**	.421**	.435**	.147	.094	.177*	.147	.165*	.439**	.402**	.274**	.274**	.412**

	Sig. (2-tailed)	.000	.000	.000	.000	.001	.000	.000		.000	.003	.002	.000	.000	.000	.075	.255	.036	.075	.046	.000	.000	.001	.001	.000
	N	148	141	146	147	148	144	149	150	148	149	149	149	148	149	148	150	141	147	147	144	145	145	145	147
B9: received care HCPs said	Correlation Coefficient	.550**	.471**	.468**	.571**	.291**	.573**	.408**	.758**	1.000	.312**	.276**	.263**	.519**	.534**	.207*	.153	.240**	.220**	.186*	.523**	.405**	.375**	.305**	.427**
	Sig. (2-tailed)	.000	.000	.000	.000	.000	.000	.000	.000		.000	.001	.001	.000	.000	.011	.061	.004	.007	.024	.000	.000	.000	.000	.000
	N	149	141	146	147	148	144	149	148	151	149	149	149	149	149	149	151	142	148	148	145	145	145	145	148
B10: waiting longer than	Correlation Coefficient	.384**	.218**	.357**	.356**	.283**	.316**	.499**	.239**	.312**	1.000	.396**	.222**	.488**	.453**	.217**	.190*	.244**	.213**	.220**	.321**	.234**	.080	.125	.463**
	Sig. (2-tailed)	.000	.009	.000	.000	.000	.000	.000	.003	.000		.000	.006	.000	.000	.008	.019	.003	.009	.007	.000	.005	.339	.134	.000
	N	149	142	147	148	149	144	150	149	149	151	150	150	149	150	149	151	142	148	148	145	146	146	146	148
B11: saw a different HCP to	Correlation Coefficient	.331**	.337**	.257**	.269**	.395**	.283**	.423**	.248**	.276**	.396**	1.000	.324**	.315**	.343**	.045	.084	.150	.136	.128	.387**	.260**	.095	.162*	.413**
	Sig. (2-tailed)	.000	.000	.002	.001	.000	.001	.000	.002	.001	.000		.000	.000	.000	.584	.302	.075	.101	.121	.000	.001	.252	.050	.000
	N	149	143	147	148	149	145	151	149	149	150	151	150	150	151	149	151	142	148	148	146	147	147	147	148
B12: HCPs missing	Correlation Coefficient	.273**	.318**	.217**	.270**	.272**	.273**	.326**	.372**	.263**	.222**	.324**	1.000	.356**	.416**	.031	-.031	.003	.127	.153	.417**	.274**	.241**	.244**	.200*
	Sig. (2-tailed)	.001	.000	.008	.001	.001	.001	.000	.000	.001	.006	.000		.000	.000	.706	.701	.975	.124	.063	.000	.001	.003	.003	.015
	N	149	142	147	148	149	144	150	149	149	150	150	151	149	150	149	151	143	148	148	145	146	146	146	148
B13: felt like complaining	Correlation Coefficient	.425**	.355**	.302**	.394**	.265**	.571**	.378**	.421**	.519**	.488**	.315**	.356**	1.000	.642**	.221**	.203*	.181*	.427**	.407**	.445**	.330**	.412**	.376**	.471**
	Sig. (2-tailed)	.000	.000	.000	.000	.001	.000	.000	.000	.000	.000	.000	.000		.000	.007	.013	.031	.000	.000	.000	.000	.000	.000	.000
	N	148	142	146	147	148	145	150	148	149	149	150	149	150	150	148	150	141	147	147	145	146	146	146	147
B14: problems with the	Correlation Coefficient	.475**	.390**	.329**	.451**	.277**	.463**	.507**	.435**	.534**	.453**	.343**	.416**	.642**	1.000	.295**	.145	.213*	.375**	.382**	.698**	.541**	.408**	.366**	.546**
	Sig. (2-tailed)	.000	.000	.000	.000	.001	.000	.000	.000	.000	.000	.000	.000	.000		.000	.075	.011	.000	.000	.000	.000	.000	.000	.000
	N	149	143	147	148	149	145	151	149	149	150	151	150	150	151	149	151	142	148	148	146	147	147	147	148
D2: ease of making changes	Correlation Coefficient	.151	.088	.127	.171*	.108	.199*	.029	.147	.207*	.217**	.045	.031	.221**	.295**	1.000	.585**	.491**	.307**	.268**	.198*	.201*	.093	.118	.293**
	Sig. (2-tailed)	.067	.301	.127	.039	.190	.017	.722	.075	.011	.008	.584	.706	.007	.000		.000	.000	.000	.001	.017	.015	.266	.157	.000
	N	149	141	146	147	148	143	149	148	149	149	149	149	148	149	151	151	142	148	148	145	145	145	145	148
D3: unsure about who to	Correlation Coefficient	.154	.035	.090	.181*	.183*	.042	.126	.094	.153	.190*	.084	-.031	.203*	.145	.585**	1.000	.445**	.362**	.335**	.047	.035	-.021	.003	.191*
	Sig. (2-tailed)	.059	.681	.276	.027	.025	.613	.123	.255	.061	.019	.302	.701	.013	.075	.000		.000	.000	.000	.571	.675	.797	.975	.019
	N	151	143	148	149	150	145	151	150	151	151	151	151	150	151	151	153	144	150	150	147	147	147	147	150
D5: satisf	Correlation Coefficient	.123	.039	.145	.175*	.064	.130	.220**	.177*	.240**	.244**	.150	.003	.181*	.213*	.491**	.445**	1.000	.287**	.305**	.057	.086	-.009	-.018	.285**

	Sig. (2-tailed)	.143	.657	.087	.039	.450	.131	.008	.036	.004	.003	.075	.975	.031	.011	.000	.000		.000	.000	.508	.317	.914	.837	.001
	N	142	135	140	140	141	136	142	141	142	142	142	143	141	142	142	144	144	144	144	138	138	138	138	141
E2: how often given an	Correlation Coefficient	.204*	.048	.076	.187*	.082	.257**	.136	.147	.220**	.213**	.136	.127	.427**	.375**	.307**	.362**	.287**	1.000	.945**	.096	.215**	.315**	.239**	.266**
	Sig. (2-tailed)	.013	.568	.365	.024	.322	.002	.099	.075	.007	.009	.101	.124	.000	.000	.000	.000	.000		.000	.254	.010	.000	.004	.001
	N	148	141	146	146	147	142	148	147	148	148	148	148	147	148	148	150	144	150	150	144	144	144	144	147
E3: how satisfied were you with	Correlation Coefficient	.167*	.082	.066	.202*	.084	.261**	.166*	.165*	.186*	.220**	.128	.153	.407**	.382**	.268**	.335**	.305**	.945**	1.000	.092	.247**	.304**	.227**	.252**
	Sig. (2-tailed)	.042	.335	.431	.015	.309	.002	.044	.046	.024	.007	.121	.063	.000	.000	.001	.000	.000	.000		.273	.003	.000	.006	.002
	N	148	141	146	146	147	142	148	147	148	148	148	148	147	148	148	150	144	150	150	144	144	144	144	147
F1: one HCP unaware of what	Correlation Coefficient	.422**	.563**	.370**	.426**	.430**	.387**	.416**	.439**	.523**	.321**	.387**	.417**	.445**	.698**	.198*	.047	.057	.096	.092	1.000	.585**	.434**	.393**	.450**
	Sig. (2-tailed)	.000	.000	.000	.000	.000	.000	.000	.000	.000	.000	.000	.000	.000	.000	.017	.571	.508	.254	.273		.000	.000	.000	.000
	N	145	138	143	144	144	140	146	144	145	145	146	145	145	146	145	147	138	144	144	147	145	145	144	147
F2: HCP giving conflicting advice	Correlation Coefficient	.357**	.480**	.332**	.378**	.380**	.362**	.410**	.402**	.405**	.234**	.260**	.274**	.330**	.541**	.201*	.035	.086	.215**	.247**	.585**	1.000	.418**	.452**	.470**
	Sig. (2-tailed)	.000	.000	.000	.000	.000	.000	.000	.000	.000	.005	.001	.001	.000	.000	.015	.675	.317	.010	.003	.000		.000	.000	.000
	N	145	139	145	145	145	141	147	145	145	146	147	146	146	147	145	147	138	144	144	145	147	147	146	147
F3: One HCP critical of another	Correlation Coefficient	.310**	.350**	.203*	.298**	.269**	.394**	.310**	.274**	.375**	.080	.095	.241**	.412**	.408**	.093	-.021	-.009	.315**	.304**	.434**	.418**	1.000	.658**	.282**
	Sig. (2-tailed)	.000	.000	.014	.000	.001	.000	.000	.001	.000	.339	.252	.003	.000	.000	.266	.797	.914	.000	.000	.000	.000		.000	.001
	N	145	139	145	145	145	141	147	145	145	146	147	146	146	147	145	147	138	144	144	145	147	147	146	147
F4: HCPs appeared to	Correlation Coefficient	.306**	.394**	.212*	.273**	.273**	.365**	.272**	.274**	.305**	.125	.162*	.244**	.376**	.366**	.118	.003	-.018	.239**	.227**	.393**	.452**	.658**	1.000	.325**
	Sig. (2-tailed)	.000	.000	.011	.001	.001	.000	.001	.001	.000	.134	.050	.003	.000	.000	.157	.975	.837	.004	.006	.000	.000	.000		.000
	N	145	139	145	145	145	142	147	145	145	146	147	146	146	147	145	147	138	144	144	144	146	146	147	146
G1: coordination rating in last 6	Correlation Coefficient	.492**	.322**	.299**	.404**	.329**	.439**	.459**	.412**	.427**	.463**	.413**	.200*	.471**	.546**	.293**	.191*	.285**	.266**	.252**	.450**	.470**	.282**	.325**	1.000
	Sig. (2-tailed)	.000	.000	.000	.000	.000	.000	.000	.000	.000	.000	.000	.015	.000	.000	.000	.019	.001	.001	.002	.000	.000	.001	.000	
	N	148	140	146	147	147	142	148	147	148	148	148	148	147	148	148	150	141	147	147	147	147	147	146	150

**. Correlation is significant at the 0.01 level (2-tailed).

*. Correlation is significant at the 0.05 level (2-tailed).

Appendix 12: Fixed 6 factor analysis solution: SPSS output pattern matrix (factor loadings) and correlation matrix

Pattern Matrix[a]

	Factor					
	1	2	3	4	5	6
HCP explained how they intended to address problems	.150	.030	**-.506**	.044	.199	.041
preferences taken into account when making decisions	-.049	.019	-**.840**	-.029	-.049	-.061
HCP took notice of views about how to manage health problems	.015	-.082	-**.911**	.020	-.038	.063
unsure about what HCPs there to do	.269	.288	-.082	.364	**.470**	-.140
unsure of what was going to happen next in care	.217	.012	-.142	-.060	**.603**	-.061
received care HCPs said you would	.118	.079	-.376	.042	.092	.227
waiting longer than expected for a service	-.075	.188	-.211	-.314	**.518**	-.129
saw a different HCP to the one you were expecting	.087	-.129	.013	-.001	**.627**	.210
HCPs missing necessary information	**.460**	-.041	.010	-.084	.166	-.012
felt like complaining about way care was organised	.388	.078	-.226	**-.546**	.128	-.021
problems with the coordination of care	**.748**	.054	-.066	-.314	.039	.181
ease of making changes	.224	**.748**	-.025	.000	-.174	.116
unsure about who to contact to make changes	-.197	**.614**	.006	-.047	.081	.005

satisfaction with these changes	-.118	.183	-.202	-.099	.077	**.552**
how often given an explanation as to what went wrong	.036	.185	.087	-.379	.091	.242
one HCP unaware of what others doing	**.788**	.075	-.054	.074	.076	.052
HCP giving conflicting advice	**.646**	.062	-.079	.188	.058	.032
HCPs appeared to disagree with each other	.381	-.070	-.062	-.033	-.018	-.120

Factor Correlation Matrix

Factor	1	2	3	4	5	6
1	1.000	.077	-.485	-.043	.465	.025
2	.077	1.000	-.256	-.179	.245	.340
3	-.485	-.256	1.000	.137	-.425	-.133
4	-.043	-.179	.137	1.000	-.167	-.255
5	.465	.245	-.425	-.167	1.000	.152
6	.025	.340	-.133	-.255	.152	1.000

Extraction Method: Principal Axis Factoring.

Rotation Method: Oblimin with Kaiser Normalization.

Appendix 13: Structural equation modelling results for final four factor model (AMOS Output)

Notes for Model (Default model)

Computation of degrees of freedom (Default model)

Number of distinct sample moments: 171
Number of distinct parameters to be estimated: 40
Degrees of freedom (171 - 40): 131

Result (Default model)

Minimum was achieved
Chi-square = 225.973
Degrees of freedom = 131
Probability level = .000

Scalar Estimates (Group number 1 - Default model)

Maximum Likelihood Estimates

Regression Weights: (Group number 1 - Default model)

			Estimate	S.E.	C.R.	P	Label
fac1	<---	coordination	1.000				
fac2	<---	coordination	.464	.133	3.492	***	par_15
fac3	<---	coordination	.900	.177	5.092	***	par_16
fac4	<---	coordination	1.487	.254	5.842	***	par_17
B12	<---	fac1	.907	.168	5.400	***	par_1
B13	<---	fac1	1.219	.170	7.154	***	par_2
B14	<---	fac1	1.510	.186	8.110	***	par_3
F1	<---	fac1	1.354	.181	7.466	***	par_4
F2	<---	fac1	1.000				
F4	<---	fac1	.374	.106	3.518	***	par_5
D2	<---	fac2	1.000				
D5	<---	fac2	1.058	.225	4.703	***	par_6
D3	<---	fac2	.643	.148	4.353	***	par_7
E2	<---	fac2	.812	.202	4.027	***	par_8
B1	<---	fac3	1.000				
B3	<---	fac3	1.277	.163	7.827	***	par_9
B4	<---	fac3	1.361	.160	8.517	***	par_10
B9	<---	fac3	.865	.154	5.626	***	par_11
B5	<---	fac4	.810	.115	7.062	***	par_12
B7	<---	fac4	1.000				
B10	<---	fac4	.917	.125	7.335	***	par_13
B11	<---	fac4	.770	.117	6.578	***	par_14

Standardized Regression Weights: (Group number 1 - Default model)

			Estimate
fac1	<---	coordination	.900
fac2	<---	coordination	.465
fac3	<---	coordination	.739
fac4	<---	coordination	.863
B12	<---	fac1	.539
B13	<---	fac1	.754
B14	<---	fac1	.903
F1	<---	fac1	.797
F2	<---	fac1	.643
F4	<---	fac1	.338
D2	<---	fac2	.714
D5	<---	fac2	.603
D3	<---	fac2	.527
E2	<---	fac2	.473
B1	<---	fac3	.715
B3	<---	fac3	.767
B4	<---	fac3	.868
B9	<---	fac3	.543
B5	<---	fac4	.629
B7	<---	fac4	.852
B10	<---	fac4	.651
B11	<---	fac4	.591

Variances: (Group number 1 - Default model)

	Estimate	S.E.	C.R.	P	Label
coordination	.201	.058	3.441	***	par_18
efac1	.047	.024	1.957	.050	par_19
efac3	.135	.037	3.627	***	par_20
efac2	.157	.047	3.333	***	par_21
efac4	.151	.062	2.457	.014	par_22
eb12	.498	.066	7.582	***	par_23
eb13	.279	.041	6.830	***	par_24
eb14	.129	.030	4.348	***	par_25
ef1	.260	.040	6.460	***	par_26
ef2	.351	.048	7.342	***	par_27
ef4	.267	.034	7.804	***	par_28
ed2	.192	.043	4.466	***	par_29
ed5	.390	.065	5.959	***	par_30
ed3	.215	.032	6.634	***	par_31
ee2	.456	.065	6.962	***	par_32
eb1	.284	.043	6.602	***	par_33

	Estimate	S.E.	C.R.	P	Label
eb3	.340	.056	6.078	***	par_34
eb4	.180	.043	4.145	***	par_35
eb9	.531	.072	7.404	***	par_36
eb5	.595	.085	7.006	***	par_37
eb7	.225	.053	4.233	***	par_38
eb10	.682	.099	6.895	***	par_39
eb11	.657	.092	7.174	***	par_40

Squared Multiple Correlations: (Group number 1 - Default model)

	Estimate
fac4	.745
fac3	.546
fac2	.216
fac1	.810
B11	.350
B10	.423
B7	.726
B5	.396
B9	.295
B4	.754
B3	.588
B1	.511
E2	.224
D3	.278
D5	.364
D2	.510
F4	.114
F2	.413
F1	.635
B14	.815
B13	.568
B12	.291

Modification Indices (Group number 1 - Default model)

Covariances: (Group number 1 - Default model)

			M.I.	Par Change
eb10	<-->	efac2	6.791	.102
eb7	<-->	efac2	4.031	-.054
eb3	<-->	eb4	6.818	.077
eb1	<-->	eb5	6.550	.106
ee2	<-->	eb5	5.892	-.124
ed3	<-->	efac1	6.856	-.042
ed3	<-->	eb10	5.744	.092
ed5	<-->	eb5	4.282	-.102
ed5	<-->	eb9	5.360	.106
ed2	<-->	eb5	5.511	.089
ef4	<-->	efac2	4.989	-.052
ef2	<-->	eb10	4.499	-.101
ef2	<-->	eb5	7.185	.119
ef2	<-->	ee2	6.563	-.099
ef1	<-->	eb10	5.529	-.102
ef1	<-->	eb5	10.183	.128
ef1	<-->	ee2	6.426	-.089
ef1	<-->	ed5	4.238	-.070
ef1	<-->	ef2	11.772	.104
eb14	<-->	efac2	4.351	.043
eb14	<-->	eb5	4.832	-.073
eb14	<-->	ee2	14.823	.112
eb13	<-->	efac2	4.256	.052
eb13	<-->	eb10	15.818	.175
eb13	<-->	eb5	9.617	-.126
eb13	<-->	ee2	4.634	.076
eb13	<-->	ef2	13.897	-.114
eb13	<-->	ef1	8.964	-.083
eb13	<-->	eb14	4.926	.049

Variances: (Group number 1 - Default model)

Regression Weights: (Group number 1 - Default model)

			M.I.	Par Change
B10	<---	fac2	5.178	.470
B10	<---	D3	8.619	.420
B10	<---	B13	6.007	.238
B5	<---	E2	4.148	-.193
B5	<---	F2	4.132	.190
B9	<---	fac2	4.757	.387
B9	<---	D5	7.847	.240
B1	<---	B5	9.214	.157
E2	<---	B14	4.980	.169
E2	<---	B13	4.472	.166
D3	<---	fac1	5.145	-.210
D3	<---	F2	5.549	-.134
D3	<---	B14	5.472	-.123
D5	<---	B9	6.748	.183
F2	<---	B5	4.898	.122
F2	<---	E2	7.347	-.194
F2	<---	B13	5.336	-.157
F1	<---	B5	5.226	.114
F1	<---	E2	7.824	-.181
F1	<---	D5	5.479	-.149
F1	<---	F2	6.548	.164
B14	<---	E2	15.147	.209
B13	<---	fac2	4.081	.269
B13	<---	B10	11.365	.156
B13	<---	E2	6.890	.172
B13	<---	F2	7.704	-.181

Model Fit Summary

CMIN

Model	NPAR	CMIN	DF	P	CMIN/DF
Default model	40	225.973	131	.000	1.725
Saturated model	171	.000	0		
Independence model	18	1036.851	153	.000	6.777

RMR, GFI

Model	RMR	GFI	AGFI	PGFI
Default model	.052	.820	.765	.628
Saturated model	.000	1.000		
Independence model	.235	.341	.263	.305

Baseline Comparisons

Model	NFI Delta1	RFI rho1	IFI Delta2	TLI rho2	CFI
Default model	.782	.745	.895	.875	.893
Saturated model	1.000		1.000		1.000
Independence model	.000	.000	.000	.000	.000

Parsimony-Adjusted Measures

Model	PRATIO	PNFI	PCFI
Default model	.856	.670	.764
Saturated model	.000	.000	.000
Independence model	1.000	.000	.000

NCP

Model	NCP	LO 90	HI 90
Default model	94.973	57.184	140.631
Saturated model	.000	.000	.000
Independence model	883.851	785.601	989.571

FMIN

Model	FMIN	F0	LO 90	HI 90
Default model	1.808	.760	.457	1.125
Saturated model	.000	.000	.000	.000
Independence model	8.295	7.071	6.285	7.917

RMSEA

Model	RMSEA	LO 90	HI 90	PCLOSE
Default model	.076	.059	.093	.008
Independence model	.215	.203	.227	.000

AIC

Model	AIC	BCC	BIC	CAIC
Default model	305.973	320.313	419.424	459.424
Saturated model	342.000	403.302	827.004	998.004
Independence model	1072.851	1079.304	1123.904	1141.904

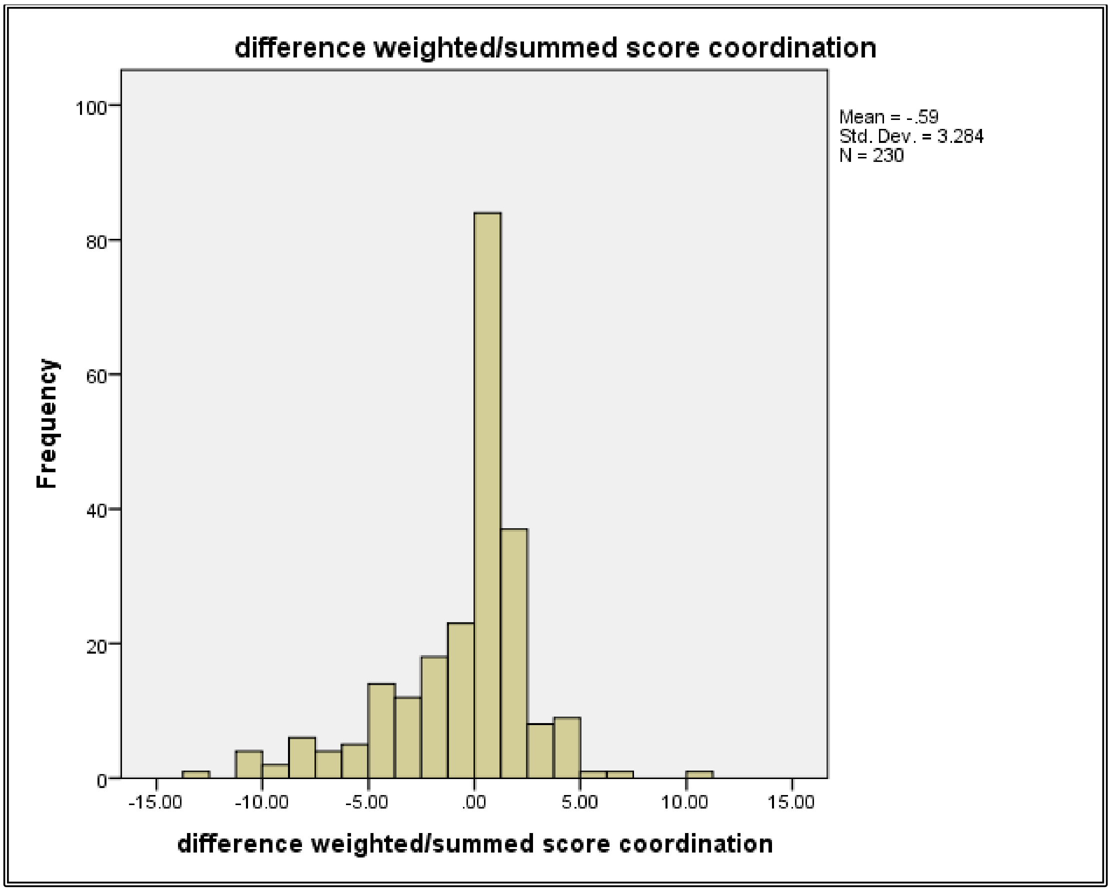
ECVI

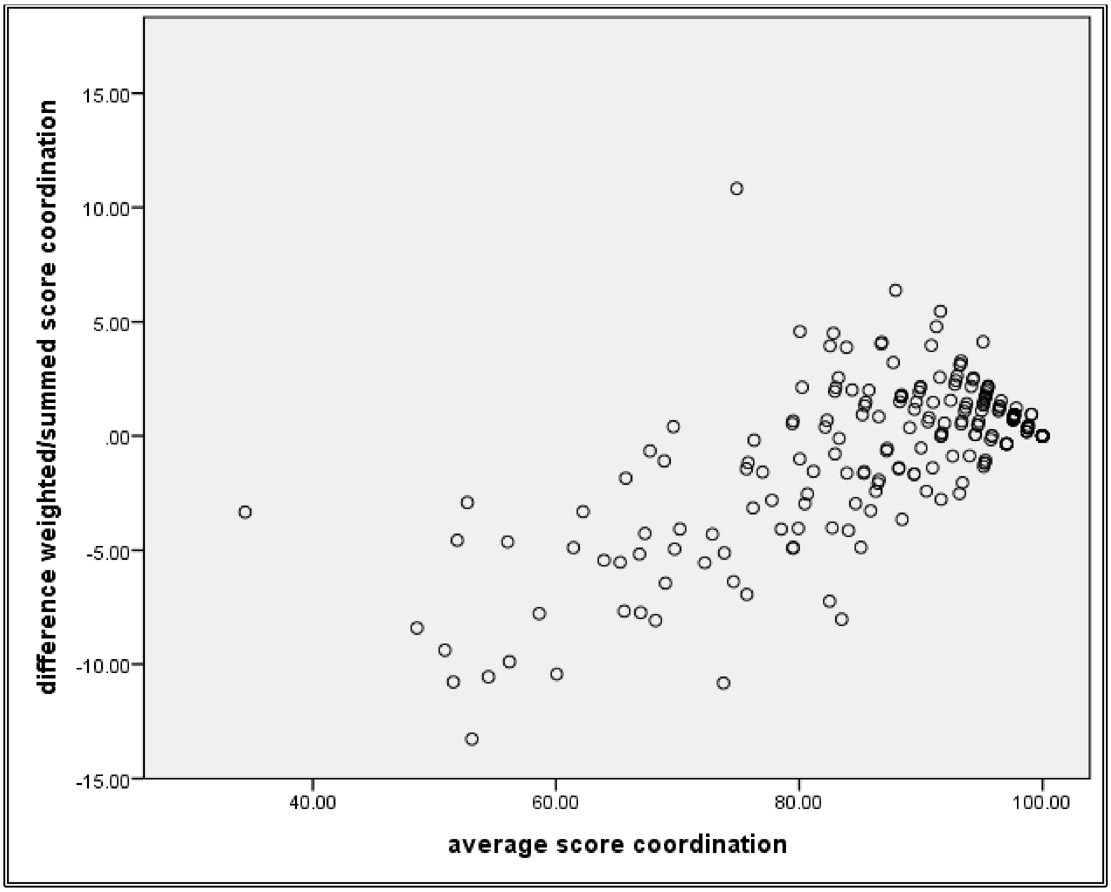
Model	ECVI	LO 90	HI 90	MECVI
Default model	2.448	2.145	2.813	2.563
Saturated model	2.736	2.736	2.736	3.226
Independence model	8.583	7.797	9.429	8.634

HOELTER

Model	HOELTER .05	HOELTER .01
Default model	88	95
Independence model	23	24

Appendix 14: Histogram and Bland Altman plot for differences in overall coordination score when weighted or summed




difference weighted/summed score coordination
15.00
10.00
5.00
.00
-5.00
-10.00
-15.00
40.00
60.00
80.00
100.00
average score coordination

Appendix 15: Client Perceptions of Coordination Questionnaire: missing responses

Item	Percentage of missing responses		
	Random	Systematic	'Not Applicable'
H1	3	1.3	
H2	4.4	1.3	
H3	14.4	1.3	
H4	3.7	1.3	1.7
H5	4	1.3	7
H6	2.7	1.3	1.7
H7	2.6	1.3	
H8	4.6	1.3	
H9	5.3	1.3	8
H10	5	1.3	15.7
H11	4.4	1.3	12.4
H12	3	1.3	
H13	3.3	0	
H14	3	0	
H15	2.7	0	
I1	6.4	0	
I2	11	0	
I3	5.7	0	3
I4	6.4	0	
I5	5.4	0	
J4	7	0	
J5	8.7	0	
J6	6.7	0	1
J7	7	0	
J8	8	0	
K2	10.3	0	
K3	11.7	0	