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An exploration of wheelchair users and caregivers involvement in decision-making through their patient journey

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Ready for the next project?

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Abstract

Background:
Patient involvement is ways in which patients can contribute to decision-making in healthcare. It has been promoted by the UK Government to increase healthcare quality and modernise the NHS. Patient benefits include improved satisfaction with care and better treatment outcomes. Current knowledge notes several factors affect an individual's involvement preferences. How and why involvement preferences alter throughout the patient journey has not been explored. This is relevant in the current context due to growing numbers of individuals with long-term conditions and caregivers. This study aims to explore the perceptions of wheelchair users and their caregivers to determine if and how long-term conditions impact on involvement preferences throughout the patient journey.

Method:
A qualitative approach was selected to explore the participants' perceptions. A single semi-structured interview was conducted with 10 participants in their homes. The interviews were transcribed and analysed, using thematic analysis. A reflexive diary was used throughout the process to enhance trustworthiness.

Findings and discussion:
Two broad themes emerged from the analysis: developing expertise and involvement, and barriers to participation. Exploring the developing expertise and involvement theme found the majority of participants preferred less involvement when deciding on their first wheelchair. This may be a result of the emotional distress and change to sense of self they experienced at the onset of impairment or loss of mobility. To adapt to the long-term condition and regain control over their condition and lifestyle, participants gained expertise in their condition, enabling them to become more involved in decision-making. Not all participants described the same journey, highlighting the complex interaction of factors affecting involvement preferences.

Conclusion:
This study achieved its aim and objectives, despite some limitations. This study has implications for healthcare professionals working with individuals with long-term conditions. Future research could explore involvement across the patient journey with other groups or look to include individuals at different stages of their journey to strengthen the findings of this study.

Key words:
Patient involvement, wheelchair user, caregiver, long-term condition, patient journey, adaptation

Introduction

Patient involvement is defined as “ways in which patients can draw on their experiences and can apply priorities to the evaluation, development, organisation and delivery of health services” (Tritter, 2009, p. 276). This indicates that patient involvement can occur in individual treatment decisions, service development and evaluation, training of health professionals and research (Tritter, 2009; UK Department of Health, 2001; UK Department of Health, 2003). Involvement in individual treatment decision-making has been most widely researched and implemented, perhaps as it directly involves greater numbers of patients and health care professionals than policy development and research can (Tritter, 2009). It is argued that enabling patients to be involved in treatment decisions alters the power and information balance from the historical, paternalistic approach towards a more equal partnership between the patient and health professional (Charles, Gafni & Whelan, 1997). This partnership approach recognises that patients have autonomy and understand their condition, values and preferences, whilst accepting that professionals also have skills and knowledge to contribute (Bradshaw, 2008). This partnership approach should improve decision-making and enhance the appropriateness of care (Bradshaw, 2008; Forbat, Hubbard & Kearney, 2009). Activities that aim to promote partnership include sharing of information, patient questions or complaints and use of self-management strategies (Kidd, Hubbard, O’Carroll & Kearney, 2009; Street, Gordon, Ward, Krupat & Kravitz, 2006; Tritter, 2009).

Patient involvement is not a new concept – the World Health Organisation advised in 1978 that it was a right of all people. The UK Government has promoted patient involvement since 1997. Policy documents from this time note that involving patients in healthcare was felt likely to increase National Health Service (NHS) efficiency, openness and accountability and promote patient ownership of the NHS, which aimed to encourage the appropriate use of health services (UK Department of Health, 1997; UK Department of Health, 1999). The Labour Government hoped this would lead to improved healthcare quality and modernisation of the NHS, key political goals at this time (UK Department of Health, 1997; UK Department of Health, 1998; UK Department of Health, 2000). Alongside these policy goals, research has found that patient involvement can deliver benefits for patients such as improved satisfaction with care, increased trust in professionals and better treatment outcomes (Bastiaens, Van Royen, Pavlic, Raposo & Baker, 2007; Carlsen & Aakvik, 2006; Grosset & Grosset, 2005; Klingenberg et al., 2005; Loh et al., 2007; Street et al., 2006; UK Department of Health & Farrell, 2004).

Despite this Government drive and research evidence, patient involvement remains a poorly defined concept with terms such as patient participation, patient partnership, collaboration and shared decision-making used interchangeably in research and practice (Entwistle, Prior, Skea & Francis, 2008; Millard, Hallett & Luker, 2005). This lack of clarity creates difficulties for health professionals in understanding how to implement involvement, and for patients in being able to understand the concept and how it should apply to them (Forbat et al., 2009).

As a physiotherapist working in the NHS, I felt patient involvement was being driven by the Government, and the application to practice was unclear to health professionals and patients. Research has focused on understanding what factors affect involvement preferences in single decisions. There is little research into whether involvement preferences alter throughout the patient journey and if so, why. Gaining an understanding of this seems appropriate given the growing numbers of individuals living with long-term conditions and therefore being likely to have ongoing contact with the health service (UK Department of Health, 2006). Alongside the growing numbers of people with long-term conditions, the number of caregivers is also set to increase (UK Department of Health, 2008). Research on caregiver involvement preferences in decision-making is also limited. Due to the increased complexity the inclusion of additional people in decision-making causes (Charles et al., 1997), understanding caregiver preferences also seems appropriate at this time. My area of work, a wheelchair service, provides an appropriate setting to explore involvement preferences throughout the patient journey, as the service users experience long-term conditions, may attend the service regularly over an extensive period of time and often have a caregiver involved. Therefore, the broad aim of the study was to explore how wheelchair users and their caregivers perceived involvement throughout their patient journey. The objectives of this study were to explore what 'being involved' meant to this group, facilitators and barriers to involvement, and if and why their involvement preferences altered throughout their patient journey. This understanding could then assist in developing recommendations for applying involvement appropriately in services for people with long-term conditions and their caregivers.

The literature review will discuss existing research into patient and caregiver perspectives on involvement and note there is little research on involvement preferences throughout the patient journey. The methodology section will outline why a qualitative method was selected. Choice of data collection and analysis methods will be described and justified. Analysis revealed two broad themes, one of which (developing expertise and involvement) will be discussed in the context of the patient journey and existing literature. Final conclusions from the study will be discussed along with its limitations and my reflexive account of the process. Concluding thoughts and future directions for research will complete the report.

Literature review

Historical context

The historical approach to decision-making in healthcare was paternalistic, with health professionals taking the dominant role (Charles, Gafni & Whelan, 1999). This approach was based on the assumption that the professional knew which single best treatment applied to each condition and patient, and was perpetuated by the power differentials that existed between the professional and the patient (Charles et al., 1999). The paternalistic approach has been challenged by a number of social and healthcare factors. These include increasing awareness of the rights and autonomy of each individual to control their life and decisions (Charles et al., 1997), increasing access to information for patients, particularly with the advent of the Internet (Thompson, 2007), growing awareness that for many conditions there is no single best treatment, making it increasingly appropriate for patient values and preferences to influence treatment selection (Charles et al., 1999; Thompson, 2007), an increasing consumer focus to health policy (Forster & Gabe, 2008), and an awareness that health professionals make mistakes, like those noted in public reports, such as the Bristol Royal Infirmary Inquiry Report (Thompson, 2007). These drivers further explain why the Government has promoted patient involvement and suggests there are social drivers supporting involvement. As these drivers are unlikely to change, developing further understanding on patient involvement in decision-making remains relevant in the current context (Thompson, 2007).

This review will explore current knowledge on patient and caregiver preferences for involvement, which has focused on factors affecting preferences in single decisions. Literature exploring changes in involvement preferences throughout the patient journey is limited and does not explain why involvement changes over time. Literature examining adjustment to long-term conditions will be explored and it will be noted that links between involvement preferences and adjustment to long-term conditions have not yet been investigated, and will be addressed by this study.

Current knowledge on involvement in decision-making

Whilst there are clear drivers and evidence of benefits to be gained from patient involvement, the literature also suggests that it is not as simple as involving all patients in every decision to the same extent. Aspects of health professional behaviour, characteristics of the individual patient and the context of the decision have been explored and found to impact on involvement.

Research exploring the behaviours and attitudes of health professionals that facilitate or hinder how involved patients feel in decision-making has found that being provided with adequate, clearly communicated information (Entwistle et al., 2008; Skea et al., 2004; Thompson, 2007), enough time to consider the information to be able to ask relevant questions (Henman, Butow, Brown, Boyle & Tattersall, 2002; Skea et al., 2004), a supportive health professional (Entwistle et al., 2008; Henman et al., 2002; Street et al., 2006), a health professional with a positive attitude towards sharing decision-making (Carlsen & Aakvik, 2006; Entwistle et al., 2008) and being listened to by the health professional (Entwistle et al., 2008; Henman et al., 2002; Thompson, 2007) promote involvement for patients. A health professional without adequate time to spend with the patient, who undervalued the patients' preferences and knowledge and did not support shared decision-making may inhibit patient involvement (Entwistle et al., 2008; Sainio, Lauri & Eriksson, 2001; Thompson, 2007). This supports the idea of decision-making being a partnership process with the health professional's attitude and behaviour impacting on the patient’s ability to be involved (Bradshaw, 2008; Charles et al., 1997).

Personal characteristics of the patient, such as age, gender and education level have also been found to impact on involvement preferences. This has been researched extensively and the findings of selected papers can be found in appendix 1. The findings are summarised in a narrative review (Say, Murtagh & Thomson, 2006), which noted that younger, more highly educated females with less severe illnesses were most likely to want to be highly involved in decision-making. Older individuals with lower education levels, making more serious decisions about their health are likely to prefer less involvement in decision-making (Beaver et al., 1996; Chamot, Charvet & Perneger, 2004; Hawley et al., 2007; Sainio et al., 2001). The research therefore suggests that involvement preferences are also affected by an individual’s personal characteristics.

Regardless of their personal characteristics, patients tend to prefer less involvement when making a decision about a serious illness or a severe exacerbation of an existing illness (Carlsen & Aakvik, 2006; Say et al., 2006, Thompson, 2007). Several studies with cancer patients noted that patients preferred less involvement when making treatment decisions, regardless of their personal characteristics (Beaver et al., 2005; Butow, Maclean, Dunn, Tattersall & Boyer, 1997; Thompson, 2007). This suggests that the context also impacts on involvement preferences.

This evidence indicates that several factors interact to affect involvement preferences, suggesting that involvement in decision-making is not stable, nor predictable, as the interaction of these factors may be different for each health decision an individual makes (Fraenkal & McGraw, 2007). The impact of these factors on decision-making throughout the patient journey is not clear from this evidence, as these studies focused on single healthcare decisions made by individuals, rather than exploring patient involvement in decisions throughout the patient journey.

Experience of illness and healthcare

Literature reviewing involvement in decisions throughout the patient journey has found some conflicting results regarding the impact of greater experience of illness and healthcare on involvement preferences (Say et al., 2006; Thompson, 2007). The authors speculated that involvement preferences for those with experience may depend more on how an individual adapts to being a patient, than the illness itself or related experience of care (Say et al., 2006). This indicates the complex interaction of factors that impact on involvement in decision-making (Fraenkal & McGraw, 2007).

Whilst the qualitative studies reviewed by Say et al., (2006) indicate that developing knowledge and experience of an illness did lead patients to prefer increased involvement, understanding how and why this occurred is somewhat limited. Caress, Beaver, Luker, Campbell & Woodcock (2005), Entwistle et al. (2008) and Fraenkal & McGraw (2007) interviewed individuals with asthma, diabetes and osteoporosis respectively about their preferences for involvement in decision-making. Some patients did note that their involvement was an on-going process, subject to change over time, but referred to this in terms of wanting more time to consider a single decision or being able to review how a medication was working over time, rather than in regard to a series of different decisions (Fraenkal & McGraw, 2007). Although these studies involved patients with long-term conditions, participants discussed a single healthcare decision and the findings related to the impact of decision context, health professional behaviour and personal characteristics on involvement preferences (Caress et al., 2005; Entwistle et al., 2008; Fraenkal & McGraw, 2007). Therefore, these studies did not explore if, how and why involvement preferences alter with experience of illness and the health system, and therefore do not provide evidence to meet the aim of this study.

Pellatt (2004) provides some insight into how and why long-term conditions may impact on involvement throughout the patient journey. Pellatt (2004) utilised a mixed methods approach (interviews and observation) to explore the perspectives of patients with new spinal cord injuries on a rehabilitation ward and patients who had been living with their injury for some years. Many newly injured patients felt that they were not involved in decision-making as much as they would have liked, although not all patients felt the same way, indicating that a combination of factors affect individual involvement preferences (Pellatt, 2004). Patients who had been living with spinal cord injury for a period of years reported they felt more involved over time due to changes in the way staff perceived involvement and because they felt more confident having gained experience with their injury (Pellatt, 2004). Pellatt (2004) concluded that the experience of living with spinal cord injury led to the development of expert patients and a preference for greater involvement, but did not explore why or how this occurred.

There is evidence to indicate that becoming an expert patient can be part of the adjustment that occurs when diagnosed with a long-term condition (Mayor, 2006). It is well documented that the onset of long-term conditions is often associated with emotional distress, a sense of loss and disruption to the individual's sense of self and lifestyle (Bury, 1982; Gallagher & Machlachlan, 2001; Irvine, Davidson, Hoy & Lowe-Strong, 2009; Mayor, 2006; Williams, 2000). The process of adapting to a long-term condition has been found to be lifelong, as the individual is constantly dealing with the uncertainty created by not knowing how their condition will develop nor how this will impact on their lifestyle (Galvin, 2005; Irvine et al., 2009; Mayor, 2006). To deal with this ongoing uncertainty, patients often seek to become experts on their condition, by seeking information on the condition, using peer support or self-help groups and taking a more active role in decision-making (Mayor, 2006). These actions allow the individual to feel they can regain control over their lifestyle and can contribute to developing a stable sense of self (Bury, 1982; Gallagher & Machlachlan, 2001; Irvine et al., 2009; Mayor, 2006).

This process of on-going adaptation has been found to occur with the loss of mobility (Finlayson & van Denend, 2003). The initial loss of mobility and acceptance of mobility aids can be perceived by the individual as 'giving up' on their ability to overcome the impairment (Finlayson & van Denend, 2003).

Therefore, accepting prescription and use of a mobility aid is often emotionally difficult for an individual and can add further distress to that related to the onset of impairment (Finlayson & van Denend, 2003). This may further affect the involvement preferences of those with long-term conditions. This evidence raises the possibility that adaptation to a long-term condition impacts on involvement preferences throughout the patient journey. Exploring this further is the aim of this study and is relevant given the current political and social context. Exploring this in a wheelchair service is appropriate as service users have long-term conditions, as eligibility for the service requires a condition that affects mobility for a long time period (National Wheelchair Managers Forum, 2002). Wheelchair users have long-term contact with the service as their initial prescription, review of equipment; repairs and maintenance should be carried out by one service (National Wheelchair Managers Forum, 2002). These factors make the wheelchair service an appropriate area to explore the current gap in knowledge around changes in involvement preferences over the patient journey with people with long-term conditions.

The role of caregivers

Charles et al. (1997) conceptualised roles for caregivers in decision-making, which included: information gatherer, negotiator, advisor and supporter of the patient's decisions. Some research carried out in mental health (Cleary, Freeman, Hunt & Walter, 2005; Goodwin & Happell, 2007) and cancer (Morris

& Thomas, 2001) identified that caregivers did take on these roles when supporting the person they cared for during decision-making. Additionally these caregivers noted that being able to support the autonomy, independence and emotional state of the person they cared for was part of their role (Morris & Thomas, 2001). Caregivers also reported having expert knowledge to contribute to decision-making, as they had extensive experience with the person they cared for (Goodwin & Happell, 2007). This suggests that caregivers develop expertise, similar to individuals with long-term conditions. This may occur as part of the process of adapting to a long-term condition, which has been found to affect caregivers as well as patients (Seamark, Blake, Seamark & Halpin, 2004). The disruption to sense of self and lifestyle, and ongoing adaptation process has been found to occur in the caregivers of those with long-term conditions (Charmaz, 1983; Gallagher & Machlachlan, 2001; Seamark et al., 2004). This may explain why caregivers also seek to develop expertise in caring for the individual with the long-term condition. Alongside this support for the person they cared for, caregivers identified their own needs from decision-making, separate to those of the patient such as their own information needs and emotional and practical support for themselves (Goodwin & Happell, 2007; Morris & Thomas, 2001). However, caregivers generally put the needs of the person they cared for first, which resulted in their individual needs becoming secondary (Morris & Thomas, 2001).

Caregivers also noted that the behaviours and attitudes of health professionals, such as being supportive and respectful impacted on their ability to be involved (Goodwin & Happell, 2007), reflecting the findings on patients.

This evidence provides background for understanding how caregivers perceive involvement in decision-making. Again, the literature has not explored whether involvement preferences alter as caregivers gain experience with a condition and the healthcare system. The wheelchair service provides an appropriate place to explore this, as caregivers often support wheelchair users. Caregivers often have individual needs, as aspects such as the caregiver's health, capability, transport and availability may impact on the equipment chosen and the effectiveness with which is it used (Batavia, Batavia & Friedman, 2001; Ham, Aldersea & Porter, 1998; Reid, Laliberte-Rudman & Hebert, 2002).

An understanding of why involvement preferences alter throughout the patient journey for people with long-term conditions and their caregivers is not clear from the literature and is relevant to explore in the current political and social climate. The wheelchair service provides a suitable setting within which to explore this topic.

Methodology

Underlying research paradigm

A qualitative methodology is appropriate when the experiences, interpretations or perceptions of individuals are being explored (Avis, 2005).

Qualitative research aims to gain an understanding from the subjective perspective of an individual or group (Avis, 2005). This stems from an interpretivist epistemology, which accepts that there is no single reality, as the context and perspective of the individual determines what 'reality' is for them (Finlay, 2006). A qualitative methodology was therefore appropriate for this study, as it aimed to explore the perceptions of wheelchair users and their caregivers regarding involvement in decision-making and accepted that perceptions may vary between individuals and throughout the patient journey.

A broadly phenomenological approach was taken to the research. Phenomenology seeks to explore the lived experience of individuals, to gain an understanding of the meaning that experience has to the individual (Finlay, 2006; Todres, 2005). The participant's description and interpretation of their involvement in decision-making was the focus of data collection and analysis in this study, and their own words were used in the reporting, keeping the data close to the participants experience. Phenomenology also acknowledges the role of the researcher in co-constructing knowledge, as the researcher shapes data collection and controls data analysis (Dean, Smith & Payne, 2006). This accepts that the researcher cannot be objective, and different researchers may interpret phenomena differently, as their interpretation will be influenced by their own experiences (Finlay, 2006). As I have worked in the wheelchair service for five years, and have my own perceptions and experiences of the subject being studied, this acknowledgement is particularly important in this study. Methods to identify and note these influences will be discussed later in this section.

Analytic methods in phenomenology are descriptive, following the work of Husserl, where the ‵essence‵ of the phenomenon is described; or interpretivist, following the work of Heidegger, where the researcher seeks to interpret meaning from the participants words (Dean et al., 2006; Finlay, 2006; Todres, 2005). As this study used thematic analysis, it cannot be strictly defined as a phenomenological study, however many of the philosophical decisions underpinning the research are based in phenomenology.

Selection of data collection method

Semi-structured interviews were selected for data collection. This choice was made after considering previous qualitative research into patient involvement, which had utilised focus groups (Thompson, 2007), interviews (Bastiaens et al., 2007; Entwistle et al., 2008; Kidd et al., 2009; Pellatt, 2004) and written questionnaires (Entwistle, Williams, Skea, MacLennan & Bhattacharya, 2006; Katz et al., 2005) to collect data.

Focus groups are useful when the researcher aims to gather a broad range of perceptions (Barbour, 2007). This method could have been suitable, given that involvement in decision-making in wheelchair services was unexplored. However, 'patient involvement' is a poorly defined concept (Entwistle et al., 2008), making it possible that participants may not have considered such ideas before. One effective way to explore an unfamiliar topic is through patient narratives (Kvale, 1996). Focus groups are not well suited to the telling of individual sequential narratives (Barbour, 2007). Additionally, the complexity of factors impacting on involvement preferences, and potential for participant communication difficulties could limit the effectiveness of focus groups, and therefore they were not selected for this study.

Questionnaires would also be of limited use due to the poor definition of 'patient involvement' (Entwistle et al., 2008). Additionally, a questionnaire would be framed by the researcher's understanding and experiences, which may restrict participant responses (Katz et al., 2005). Therefore, a questionnaire was not felt to be the most appropriate method of data collection for this study.

The concerns arising from the use of focus groups and questionnaires can be addressed by using interviews. Interviews allow narratives to be told, with prompting from the researcher to guide the discussion to explore more abstract concepts (Kvale, 1996). With a semi-structured or unstructured interview, participants have the opportunity to explore concepts that are important to them, rather than being restricted by the researchers understanding and experiences (Kvale, 1996). Although it could be argued that the researcher controls interviews, as they select the topic and initiate the interaction with a participant who may otherwise never have considered the topic of interest (Speer, 2002), flexibility in the interview structure aims to overcome this and allow issues of importance to the participant to be explored. The individual nature of involvement and any concerns about communication could also be managed in an interview. Semi-structured interviews were therefore identified as being the most appropriate method of data collection, in keeping with a phenomenological approach. The interviews were audio-recorded to ensure full and accurate transcription could occur.

Sponsorship and approvals

Scrutiny of planned research is necessary to ensure that the rights, safety and dignity of participants are protected (UK Department of Health, 2005). Scrutiny also ensures that the research has scientific value and uses available resources effectively (UK Department of Health, 2005). Ethical and research and development approval for this project were gained prior to recruitment of participants from the Wandsworth Research Ethics Committee and the North Central London Research Consortium respectively (appendices 2 and 3). The Posture and Mobility Group Research and Development sub-committee also scrutinised the project in relation to the grant application made (appendix 4). The research was sponsored by the University of Hertfordshire (appendix 5) and registered with University of Hertfordshire Health and Emergency Professions Ethics Committee.

Selection of participants

To explore the development of involvement preferences throughout the patient journey, wheelchair users who had had more than one interaction with the service were the focus for recruitment. It is recognised that carrying out interviews at a single point in time will elicit the perspectives of participants at that time only, and that their views may change and develop over time, leading to different perceptions (Avis, 2005; Kvale, 1996). Exploring the changes in perspectives over time more robustly would require several interviews over an extended time period, which was beyond the scope of this work.

Participants who had been seen at the service in the last six months were selected, as it was anticipated that they would have a recent decision to discuss, which could provide participants with a narrative to help them begin the interview. As it is best ethical practice for health professionals carrying out research to avoid interviewing patients with whom they have current clinical involvement, only wheelchair users who had had recent clinical contact with a staff member other than the researcher were included. This aimed to minimise any concerns participants had about a change to their relationship with the researcher and the wheelchair service. This was outlined in participant information sheets (appendices 6 and 7).

The inclusion criteria were not otherwise restricted, as it was hoped this would allow a diversity of participants to be included, to reflect the diversity of the service. Consideration of restricting the group by using an age range or particular diagnosis was made, however, as I did not want to restrict the experiences discussed, no restrictions were made.

The selected wheelchair users could identify their caregivers for inclusion in the study. The wheelchair users were invited to select the person they thought 'provides most of your daily care and helps you use and look after your wheelchair' to pass the caregiver information sheet to. Wheelchair users without caregivers or those who did not want to involve their caregiver continued to be included in the study. Caregivers could also choose to participate, even if the wheelchair user they cared for chose not to. This resulted in unequal numbers of wheelchair users and caregivers being included in the study, but it was anticipated rich data could still be obtained.

Potential participants were excluded if they were unable to give informed consent, unable to read or speak English adequately or had been assessed by the service, when carrying out clinical home visits, as having an unsafe home environment for lone working. These criteria were designed to protect the rights and dignity of participants and the safety of the researcher.

Recruitment strategy

The mobility technician reviewed the wheelchair service database and file notes to identify potential wheelchair user participants. Thirty recruitment packs (comprising invitation letters and participant information sheets, appendices 6 to 8) were posted to wheelchair users in two batches, to minimise the risk of over-recruitment. Wheelchair users could then choose to pass the caregiver material to their caregiver, if appropriate. The recruitment material invited potential participants to contact the researcher directly by phone or reply form (appendix 9). This method of recruitment was selected to avoid participants feeling coerced to participate.

The aim was to recruit up to 10 participants. This number was selected as being appropriately small for the planned method of analysis, but large enough for a deep understanding on the topic to be developed. Developing a deeper understanding was possible as information from earlier interviews was used to develop the interview guide, to ensure subsequent interviews elicited deeper data on issues of importance to the participants (Kvale, 1996; Pope, Ziebland & Mays, 2006).

Eleven responses were received to the recruitment packs. Eight potential participants agreed to participate without requesting further information, two potential participants requested further information before agreeing to participate and the final volunteer was thanked for their offer to participate and advised that recruitment was complete. Interview dates were arranged with all potential participants a minimum of two days in advance to allow the participants time to reflect on their involvement in the study and ask any questions. A flow chart of this process is outlined in appendix 10.

Data collection process

Wheelchair users and caregivers were given the choice to be interviewed separately or together. Interviewing the wheelchair user and caregiver separately would allow exploration of both perspectives, without any impact from the possible power relationships between the wheelchair user and caregiver. However, it was recognised that the wheelchair user and caregiver might want to be interviewed together, to increase confidence or as they may feel that their perspectives overlap. Caregivers could also support wheelchair users in their communication where required. It was felt likely that both separate and joint interviews would provide rich data, and so the choice was left to the participants. This resulted in seven audio-recorded interviews being conducted, with each participant interviewed once. Five interviews were conducted with a single participant, one with a wheelchair user and caregiver, the other with two caregivers and one wheelchair user.

All interviews lasted approximately 30 minutes to one hour and took place in the participants' own home or the home of the person they cared for. Allowing the participant to choose the interview venue empowers the participant and allows a more equal discussion between researcher and participant (Manderson, Bennett & Andajani-Sutjahjo, 2006). The lone working policy of the Trust where the research was carried out was applied to each interview to ensure the researcher's safety.

At the planned interview time, the study information was reviewed with each participant before they signed the informed consent form (appendices 11 and 12) and then began the interview. The interview topic guide (appendix 13) was used flexibly to direct the interview to ensure what was discussed addressed the study aim but also explored issues of importance to each participant. The guide was developed using existing literature on involvement in decision-making and feedback from the local wheelchair user group. The topic guide developed over the series of interviews as directed by participants and covered areas of: initial wheelchair prescription, follow-up dealings with wheelchair service, other healthcare decision-making and patient involvement as a concept. Each interview began by asking the participant/s 'Can you tell me about when you first got a wheelchair?' This led into narratives about the onset of impairment and was guided into the experience of decision-making by the researcher.

Trustworthiness

In qualitative research, trustworthiness includes the credibility, transferability, confirmability and dependability of the research (Avis, 2005; Finlay, 2006). Credibility can be enhanced by participant verification of transcripts and the use of a reflexive diary throughout the research process (Forbat & Henderson, 2005; Mays & Pope, 2006). Transcripts were sent to each participant for them to verify the accuracy of the transcription and provide any additional information (appendix 14). Participant verification of transcriptions ensures the analysis is carried out on accurate data, which improves the quality of the analysis and hence improves the credibility of the findings (Forbat & Henderson, 2005).

A reflexive diary was used throughout the research process. The aim of a reflexive diary is to help the researcher monitor and document their influence on the research process (Mays & Pope, 2006). The researcher can then use this account to acknowledge these influences and the impact of these on decisions made throughout the research process (Mays & Pope, 2006). The diary also keeps the research open for external monitoring and auditing (UK Department of Health, 2005). In this study the reflexive diary was used to note how my experiences and perceptions impacted on the choices made throughout data collection and analysis, and for field notes made during and after each interview. During the interview, notes were made on any relevant body language of participants, which could affect the interpretation of their words. Notes made immediately after each interview reflected on the content and key message of the interview, as well as noting observations about interviewing skills, to help improve the quality of subsequent interviews. These notes aimed to improve data quality and hence the credibility of the subsequent analysis.

The transferability and confirmability of the study were enhanced by the documentation of a detailed method, which allows auditing of how the findings were reached, and allows readers to determine the relevance of these findings to their setting (Cutcliffe & McKenna, 1999).

The dependability of the study was enhanced by including more than one perspective, as more than one view of the phenomenon is gained and triangulation can occur (Mays & Pope, 2006). Although the wheelchair user and caregiver may have different perspectives, including both perspectives enhances the dependability and trustworthiness of the research.

Data analysis

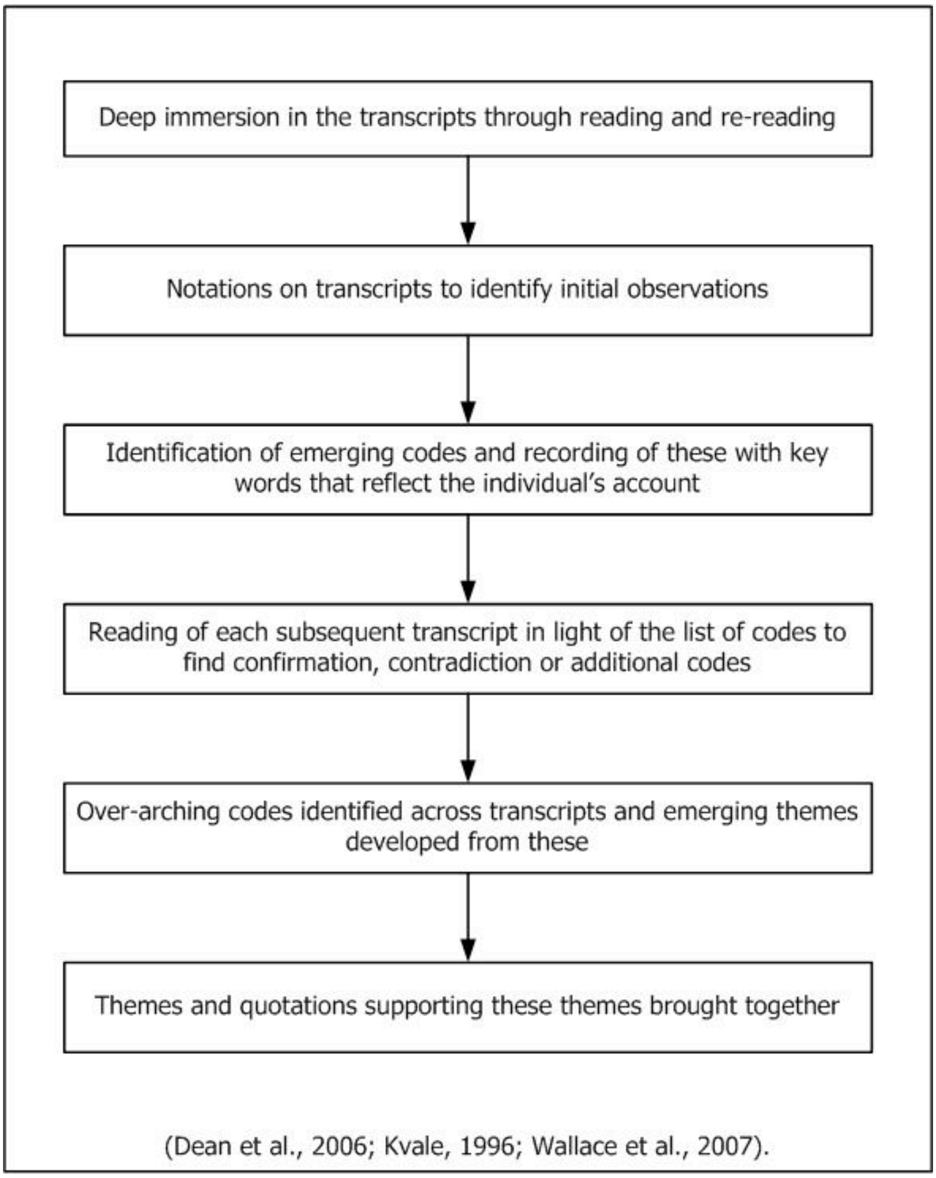
The interviewer carried out the subsequent data analysis. This enhanced data immersion and allowed interpretations to remain consistent between the interviews and analysis (Wallace, Harcourt, Rumsey & Foot, 2007). Support and review from academic supervisors with qualitative research experience occurred throughout the analysis process. This ensures analysis follows a logical and robust process, and can highlight any aspects missed by the primary researcher, improving the credibility of the findings (Cutcliffe & McKenna, 1999).

The interviews were transcribed fully from the audio recordings, and relevant field notes added. Each transcription was completed by the day after the interview, to aid recall and understanding of what had been said by participants. The transcripts were sent to each participant for them to verify the accuracy of the transcription and provide any additional information. No transcripts were returned. The full transcripts from each interview are included on the CD in the back cover of this report.

Analysis followed an inductive thematic analysis method. This allowed themes to emerge from the data, rather than being determined before data collection (Murray, 2009), again in keeping with a phenomenological approach focusing on the participants' reality. Detailed attention was given to each participant's experience, justifying the recruitment of a small number of participants (Dean et al., 2006; Wallace et al. 2007).

Analysis involved several steps, as outlined in figure one.

Figure 1: Steps involved in analysis



(Dean et al., 2006; Kvale, 1996; Wallace et al., 2007).

Analysis began in the interview as the researcher reflected participant's statements back to them to confirm what had been said had been correctly interpreted. This continued in the field notes written immediately after each interview as the researcher reflected on what key messages the participant had been trying to convey. Formal analysis took place on the first few transcripts whilst the final interviews were being carried out, allowing the opportunity to reflect what was being found through analysis into subsequent interviews. This can assist in promoting deeper exploration of areas of interest through subsequent interviews (Kvale, 1996; Pope et al., 2006). Initial thoughts after immersion in the transcripts were very literal and related to gaining an understanding of what involvement meant to the participants, factors that facilitated and hindered involvement and reactions to impairment and wheelchair prescription. The literature was re-read at this stage to note similarities and differences with emerging codes. These processes resulted in a large number of literal codes, which required further interpretation. Moving to a more interpretative level of analysis involved re-reading the transcripts to note links between these codes and possible over-arching meanings of these. Reading literature on the response to the onset of a long-term condition broadened my thoughts and assisted interpreting the deeper meaning of the more literal codes. This allowed the two over-arching themes and related sub-themes to emerge. More detail and reflections on this process can be found in appendix 15.

Findings and discussion

Data from all seven interviews was included in the analysis. Demographic information demonstrates that there were six wheelchair users, all diagnosed with an acquired neurological condition, and four caregivers. Participants had spent an average of nine years using wheelchairs (range three to 28 years). More detailed demographic information can be found in appendix 16, along with the codes used to identify participant quotes throughout this section. Wheelchair user participants are identified with a W and caregivers with a C.

Two broad themes emerged from analysis: developing expertise and involvement and barriers to participation. These themes and related sub-themes are outlined in table one:

Table 1: Themes and sub-themes emerging from analysis

Themes	**Sub-themes**
Developing expertise and involvement	Initial responses to impairment Initial equipment provision Developing expertise Control, independence and individuality
Barriers to participation	Environmental Attitudinal Equipment Health related Health service limitations

Within the barriers to participation theme, participants discussed barriers they experienced in participating in society as well as in decision-making. As this theme and related sub-themes did not directly address the study aim, it is not the focus of analysis and discussion. The developing expertise and involvement theme directly related to the aim of the study and is therefore the focus of the following discussion. This theme will be explored under three sub-headings: the sub-themes of initial responses to impairment and initial equipment provision will be discussed under the sub-heading initial responses to impairment and equipment provision. The remaining sub-themes will be discussed under the sub-heading developing expertise and ongoing impact on involvement. Aspects of the theme related specifically to caregivers will be discussed under the sub-heading caregivers perspective. Breaking up the sub-themes in this way allowed the discussion to follow the patient journey. Existing literature will be incorporated to provide context for the analysis.

Initial responses to impairment and equipment provision

When first requiring a wheelchair, the majority of wheelchair users and caregivers expressed uncertainty about being involved in decision-making and preferred to leave it to the health professional. They expressed that this was because they did not have adequate knowledge of equipment and that the equipment was often needed urgently, which limited the time available to obtain information and be fully involved in decision-making.

> ***W1:*** *If you're coming the first time, you need a wheelchair then they've got to leave it to the… people who are the wheelchair service… you've got… no information to be involved… nor do you want to waste time trying to find this information, you just want your new wheelchair...*

> ***C4:*** *… you don't understand what they do.*

Several participants also described feeling that they did not understand their impairment, nor the way the health system functioned. Some wheelchair users and caregivers described this first contact as being a time when they passively accepted the way things happened around them, as they did not have the experience to recognise what was usual practice.

> ***W6:*** *It started from the (hospital), they gave me a chair to sit in… I thought it was sort of natural to be in a chair.*

For most participants, contact with the wheelchair service occurred around the same time they were diagnosed with their impairment. For others, deteriorating mobility led to contact with the service. Both the onset of impairment and loss of mobility are often associated with distress, loss, and disruption to sense of self and lifestyle for both the individual experiencing the impairment and those around them (Bury, 1982; Charmaz, 1983; Finlayson & van Denend, 2003; Gallagher & Machlachlan, 2001; Mayor, 2006; Seamark et al., 2004). Thus, it is possible that study participants were experiencing emotional distress and disruption to their sense of self when they first came into contact with the wheelchair service.

> ***W4:*** *…my husband and friends went in it, but I didn't, for a long time. I wouldn't get into it, I mean. Because it was just such a…**step**…*

This emotional response and loss of identity combined with an unfamiliar impairment and situation, and a lack of knowledge about the functions and features of a wheelchair, may explain why participants felt less able to be involved in decision-making at this time.

In keeping with this sense of loss, several participants also expressed views on disability fitting the tragedy model of disability. They described the loss felt when being diagnosed with the impairment, and that the goal at this time was for the impairment to be overcome and for them to return to their pre-impairment function.

> ***W6:*** *... If you don't do your exercises, you stay a cabbage believe me. But if you do your exercises regular… it's not easy, nothing's easy, you've all got to go through a little bit of pain to get to wherever you want to.*

Reflecting this goal of returning to pre-impairment function, loss of mobility and acceptance of a wheelchair can be perceived by the individual as 'giving up' on their ability to overcome their impairment, making accepting prescription and use of mobility equipment often emotionally difficult for an individual (Finlayson & van Denend, 2003). This emotional distress and goal to return to pre-impairment function, may further explain why the majority of participants felt more comfortable with less involvement in decision-making at this time. Allowing the health professional to take the primary role in decision-making about mobility equipment may have allowed both wheelchair users and caregivers to feel they were not responsible for the decision to use a wheelchair and therefore they had not made the decision to 'give up' on returning to their pre-impairment state (Finlayson & van Denend, 2003; Williams, 2000). Avoiding involvement in this decision may therefore allow the participants to lessen their emotional distress and continue to feel that they could return to pre-impairment function. This may be a way that participants attempted to retain their pre-impairment sense of self and deal with the emotional distress they were experiencing (Williams, 2000).

One wheelchair user differed from all other participants and expressed a view that he was highly involved in decision-making about his first wheelchair and this was his preference at the time.

> ***W3:*** *… they… give me different types of wheelchair, but…I selected this one. I selected it myself.*

This participant's impairment resulted from a surgical error, so he may have felt less trust in health professionals, and wanted to take greater control and responsibility in decision-making as a result of this. Alternatively, this participant's preference for a high level of involvement from the onset of impairment may simply be reflecting the interaction of factors such as health professional behaviour, personal characteristics and the context of decision-making that result in involvement preferences being individual and unpredictable (Fraenkal & McGraw, 2007; Pellatt, 2004; Say et al., 2006).

Developing expertise and ongoing impact on involvement

As participants gained experience with equipment, all felt more able to be involved in decision-making in partnership with health professionals.

> ***W1:*** *the wheelchair user …saying what they wanted but the wheelchair service with their knowledge and the two things have to come together and so a balanced decision is made together.*

The ability to be more involved with experience may occur as a result of the adjustment process that often occurs with long-term conditions. The initial emotional distress and disruption to sense of self that occurs with onset of impairment or loss of mobility does not cease soon after the onset of impairment (Bury, 1982; Williams, 2000). Long-term conditions have been found to result in life-long adjustments to identity and lifestyle, due often to ongoing uncertainty about the long-term condition and the future (Bury, 1982; Galvin, 2005; Mayor, 2006). One method of overcoming this uncertainty is to develop expertise on living with the long-term condition (Bury, 1982; Mayor, 2006). Participants in this study supported this view by discussing the importance of developing expertise in their equipment management. Both wheelchair users and caregivers expressed that the development of expertise occurred experientially, through discussions with peers and with information from health professionals.

> ***C3:*** *I kinda like know how to do it… you… learn from your mistakes.*
>
> ***W1:*** *…given information on the Internet…the people running the wheelchair service must know… respite care especially I saw lots of people… with different types of wheelchairs.*

Developing expertise in these ways may have given these individuals with long-term conditions and their caregivers a feeling of control over the equipment and their condition, and may have contributed to developing a stable sense of self and lifestyle (Mayor, 2006). This expertise, growing control and more stable sense of self may have allowed the individual to feel more able to be involved in decision-making. This supports other qualitative studies noting that increasing experience of illness and the healthcare system resulted in a preference for increased involvement (Pellatt, 2004; Say et al., 2006).

It is likely that wanting to maintain control led several participants to express their preference to continue using equipment with which they were familiar when making decisions about equipment replacement.

> ***W2:*** *I'm very happy with this chair. I mean I'm used to it now.*
>
> ***C3:*** *I probably would say we'll have the same again, if they have.*

Being involved in decisions which result in ongoing use of familiar equipment is likely to enable some participants to feel in control of this aspect of their life. Due to the on-going adjustment to long-term conditions, this familiarity is likely to inspire confidence in participants that one aspect of their life will remain constant, when others such as their impairment could fluctuate (Mayor, 2006). Familiar equipment may minimise the stress they feel, as experience and understanding of the equipment may give confidence that their mobility can be relied on. Taking control by being involved in decisions that enable stability in one aspect of their life could contribute to developing a stable sense of self and to the ongoing adjustment to the long-term condition (Bury, 1982; Williams, 2000).

Several wheelchair users contrasted with these participants who wished to retain familiar equipment. For these wheelchair users, being involved in decision-making was about being provided with choices and being able to make the final decision on equipment.

> ***W3:*** *Very important …let's say you go and buy a car… without allowing me to… choose the one I want … I don't think it's right. So I want to be involved… make my choice what I want… even though I'm in a wheelchair… I can still…think and make my own decision.*
>
> ***W1:*** *For example, there was a range of colours available... I would certainly want to see them and chosen what… was suitable… A conservative colour but… something different.*

For these participants, their identity and the external image they presented were incorporated into their equipment. Therefore, as they wanted to control their identity, their involvement in decision-making and ability to choose was essential in achieving this (Mayor, 2006). For these participants, having a choice of equipment was important to them as it allowed them to express their individuality and gave a sense of control over their identity, as they were highly involved in decision-making and felt they had chosen the equipment. Recognising the participant's individuality in decision-making links in with the participants on-going adjustment and development of sense of self, control over their lifestyle and feeling of being a valid individual (Bury, 1982; Swain & French, 2000).

The concept of a developing sense of self has been discussed throughout this analysis. Evidence that this was occurring was noted as most wheelchair users demonstrated a changed view of their impairment and wheelchair with experience. For most participants, the wheelchair became part of their self-image and lifestyle.

> ***W6:*** *… I could get out on my own… it was marvelous, marvelous to have the wheelchair… I felt a lot better, a lot happier… knowing that I wasn't stuck indoors all the time.*

The way wheelchair users now seemed to perceive their disability had moved from their initial responses, where a sense of loss and 'giving up' were expressed, towards an affirmative model: where their impairment and wheelchair use were part of who they were as an individual (Swain & French, 2000). Developing and having this individuality recognised through their involvement in decision-making may be important for people with long-term conditions in developing their sense of self (Swain & French, 2000). Participants expressed this by discussing the behaviour and attitudes of health professionals involved in decision-making. All participants felt their involvement in decision-making was enhanced by the health professional providing adequate information and spending enough time with them to understand their individual needs.

> ***W4:*** *... I felt that they had... chosen this one as really the exactly the best one for me, (W4)... they all made time, you know how busy you are... there they all were at the same time!*

This preference for adequate information and time spent by health professional's parallels previous research on involvement (Entwistle et al., 2008; Henman et al., 2002; Skea et al., 2004). Participants noted that these health professional behaviours supported their feeling of being a valid individual, which links in with the developing sense of self and on-going adjustment to the long-term condition (Williams, 2000; Swain & French, 2000).

Caregiver perspectives

Caregivers viewed the decision-making process as one in which the wheelchair users views, preferences and individuality should be considered uppermost. All caregivers felt that any experience and input they contributed to decision-making was secondary to that of the wheelchair user, supporting Morris & Thomas' (2001) findings. Caregivers were very supportive of the identity of the wheelchair users they cared for and reported advocating for the inclusion of the wheelchair users in decision-making as a way to support the wheelchair users individuality and confidence.

> ***C1:*** *… if you don't involve the person it's like… there's no respect… because it is him, he is sitting on the chair, and he knows how he's feeling, we don't know how he's feeling…*

The caregivers in this study mainly described their role in decision-making as advocating for the wheelchair user, reflecting Morris & Thomas' (2001) findings but not the roles described by Charles et al. (1997). This may be because this group of caregivers worked with cognitively intact wheelchair users and the focus of decisions on equipment may have been on promoting their independence.

Caregivers also noted that they had their own individual needs that were affected by equipment.

> ***C4:*** *Because when he gets a problem with the wheelchair, I have to go with him… I need the wheelchair to get easy and he go out himself and I stay at home…*

Several caregivers discussed the importance of equipment reliability as problems with the chair limited their ability to carry on with their preferred lifestyle.
This suggests caregivers' involvement in decision-making is important as caregivers can assist wheelchair users to maximise their involvement by advocating for them (Morris & Thomas, 2001), and have individual needs that should also be addressed in decision-making (Batavia et al., 2001; Goodwin & Happell, 2007; Morris & Thomas, 2001).

Analysing the theme of developing expertise and involvement has indicated that the majority of participants wanted less involvement in decision-making when first in contact with the wheelchair service, perhaps due to distress at the onset of impairment. Developing expertise as part of adaptation to a long-term condition enabled greater involvement. However, not all participants followed the same journey, suggesting a number of factors interact to affect involvement preferences.

Final Discussion

Summary

The key finding of this study is that individuals with long-term conditions and their caregivers demonstrated a preference for more involvement throughout their patient journey. This supports findings of previous work that more involvement was preferred as the experience of illness and the healthcare system increased (Pellatt, 2004; Say et al., 2006). This study adds to current knowledge in this area by noting a link between these preferences and the process of adjustment to a long-term condition. The initial distress at the onset of impairment or loss of mobility (Finlayson & van Denend, 2003; Williams, 2000) was reflected in a preference for less involvement when first in contact with the service. As participants gained expertise in their condition and the health service, they felt able to be more involved in decision-making. This study also supported previous research, which noted involvement is individual and affected by the interaction of several factors (Fraenkal & McGraw, 2007; Say et al., 2006; Thompson, 2007). This was demonstrated in this study with one participant preferring high involvement from the onset of his long-term condition, and with groups of participants expressing differences in the way they wanted to be involved throughout the patient journey.

This study also notes caregivers have individual needs and that these needs are made secondary to the patients needs and preferences by the caregivers. These findings had been noted in previous work (Goodwin & Happell, 2007; Morris & Thomas, 2001), but this study contributes to current knowledge by recognising that caregivers go through as similar journey to people with long-term conditions in gaining expertise and preferring more involvement in decision-making throughout the journey.

These findings have value for all health professionals working with individuals with long-term conditions and their caregivers. Recognising that adjustment to long-term conditions may impact on preferences for involvement is useful for health care professionals to consider when approaching decision-making with their patients and caregivers, as it can promote empathy and involvement in decision-making that meets the needs of patients and caregivers.

These findings highlight how important time is in encouraging the patient and caregiver to feel like valid individuals. In a rushed clinical setting, the impact of spending time to make a one-off decision with a patient or caregiver may be underestimated. Recognising that decision-making has an impact on the patient's developing sense of self and adaptation to long-term condition indicates just how important this process can be in the context of that individual's life.

This study has therefore achieved its aim of exploring wheelchair user and caregiver perspectives on involvement throughout the patient journey. The objectives were also achieved, although the focus of this paper has been largely on why involvement preferences change over time. These findings have been the focus as they increase current knowledge on involvement, whereas findings in relation to the other objectives confirmed current evidence.

Limitations of the study

This study is limited by the nature of qualitative research, the defined role I gave to caregivers, conducting a single interview that asked about past experiences and the non-return of transcripts.

It is recognised that as a piece of qualitative research, which is highly context dependent, these findings have limited transferability (Avis, 2005). This is particularly true given that all wheelchair users in this study experienced an acquired neurological condition, making them not representative of all wheelchair users at this single service. However, as a clearly planned and documented process was followed in the research, there is the possibility for readers to determine whether what was found has relevance to their setting, and to use the findings accordingly (Cutclliffe & McKenna, 1999). This well documented process keeps the research open to auditing and could allow other researchers to use a similar method with other groups of participants to discover similar or contradictory results (Cutcliffe & McKenna, 1999).

My experience working in the wheelchair service impacts on the research. I have developed opinions on the topic, which have influenced the research throughout, from choosing involvement as a topic of interest to the conclusions reached in the analysis. As with all qualitative work, it is possible that a different researcher would have reached different conclusions (Avis, 2005; Finlay, 2006). Keeping a reflexive diary throughout the research process is the most effective way of noting where my influence has impacted on the research. This enhances the transparency of the research process and thus enhances credibility (Avis, 2005).

The results of this study in relation to caregivers may be affected by the way in which they were invited to participate. Caregivers were invited to participate in the study by the wheelchair user they cared for. Defining the role for a participant may limit what the participant shares in the study (Speer, 2002). This may have affected this study, as the caregivers may have felt the study was interested primarily in the wheelchair user, with their contribution of lesser importance, and this may have led to them describing their needs as secondary to the wheelchair user. Different results and a deeper understanding about caregivers’ involvement preferences may have been obtained with a different approach to inviting caregivers. Directly recruiting caregivers via a poster at a carers centre for example, may have defined the caregiver differently, and allowed them to discuss involvement in a different way.

The study findings are affected by carrying out a single interview, focusing on past experiences. Participants may have difficulty remembering these experiences and are likely to have filtered them in accordance with subsequent events (Entwistle, Tritter & Calnan, 2002). Therefore, perceptions reported now may differ from what participants felt at the time (Cutcliffe & McKenna, 1999; Entwistle et al., 2002). However, the time gap also offers an opportunity to reflect without being subject to the emotional states present at the time (Entwistle et al., 2008). This is relevant in this study as participants were discussing times when they may have been distressed. Future research

could overcome this by involving participants at different stages of their journey, to deepen the findings of this study.
Repeating interviews allows clarification of issues raised in the first interview and provides an opportunity to gain deeper information, which could enhance the credibility of findings (Kvale, 1996). However, this would require a greater time commitment from participants and may lead to recruitment difficulties (Cutcliffe & McKenna, 1999). Given the time scale for this project, follow-up interviews were not possible but could be considered to strengthen future work.

No participants formally verified the accuracy of their transcripts, which affects the credibility of the findings. Difficulty with transcripts being verified is not isolated to this study, as seeing the transcript may make the participant feel inarticulate (Forbat & Henderson, 2005). To overcome this, I adjusted the transcription style with later transcripts by removing my encouragers and tidying the language in a way I felt would make it more readable for the participants. I felt this was acceptable in this study as I was analysing the content, and was not carrying out conversation or discourse analysis where transcribing verbatim is more important as the language and intonation have greater significance (Forbat & Henderson, 2005; Kvale, 1996). Overcoming this issue is difficult as allowing participants to choose to verify their transcript gives control to the participants and this seems most appropriate to respect the rights of participants (Forbat & Henderson, 2005).

Reflections on the research process

This study provides a theoretical background to what I had noticed in practice. I had noted that wheelchair users and caregivers wanted to be involved in different ways, but I had assumed this was down to individual preferences, and wondered how I would be able to determine each person’s preference when they came into clinic. Carrying out this research has identified the impact of adjustment to a long-term condition as being a relevant factor to consider when working with wheelchair users and their caregivers. This could promote empathy, and re-enforces the importance of a client-centred approach.

As I had worked in the service for five years before undertaking this study, I had seen six of the participants clinically previously, and had known some participants for several years. This affects the trustworthiness of the research as a close relationship with participants may influence their responses (McConnell-Henry, James, Chapman & Francis, 2010). Participants may have felt more able to share their experiences, as they may have felt I understood this area and their experiences. Conversely, participants may have felt pressured to give the ‘right’ answers, to preserve a relationship with me, and to ensure their participation did not affect their future equipment provision. Carrying out this project in another service or using an individual not known to participants to conduct the interviews were considered to avoid this close relationship with participants. However, as I wanted my service to benefit from the time I spent on research, and I wanted to gain interview skills, I elected to carry out the interviews in my own service and accept this close relationship with participants. The recruitment method aimed to minimise concerns service users may have had about participating, by being non-coercive. I would carefully consider this relationship when undertaking any future research, and may try and avoid such a close relationship with participants in future studies as I do feel that my relationship with the participants has changed, and this may impact on future clinical contact.

Completing this project enabled me to develop a deep understanding of the research process. Initial discussions with my supervisors indicated the importance of detailed planning when embarking on a study. Initially I found it difficult to narrow down the topic and to select a trustworthy and practical method for achieving the aim and objectives. This taught me that rarely is there a 'perfect' research method and that difficult choices need to be made. Being able to justify these choices and have a process that is open to scrutiny are important factors to consider when selecting a methodology.

I enjoyed the data collection process. It provided an opportunity to speak to patients in a way that is not usually possible in the time-pressured clinical environment. Being able to interview clients for research highlighted the differences between clinical practice and research. I feel there are skills I have learnt through interviewing, such as using open questions to invite narratives and allowing these to continue without interruption, that can be brought to my clinical practice to enhance the way I work with individuals.

I found the analysis difficult. Moving from a literal to more interpretative analysis took more time than I anticipated. I found my supervisors and peers useful in this process, as they were able to provide a different perspective, not having been as close to the data. This helped me to reach a more interpretative and trustworthy result than would otherwise have been achieved.

Future directions

Future work could involve looking at involvement preferences of individuals with different types of long-term conditions, as research suggests individuals with congenital or orthopaedic impairments may respond differently to individuals with acquired neurological conditions (Hearst, 2007; Murray, 2009; Williams, 2000).

This study also involved decision-making in a single service. Patients with long-term conditions are often involved in a variety of services and exploring how involvement in decision-making operates across services could benefit the holistic care of patients across multi-disciplinary teams.

Exploring involvement preferences over a longer time period could allow individual perceptions to be followed throughout the course of their journey, rather than at a single point in time, which could promote deeper understanding of involvement preferences throughout the patient journey.

Conclusion

The key finding of this study is a link between adaptation to a long-term condition and involvement preferences for individuals and their caregivers. Previous work on involvement had noted that individuals with experience of illness and the health system tended to prefer more involvement in healthcare decision-making (Say et al., 2006; Fraenkal & McGraw, 2007). This study adds to this knowledge by offering an understanding of why this occurs for people with long-term conditions and their caregivers.

The research also notes that not all individuals go through the same process, which supports previous work noting that involvement is not predictable, as a complex interaction of factors influence preferences (Say et al., 2006; Thompson, 2007).

This study achieved its broad aim to explore how wheelchair users and their caregivers perceived involvement throughout their patient journey and focused on achieving the objectives of determining why this occurred and making recommendations based on the findings.

This understanding can improve the way health professionals work with individuals with long-term conditions and their caregivers, by promoting empathy and enabling decision-making to be approached in a way that supports the individuals’ developing sense of self.

Future work in this area could look at decision-making in other long-term conditions and across services or multi-disciplinary teams.

Word Count - 9 999words

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Appendices

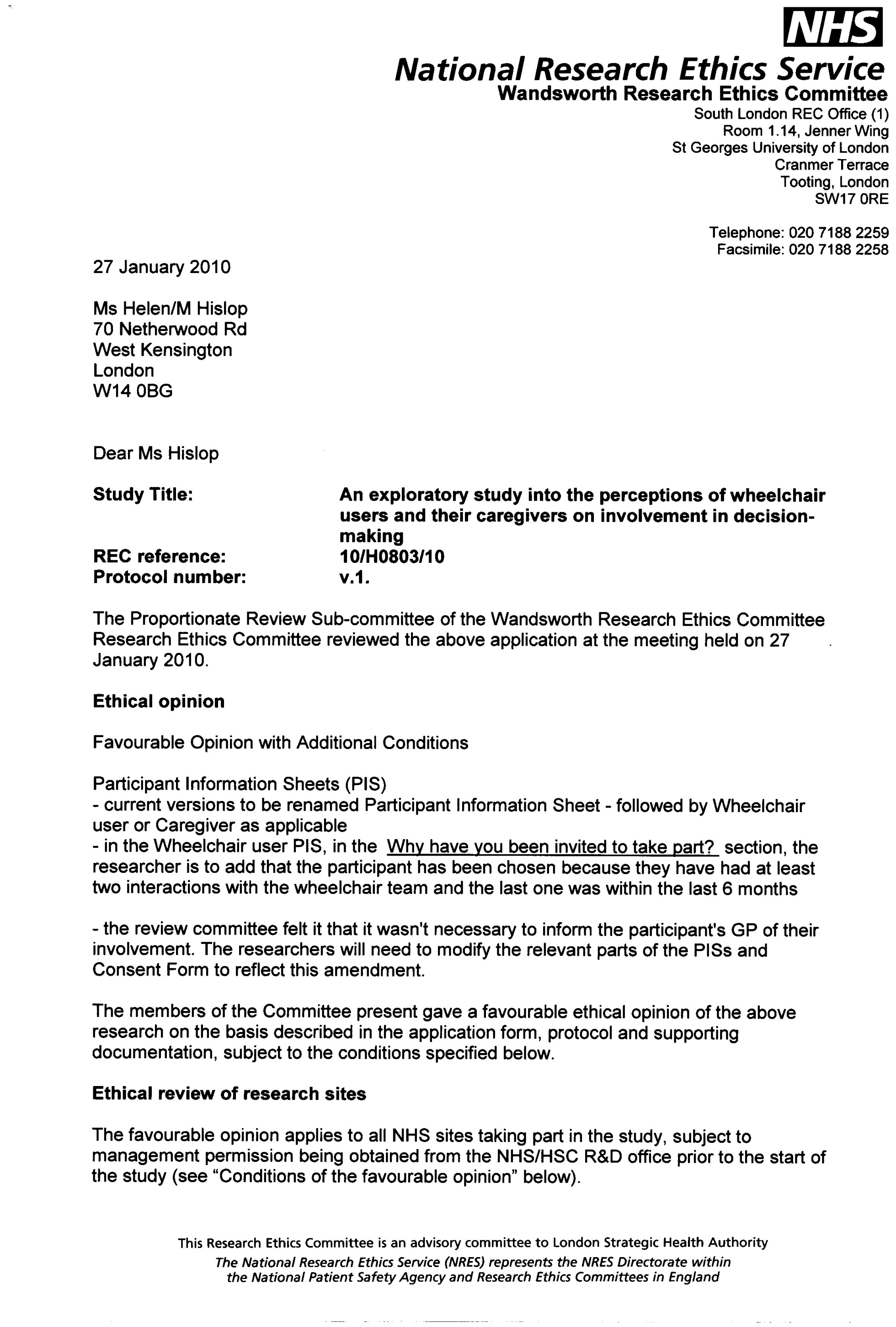
Appendix 1: Literature on personal characteristics affecting involvement

Author/s	**Higher involvement preferred**	**Lower involvement preferred**	**Unclear/contradictory results**	**Area of health care participants drawn from**
Arora & Mc Horney, 2000	Younger patients Women Higher education Active coping strategies Less severe illness	Severe diabetes Unsevere heart disease Patients placing a higher value on their health	Race Active lifestyle Employment status Marital status Income Social support	Patients with chronic disease (hypertension, diabetes, myocardial infarction, congestive heart failure and depression)
Beaver et al., 1996		Lower education levels Older age Lower social class	Marital status Family history of breast cancer Method of reaching diagnosis Type of surgery planned	Women diagnosed with benign breast disease or breast cancer
Butow, Maclean, Dunn, Tattersall & Boyer, 1997		Patients whose condition is worsening		Cancer patients seen in outpatients by two oncologists at a university teaching hospital in New South Wales, Australia
Chamot, Charvet & Perneger, 2004		Older age Immigrant background Wish to know as late as possible about having cancer		Women in Geneva between 50 and 69yrs about to be invited for the first round of organised breast cancer screening

Hawley et al., 2007	Younger age Higher education level	Older age Lower education level		Women diagnosed with breast cancer in Detroit and Los Angeles with ductal carcinoma in situ
Little et al., 2001	Not in paid work Attending practice more than 5times per year Feeling unwell Worried about problem			Three GP practices in the UK
O’Connor et al., 2003	Younger age	Lower education levels		National sample of Canadians over 18 making ‘complex’ health decisions
Sainio, Lauri & Eriksson, 2001	In good health Able to access information Assertive Good relationships with health care professionals Encouragement to participate from healthcare professionals	In poor health Ignorance Anxiety Lack of time High staff turnover Poor relationships Older age		Cancer patients on oncology and haematology wards in one university hospital in Finland
Street et al., 2006	Higher education levels White Physician encouraged partnership Patients with lung cancer	Lower education levels		Data from patients with SLE in California, primary care patients in California and patients with lung cancer in Texas pooled

Thompson, 2007	Chronic illness Less severe illness Low level of trust in professional Active personality	Acute illness Serious illness High level of trust in professional Passive personality	Knowledge of condition Experience of health care	From six GP practices and random samples from voluntary/community, particularly those representing minority groups

Appendix 2: Approval letter from Wandsworth Research Ethics Committee



NHS
National Research Ethics Service
Wandsworth Research Ethics Committee
South London REC Office (1)
Room 1.14, Jenner Wing
St Georges University of London
Cranmer Terrace
Tooting, London
SW17 0RE

Telephone: 020 7188 2259
Facsimile: 020 7188 2258

27 January 2010

Ms Helen/M Hislop
70 Netherwood Rd
West Kensington
London
W14 0BG

Dear Ms Hislop

Study Title:	**An exploratory study into the perceptions of wheelchair users and their caregivers on involvement in decision-making**
REC reference:	**10/H0803/10**
Protocol number:	**v.1.**

The Proportionate Review Sub-committee of the Wandsworth Research Ethics Committee Research Ethics Committee reviewed the above application at the meeting held on 27 January 2010.

Ethical opinion

Favourable Opinion with Additional Conditions

Participant Information Sheets (PIS)
- current versions to be renamed Participant Information Sheet - followed by Wheelchair user or Caregiver as applicable
- in the Wheelchair user PIS, in the Why have you been invited to take part? section, the researcher is to add that the participant has been chosen because they have had at least two interactions with the wheelchair team and the last one was within the last 6 months

- the review committee felt it that it wasn't necessary to inform the participant's GP of their involvement. The researchers will need to modify the relevant parts of the PISs and Consent Form to reflect this amendment.

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.

Ethical review of research 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.

For NHS research sites only, management permission for research ("R&D approval") should be obtained from the relevant care organisation(s) 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 the only involvement of the NHS organisation is as a Participant Identification Centre, management permission for research is not required but the R&D office should be notified of the study. Guidance should be sought from the R&D office where necessary.

Sponsors are not required to notify the Committee of approvals from host organisations.

It is the 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*
Covering Letter	1.0	11 January 2010
REC application	1.0	12 January 2010
Protocol	v.1.	11 January 2010
Investigator CV	1.0	11 December 2009
Participant Information Sheet: Wheelchair user	v.1	11 January 2010
Participant Information Sheet: Caregiver	v.1	11 January 2010
Participant Consent Form: Wheelchair user	v.1	11 January 2010
Participant Consent Form: Caregiver	v.1	11 January 2010
Letter of invitation to participant	v.1	11 January 2010
GP/Consultant Information Sheets	v.1.	11 January 2010
Evidence of insurance or indemnity	1.0	01 August 2009
Letter from Sponsor	1.0	12 January 2010
Referees or other scientific critique report	1.0	17 December 2009
Interview Schedules/Topic Guides	v.1	11 January 2010
Student CV - Helen Hislop	1.0	11 January 2010
Reply form	v.1	11 January 2010
Summary/Synopsis	v.1	11 January 2010
Letter from funder	1.0	11 January 2010

Membership of the Proportionate Review Sub-Committee

The members of the Sub-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.

10/H0803/10 **Please quote this number on all correspondence**

With the Committee's best wishes for the success of this project

Yours sincerely

Dr Christine Heron
Chair

Email: samantha.roper@gstt.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"

NHS
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Cranmer Terrace
Tooting, London
SW17 0RE

Telephone: 020 7188 2259
Facsimile: 020 7188 2258

01 February 2010

Ms Helen M Hislop
70 Netherwood Rd
West Kensington
London
W14 0BG

Dear Ms Hislop

Full title of study: **An exploratory study into the perceptions of wheelchair users and their caregivers on involvement in decision-making**
REC reference number: **10/H0803/10**
Protocol number: **v.1.**

Thank you for your letter of 28 January 2010. I can confirm the REC has received the documents listed below as evidence of compliance with the approval conditions detailed in our letter dated 27 January 2010. Please note these documents are for information only and have not been reviewed by the committee.

Documents received

The documents received were as follows:

Document	*Version*	*Date*
Participant Information Sheet: Wheelchair user	v.2	27 January 2010
Response to Request for Further Information	1.0	28 January 2010
Participant Information Sheet: Caregiver	v.2	27 January 2010
Participant Consent Form: Wheelchair user	v.2	27 January 2010
Participant Consent Form: Caregiver	v.2	27 January 2010

You should ensure that the sponsor has a copy of the final documentation for the study. It is the sponsor's responsibility to ensure that the documentation is made available to R&D offices at all participating sites.

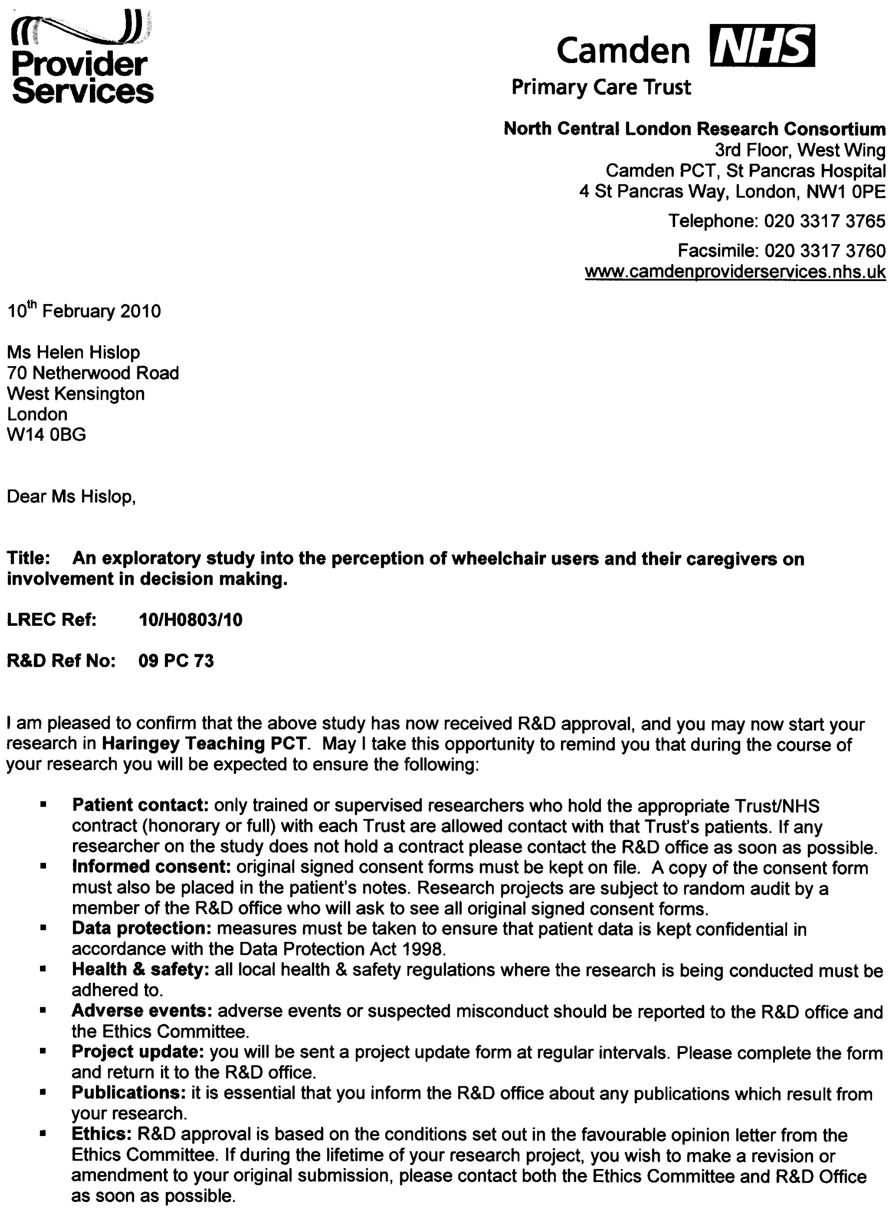
10/H0803/10 **Please quote this number on all correspondence**

Yours sincerely

Samantha Roper
Committee Co-ordinator
E-mail: samantha.roper@gstt.nhs.uk

This Research Ethics Committee is an advisory committee to London 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

Appendix 3: Approval letter for North Central London Research Consortium



Provider
Services

Camden NHS
Primary Care Trust

North Central London Research Consortium
3rd Floor, West Wing
Camden PCT, St Pancras Hospital
4 St Pancras Way, London, NW1 0PE
Telephone: 020 3317 3765
Facsimile: 020 3317 3760
www.camdenproviderservices.nhs.uk

10th February 2010

Ms Helen Hislop
70 Netherwood Road
West Kensington
London
W14 0BG

Dear Ms Hislop,

Title: An exploratory study into the perception of wheelchair users and their caregivers on involvement in decision making.

LREC Ref: 10/H0803/10

R&D Ref No: 09 PC 73

I am pleased to confirm that the above study has now received R&D approval, and you may now start your research in **Haringey Teaching PCT**. May I take this opportunity to remind you that during the course of your research you will be expected to ensure the following:

- **Patient contact:** only trained or supervised researchers who hold the appropriate Trust/NHS contract (honorary or full) with each Trust are allowed contact with that Trust's patients. If any researcher on the study does not hold a contract please contact the R&D office as soon as possible.
- **Informed consent:** original signed consent forms must be kept on file. A copy of the consent form must also be placed in the patient's notes. Research projects are subject to random audit by a member of the R&D office who will ask to see all original signed consent forms.
- **Data protection:** measures must be taken to ensure that patient data is kept confidential in accordance with the Data Protection Act 1998.
- **Health & safety:** all local health & safety regulations where the research is being conducted must be adhered to.
- **Adverse events:** adverse events or suspected misconduct should be reported to the R&D office and the Ethics Committee.
- **Project update:** you will be sent a project update form at regular intervals. Please complete the form and return it to the R&D office.
- **Publications:** it is essential that you inform the R&D office about any publications which result from your research.
- **Ethics:** R&D approval is based on the conditions set out in the favourable opinion letter from the Ethics Committee. If during the lifetime of your research project, you wish to make a revision or amendment to your original submission, please contact both the Ethics Committee and R&D Office as soon as possible.

Please ensure that all members of the research team are aware of their responsibilities as researchers. For more details on these responsibilities, please check the R&D handbook or NoCLoR website: http://www.noclor.nhs.uk

We would like to wish you every success with your project

Yours sincerely,

Angela

Angela Williams
Research & Development Manager

Appendix 4: Grant approval letter from the Posture and Mobility Group Research and Development sub-committee

POSTURE &
MOBILITY
GROUP

29 MYRTLE CLOSE
ALPHINGTON
EXETER
EX2 8UX
TEL/FAX: 0845 1301 764
e-mail:olwen.ellis@pmguk.co.uk

20th January 2010

Helen Hislop
Haringey Wheelchair Service
St Ann's Hospital
St Ann's Rd
Tottenham
London N15 3TH

Dear Helen Hislop

Re: ***How do wheelchair users and their carers want to be involved in making decisions about their equipment at the wheelchair service?***

Thank you for your recent application for funding from the PMG small research study scheme.
The PMG R&D sub-committee met on January 15th 2010 and agreed to offer funding for the study through the scheme.

The grant offered is the full amount requested: **£3,885.00** *(but see 2 on next page)*

Please read the terms and conditions of the grant below and, if your are happy, sign both copies of this letter to signify your agreement to the contents, keeping one for your own records and posting the other to Olwen Ellis at the PMG office, address above.

i) A brief (one or two sides of A4) progress report should be provided 2-3 months after commencement of the study.
ii) A full report with an executive summary (one side of A4) must be submitted within two months of completion of the work. With your consent, and unless the report is confidential, PMG reserves the right to publish either the full report and/or summary (both provided by the project co-ordinator) on the PMG website and/or in the PMG publication.
iii) PMG holds a conference, the National Training Event, every year at which you may be requested to present the findings from your studies.
iv) The financial support of Posture & Mobility Group must be acknowledged in all reports and papers written as a result of the funded project.
v) If, for any reason, the project is cancelled, all monies paid must be returned to Posture & Mobility Group.
vi) If, for any reason, the project programme is delayed, approval of the revised schedule must be sought from PMG Research & Development committee immediately.
vii) PMG asks that your institution gives full support to ensuring that the grant is spent in the appropriate amounts relating to the purposes specified within the budget. We are working with a start date of **January 31st 2010.** Please let us know if this changes.

viii) The grant will be paid as follows:

- **1st instalment: £970.00** to be paid to your administrative body on receipt of the initial progress report.
- **2nd instalment: £1940.00** at the end of the project.
- **3rd instalment:** the outstanding amount will be paid on receipt of the final report.
- Copies of proof of payment for any equipment purchased, or other expenses incurred for the project, will be required. All costs and claims associated with this project may be subject to independent audit by the Posture & Mobility Group, its officials or auditors.

The sub-committee noted two issues that may be of concern to the research ethics committee when applying for ethical approval:

1. The participation in your study of clients from the wheelchair service of which you are manager. We recognised that you will be inviting participants "who have had their most recent clinical contact with a staff member other than the researcher." However, we thought that this may still prove problematic when seeking ethical approval. We recommend you discuss this issue with the research ethics committee.

2. The exclusion of participants who are unable to read or speak English adequately. When applying for ethical approval this is sometimes justified if the research budget is insufficient to fund interpreter services. However, given the diversity of the community in your area, we thought that restricting the study to English speaking people only might undermine the research objective and, as a consequence, be of concern to the ethics committee. To this end the sub-committee would be willing to provide extra funding to help pay for interpreter services. The maximum grant available to you is **£5,000.00**, and therefore you could ask PMG for up to **£1,115.00** for this purpose. The sub-committee wondered whether you might be able to find affordable interpreting services when required within the various local communities in Haringey.

I look forward to receiving your signed agreement to the grant conditions, but do contact the PMG office if you have any questions or concerns. Please ensure that bank details for your administrative body are provided on invoices presented, so that the PMG treasurer can pay the grant via bank transfer.
Yours sincerely

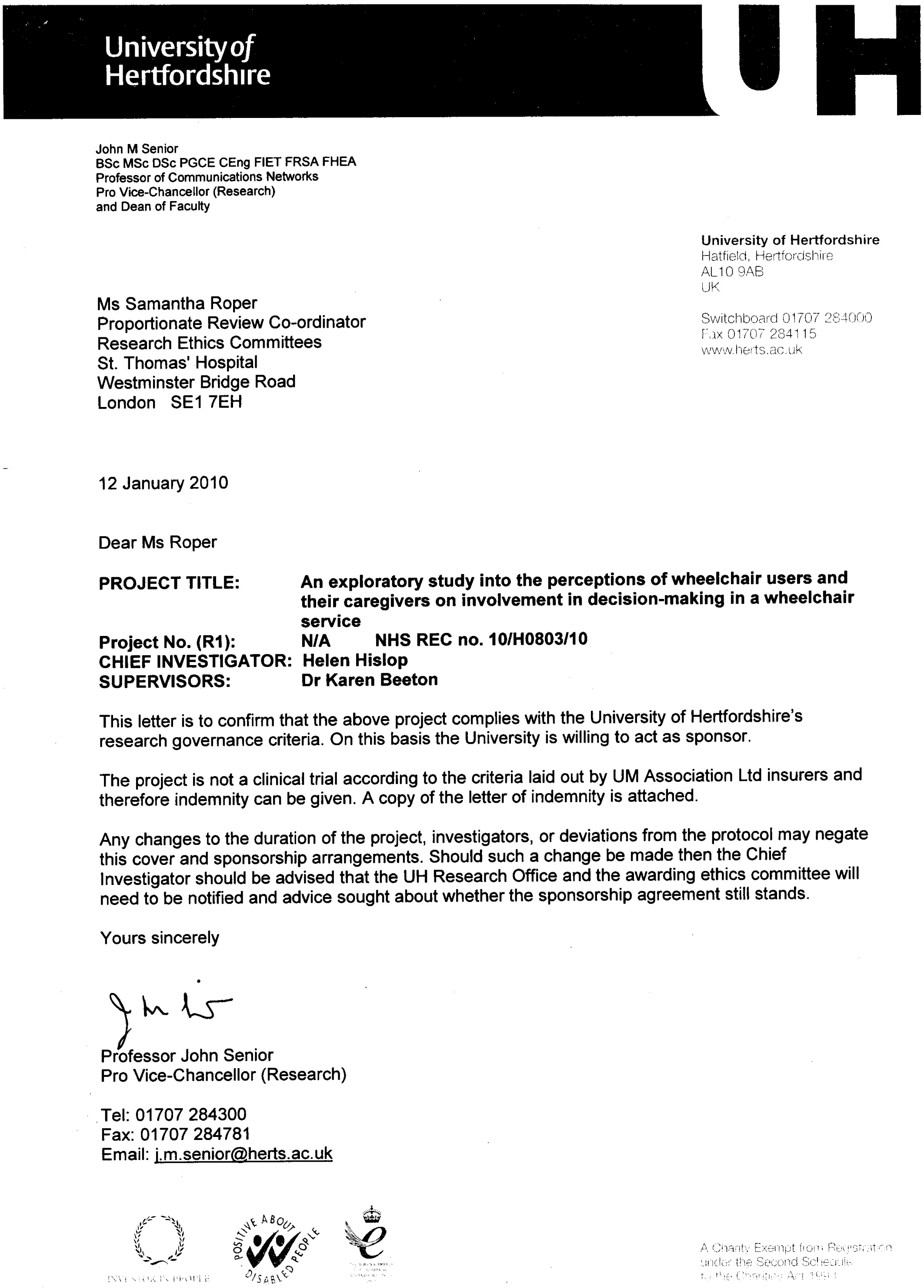
Dr David Porter
Chair, PMG R&D sub committee

I agree to the Terms & Conditions stated above:

Signed ____
(Helen Hislop, project co-ordinator)

Signed ____
(Christine Coleman, administrative authority)

Appendix 5: Sponsorship confirmation from University of Hertfordshire



University of Hertfordshire

John M Senior
BSc MSc DSc PGCE CEng FIET FRSA FHEA
Professor of Communications Networks
Pro Vice-Chancellor (Research)
and Dean of Faculty

University of Hertfordshire
Hatfield, Hertfordshire
AL10 9AB
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www.herts.ac.uk

Ms Samantha Roper
Proportionate Review Co-ordinator
Research Ethics Committees
St. Thomas' Hospital
Westminster Bridge Road
London SE1 7EH

12 January 2010

Dear Ms Roper

PROJECT TITLE: **An exploratory study into the perceptions of wheelchair users and their caregivers on involvement in decision-making in a wheelchair service**
Project No. (R1): **N/A NHS REC no. 10/H0803/10**
CHIEF INVESTIGATOR: **Helen Hislop**
SUPERVISORS: **Dr Karen Beeton**

This letter is to confirm that the above project complies with the University of Hertfordshire's research governance criteria. On this basis the University is willing to act as sponsor.

The project is not a clinical trial according to the criteria laid out by UM Association Ltd insurers and therefore indemnity can be given. A copy of the letter of indemnity is attached.

Any changes to the duration of the project, investigators, or deviations from the protocol may negate this cover and sponsorship arrangements. Should such a change be made then the Chief Investigator should be advised that the UH Research Office and the awarding ethics committee will need to be notified and advice sought about whether the sponsorship agreement still stands.

Yours sincerely

Professor John Senior
Pro Vice-Chancellor (Research)

Tel: 01707 284300
Fax: 01707 284781
Email: j.m.senior@herts.ac.uk

Hasilwood House
60 Bishopsgate
London EC2N 4AW
Tel: 020 7847 8670
Fax: 020 7847 8689

UMAL

TO WHOM IT MAY CONCERN

1st August 2009

Dear Sir/Madam

**UNIVERSITY OF HERTFORDSHIRE
AND ALL ITS SUBSIDIARY COMPANIES**

We confirm that the above Institution is a Member of U.M. Association Limited, and that the following cover is currently in place:-

PROFESSIONAL INDEMNITY

Certificate of Entry No.	UM039/97
Period of Cover	1 August 2009 - 31 July 2010
Limit of Indemnity	£5,000,000 any one claim and in the aggregate except for Pollution where cover is limited to £1,000,000 in the aggregate.
Cover provided by	U.M. Association Limited and Excess Cover Providers led by QBE Insurance (Europe) Limited

If you have any queries in respect of the above details, please do not hesitate to contact us.

Yours faithfully

Susan Wilkinson

Susan Wilkinson
For U.M. Association Limited

U.M. Association Limited
Registered Office: Hasilwood House, 60 Bishopsgate, London, EC2N 4AW
Registered in England and Wales No. 2731799

Appendix 6: Participant information sheet – wheelchair user

NHS
Haringey

Participant Information sheet – Wheelchair user

Study title: Involvement in decision-making with wheelchair users and caregivers

Study reference no. 01HH

I would like to invite you to take part in this research project. Before you decide, please read the information below which explains what the study hopes to explore and how you could be involved. You will be able to ask for more information and ask any questions about the research before deciding to take part.

Why is this study being undertaken?

I am a physiotherapist at Haringey wheelchair service and am completing a Masters degree in Physiotherapy at the University of Hertfordshire. To complete this degree, I have chosen to look at the views of wheelchair users and their caregivers on making decisions about equipment.

We all make many decisions throughout our lives, from what we want to watch on TV to serious decisions about our healthcare. Some research about wheelchair decision-making has found that people think about many aspects of the equipment, such as its performance, impact on work and appearance. This study will explore the views of wheelchair users and caregivers on being involved in making these types of decisions. The information found in this study could help to increase knowledge on this topic.

Why have you been invited to take part?

You have been invited to take part as you have had at least two interactions with Haringey wheelchair service, the most recent being in the last six months. I will be asking up to 10 wheelchair users and their caregivers for their views.

Do you have to take part?

It is up to you to choose to take part or not. It does not matter whether your caregiver chooses to take part or not; your decision can be different from theirs. You will be able to choose to take part together with your caregiver or on your own.

Whether you choose to take part or not, your care from the wheelchair service will not be affected. I can provide you with more information and answer any questions you have before you decide to take part. I can do this over the phone or can come and visit you at home or at another location of your choice.

If you decide to take part, I will ask you to sign a consent form, to show you have agreed. This does not mean you are ‘locked in’ to the study - you are free to withdraw at any time, without giving a reason.

What will happen if you do agree to take part?

If you agree to be involved, you will take part in an interview in your own home or another location that you choose. You can choose to be interviewed by yourself or together with your caregiver (if you have one whom you wish to invite to take part). This interview may last up to one hour. The interview will be audio recorded so no details are missed. You will be sent a copy of the interview transcript when it is typed up, to make sure your views have been noted correctly. It is your choice to read, comment on this and return it to me, but you do not have to.

What will happen if you decide not to take part?

If you decide not to take part, you will not be contacted any further about this study. Whatever you decide, your care from the wheelchair service will not be affected.

What benefits are gained by taking part?

The information gained could be used to increase the knowledge on involvement of wheelchair users and caregivers in decision-making.

Will your taking part in this study be kept confidential?

Yes, all information gathered will be kept in strictest confidence. Your name and other personal details will not appear in any reports. The audio recordings, written and electronic documents created by the study will all be securely stored. This will be done according to NHS Haringey and University of Hertfordshire policies on data protection. Any personal information will be securely destroyed once the research is complete. The only time any information you share could be passed on to the service is if you raise an issue that causes concern for your safety. As your safety is very important, this information would need to be shared with the service to make sure action could be taken to keep you safe.

What if there is a problem?

You can choose not to answer a particular question or to stop the interview if you feel uncomfortable. If you would like to speak to someone following the interview, contact details for a member of staff who is not involved in the research and the Patient Advice and Liaison Service (PALS) will be given to you. These contact details will be given to you before the interview begins.

What will happen with the results of the research?
You will be told about of the results of this study by letter once it is complete. The results will be shared with the local wheelchair user group, other wheelchair services, in presentations and will hopefully be published in a journal. Your name and personal information will not appear in any reports.

Who has reviewed this study?
All research in the NHS is looked at independently by a research ethics committee, to ensure participants are treated fairly. The Wandsworth Research Ethics Proportionate Review Sub-Committee, The North Central London Research and Development committee and the University of Hertfordshire have reviewed this research.

Making contact
If you would like to take part in the study, please phone me on 0208 442 6020 and leave your details for me to phone you back, or fill in the reply form enclosed with this letter and return in the stamped envelope. If you would like to ask any questions or find out further information before deciding, please phone me on 0208 442 6020 and leave your details for me to phone you back.
If I do not hear from you within 7days of receipt of this letter, I will assume you do not wish to take part in the study. I will not contact you again in relation to this study.
If you have any queries relating to the research or academic process for this study, please contact my supervisor, Dr Karen Beeton, Deputy Head of School, School of Health and Emergency Professions, University of Hertfordshire, on 01707284114 or k.s.beeton@herts.ac.uk.
Thank you for taking the time to consider this request.
Yours Sincerely,

Helen Hislop
HPC registered Physiotherapist
Principal Investigator
Phone. 0208 442 6020

Appendix 7: Participant information sheet – caregiver

NHS
Haringey

Participant Information sheet – Caregiver

Study title: Involvement in decision-making with wheelchair users and caregivers
Study reference no. 01HH

I would like to invite you to take part in this research project. Before you decide, please read the information below. It explains what the study hopes to explore, and how you could be involved. You can ask for more information or ask any questions about the research before deciding to take part.

Why is this study being undertaken?

I am a physiotherapist at Haringey wheelchair service and am completing a Masters degree in Physiotherapy at the University of Hertfordshire. To complete this degree, I have chosen to look at the views of wheelchair users and their caregivers on making decisions about equipment.
We all make many decisions throughout our lives, from what we want to watch on TV to serious decisions about our healthcare. Some research about wheelchair decision-making has found that people think about many aspects of the equipment, such as its performance, impact on work and appearance. This study will explore the views of wheelchair users and their caregivers on being involved in making these types of decisions. The information found in this study could help to increase knowledge on this topic.

Why have you been invited to take part?

A wheelchair user from Haringey Wheelchair Service has identified you as their caregiver. I will be asking up to 10 wheelchair users and caregivers about their views.

Do you have to take part?

It is up to you to choose to take part or not. It does not matter whether the person you care for chooses to take part or not; your decision can be different from theirs. You will be able to choose to take part together with the person you care for or on your own.
Whether you decide to take part or not, your involvement with the wheelchair service will not be affected. I can provide you with more information and answer any questions you have before you decide to take

part. I can do this over the phone or can come and visit you at home or at another location of your choice.

If you decide to take part, I will ask you to sign a consent form, to show you have agreed. This does not mean you are ‘locked in’ to the study - you are free to withdraw at any point, without giving a reason.

What will happen if you do agree to take part?

If you agree to be involved, you will take part in an interview in your own home or another location that you choose. You can choose to be interviewed alone or together with the person you care for. This interview may last up to one hour. The interview will be audio recorded so no details are missed. You will be sent a copy of the interview transcript when it is typed up, to make sure your views have been noted correctly. You can choose to read, comment on this and return it to me, but you do not have to.

What will happen if you decide not to take part?

If you decide not to take part, you will not be contacted any further about this study. Whatever you decide, your involvement with the wheelchair service will not be affected.

What benefits are gained by taking part?

The information gained could be used to increase the knowledge on involvement of wheelchair users and caregivers in decision-making.

Will my taking part in this study be kept confidential?

Yes, all information gathered will be kept in strictest confidence. Your name and other personal details will not appear in any reports. The audio recordings, written and electronic documents created by the study will all be securely stored. This will be done according to NHS Haringey and University of Hertfordshire policies on data protection. Any personal information will be securely destroyed once the research is complete.

What if there is a problem?

You can choose not to answer a particular question or to stop the interview if you feel uncomfortable. If you would like to speak to someone following the interview, contact details for a member of staff who is not involved in the research and the Patient Advice and Liaison Service (PALS) will be given to you. These contact details will be given to you before the interview begins.

What will happen with the results of the research?

You will be told about the results of this study by letter once it is complete. The results will be shared with the local wheelchair user group, other wheelchair services, in presentations and will hopefully be published in a journal. Your name and personal information will not appear in any reports.

Who has reviewed this study?

All research in the NHS is looked at independently by a research ethics committee, to ensure participants are treated fairly. The Wandsworth Research Ethics Proportionate Review Sub-Committee, The North Central London Research and Development committee and the University of Hertfordshire have reviewed this research.

Making contact

If you would like to take part in the study, please phone me on 0208 442 6020 and leave your details for me to phone you back or fill in the reply form enclosed with this letter and return in the stamped envelope. If you would like further information or to ask any questions before deciding, please phone me on 0208 442 6020 and leave your details for me to phone you back.

If I do not hear from you within 7days of receipt of this letter, I will assume you do not wish to take part in the study. I will not contact you again in relation to this study.

If you have any queries relating to the research or academic process for this study, please contact my supervisor, Dr Karen Beeton, Deputy Head of School, School of Health and Emergency Professions, University of Hertfordshire, on 01707284114 or k.s.beeton@herts.ac.uk.

Thank you for taking the time to consider this request.

Yours Sincerely,

Helen Hislop
HPC registered Physiotherapist
Principal Investigator
Phone. 0208 442 6020

Appendix 8: Participant invitation letter

NHS
Haringey

Date:

Dear…………,

I am currently undertaking a research project as part of my Masters degree in Physiotherapy at the University of Hertfordshire.

I would like to invite you to participate in this research project. The research will be exploring the views of wheelchair users and their caregivers about their involvement in decision-making.

Please find enclosed two information sheets – one is titled ‘wheelchair user’ and one ‘caregiver’. The ‘caregiver’ sheet can be passed on if you think there is somebody who provides most of your daily care and helps you use and look after your wheelchair. If you do not have somebody who fits this description, or you would prefer not to involve your caregiver, please do not worry about the caregiver information sheet. You do not need to have a caregiver to take part in the research. You can take part with or without your caregiver, and they may also take part without you being involved, if you choose to pass the information sheet to them.

Taking part in the research would involve one interview, which may last up to one hour. Anything you say in the interview would be reported anonymously. Taking part in this research could help increase knowledge about this topic.

Please take the time to read the enclosed information sheet. If you would like to take part, or if you have any questions or would like more information, please contact me within 7days. You can phone me on 0208 4426020 and leave your contact details, or you can return the enclosed reply form in the stamped envelope.

If I do not hear from you within 7days of receipt of this letter, I will assume you do not wish to take part and will not contact you again in relation to this study.

Your decision to take part or not in this study will have no effect on the care you receive from the wheelchair service.

If you have any queries relating to the research or academic process for this study, please contact my supervisor, Dr Karen Beeton, Deputy Head of School, School of Health and Emergency Professions, University of Hertfordshire, on 01707284114 or k.s.beeton@herts.ac.uk.

Thank you for taking the time to consider this request. I look forward to working with you if you decide to take part in the study.

Yours Sincerely,

Helen Hislop – HPC registered Physiotherapist
Principal Investigator (Phone 0208 442 6020)

Appendix 9: Participant reply form

NHS
Haringey

Research project: Involvement in decision-making with wheelchair users and caregivers.

Study reference number: 01HH

Dear Helen Hislop – Principal Investigator,

Please initial the box that applies to you:

I am interested in taking part in this study, as described on the participant information sheet. ☐

I would like more information on this study before I decide whether or not to take part in this study. ☐

Please contact me according to the details below as soon as possible regarding this study.

Name:
Address:

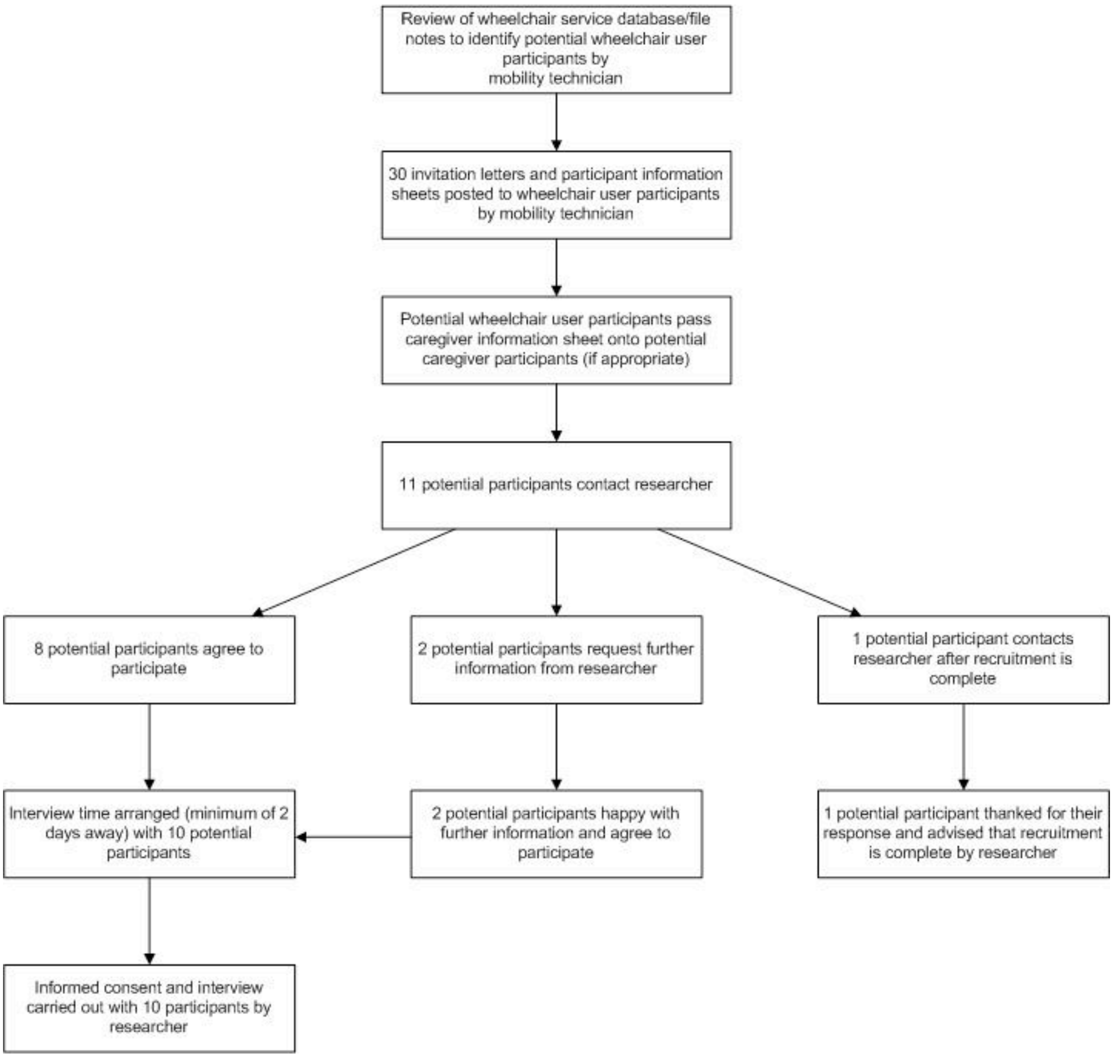
Contact phone number:

Signature:…………………………………………Date:………………

Please advise of any days/times when it is not convenient for you to be contacted:
……………………………………………………………………………
……………………………………………………………………………

You can also phone Helen Hislop (principal investigator) on 0208 442 6020 and leave a message for your call to be returned regarding this study.

Appendix 10: Flow chart of recruitment process



Appendix 11: Interview consent form – wheelchair user

NHS
Haringey

Study reference number: 01HH
Participant Identification Number for this project:

CONSENT FORM (Wheelchair user)

Title of Project: Involvement in decision-making with wheelchair users and their caregivers
Name of Researcher: Helen Hislop

Please initial box

1. I confirm that I have read and understand the information sheet dated 27/1/10 (version two) for this study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my legal rights or care from the wheelchair service being affected. ☐

3. I understand that individuals from University of Hertfordshire, from regulatory authorities or from NHS Haringey may look at information collected during the study. I give permission for these individuals to have access to this data. ☐

4. I give permission for the interview I give to be audio-recorded. I understand that this recording will be written up and analysed for the study. I understand that quotes from the interview may be used when the study is reported, and that any information used will be anonymous. ☐

5. I agree to take part in the above study. ☐

Name of Participant Date Signature

………………………………………………………………………………………

Name of Person taking consent Date Signature

………………………………………………………………………………………

Appendix 12 : Interview consent form - caregiver

NHS
Haringey

Study reference number: 01HH
Participant Identification Number for this project:

CONSENT FORM (Caregiver)

Title of Project: Involvement in decision-making with wheelchair users and their caregivers
Name of Researcher: Helen Hislop

Please initial box

1. I confirm that I have read and understood the information sheet dated 27/1/10 (version two) for this study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my legal rights or involvement with the wheelchair service being affected. ☐

3. I understand that individuals from the University of Hertfordshire, from regulatory authorities or from NHS Haringey may look at information collected during the study. I give permission for these individuals to have access to this information. ☐

4. I give permission for the interview I give to be audio-recorded. I understand that this recording will be written up and analysed for the study. I understand that quotes from the interview may be used when the study is reported, and that any information used will be anonymous. ☐

5. I agree to take part in the above study. ☐

Name of Participant Date Signature

……………………………………………………………………………………

Name of Person taking consent Date Signature
……………………………………………………………………………………

Appendix 13: Topic guide for interviews

Getting a wheelchair for the first time

Possible prompt questions:
Can you tell me about when you/the person you care for first got your/their wheelchair?
How long ago was this?
What decisions needed to be made in that consultation?
Were you happy with the way the decisions were made or would you have liked this consultation to be different in some way? Please explain.
How involved did you feel in the decision-making?
How involved would you like to have been? Please explain what you like about being involved in that way.
What things would have made it easier to be involved in decisions at that time?
What factors made it difficult to be involved in decisions at that time?

Needing to change the chair

Possible prompt questions:
Can you tell me about how it was decided that your/the person you care for's chair needed changing?
What decisions needed to be made in that consultation?
How involved did you feel in the decision-making?
How involved would you like to have been? Please explain what you like about being involved in that way.
What things would have made it easier to be involved in decisions at that time?
What factors made it difficult to be involved in decisions at this time?
Was it different to how you felt about making decisions the first time you were seen about your/the person you care for's wheelchair?
Did you feel you wanted to be more or less involved when your/their chair needed to be changed? Please explain why you felt you wanted to be involved differently, if you did.

Things that make it easier or more difficult to be involved in decision-making

Possible prompt questions:
There is a drive from the Government to engage the users of health care and empower them in decision-making. There have been lots of government policies on this. What does this mean to you as someone who uses/cares for someone who uses health care?
What does 'being involved' in decision-making mean to you? Have you heard that term before?
Would you like to be more involved or less involved in decisions about your/their health care?
What things make you feel involved in making decisions?
What things stop you feeling involved in making decisions?

Some research about decision-making into wheelchair prescription found that people consider lots of things, such as:
ability to do daily tasks
equipment appearance and performance
pressure management
the environment
work
when deciding which chair to choose. Are any of those things important to you when you decide on your/their equipment? Do you feel any of them are more important for you to be involved in than others?
How does decision-making about your wheelchair compare with other decision-making about your/their health? Do you like to be involved differently depending on the decision to be made?
Research that has been done about involvement has noted that some people feel more involved if they are given all the information about a particular decision OR have good relationships with health staff OR are encouraged to participate by staff. Does that factor have an impact on how involved you feel when making decisions about your/their health?
Research that has been done on involvement has noted that some people feel they aren't involved if there is little information provided OR there is little time available for the decision OR they don't feel listened to by health professional OR they don't trust health professional. Does that factor impact on how involved you feel when making decisions about your/their health?

Decision making in the future
Possible prompt questions:
How would you like to be approached about your involvement in decision–making?
How much do you think you can be involved in decisions about your/the person you care for's chair?
If you were visiting the wheelchair service tomorrow, how would you like to be involved in making the decisions?

Is there anything else you would like to say about your involvement in decision-making?

Thank-you for your time.
I will now transcribe the interview we have done together and send a copy of it to you for checking over. You don't have to do this if you don't want to. If you do, please make any notes on the copy to correct anything I may have written wrongly or to add to anything you have said. There will be a stamped envelope for you to return the copy you have added to to me.

Appendix 14: Letter to participants regarding transcript

NHS
Haringey
Helen Hislop
Principal Investigator
Ph. 0208 442 6020
helen.hislop@haringey.nhs.uk

Date

Participant name and address

Dear ……………..,

Re: Research project: Involvement in decision-making with wheelchair users and caregivers

Thank- you for contributing to this research project through your interview. I really appreciate your time and comments.

I have enclosed the transcription of your interview, for you to review and comment on if you would like to. You can also add any additional comments. Please write onto the transcript as you like.

You do not have to read and comment on the transcript if you don't want to.
If you do make comments, please return the transcript to me in the stamped addressed envelope within 7days of receiving it.

If you have any queries about this process, please contact me on 0208442 6020 or my supervisor, Dr Karen Beeton, Deputy Head of School, School of Health and Emergency Professions, University of Hertfordshire, on 01707284114 or k.s.beeton@herts.ac.uk.

I will write again when I have finished analysing the results of the study, to let you know what has been found through this research.

Yours Sincerely,

Helen Hislop
Principal Investigator

Appendix 15: Process of and reflection on theme development

I began the analysis of my data through writing my field notes; by documenting what I felt had been the key message each participant had wanted to convey through their interview.

These were as follows:

Interview	**Key message**
1	Involvement increased over time as knowledge, experience and time available to make choices increased. Decisions on chairs differed to other medical decisions, as appearance for example doesn't require professional expertise. Involvement gives feelings of choice, control, independence and individuality
2	Familiarity of equipment important Choice and appearance of equipment not important (My reflexive diary notes at this point that the first 2 participants were quite different and this perhaps indicates that each individual has a particular 'non-negotiable' point)
3	Importance of choice, control and independence Negative feelings about involvement - lack of time and recognition as an individual inhibits involvement

These first three interviews were transcribed first. I decided not to begin the formal analysis until I had completed at least three interviews, as I did not want to become focused on what a single participant may have said, and risk skewing subsequent interviews according to analysis that was carried out too early. As five participants had been involved in the first three interviews, I felt it was appropriate at this point to begin more formal analysis. I began writing over the printed transcriptions with ideas for codes. At this stage, these included:

Codes	**Sub-categories**
Independence	
Control	
Choice	
External control	Health care system Professional/paternalism
Things that facilitate involvement	Choice Information Seeing Test/trial User experience Service knowledge/experience Peer contact Coming together – user and service

Staff attitudes and behaviours	Listening Empathy Open Experience Relationship Explaining Trust
Things that hinder involvement	Time limitations Lack of information Lack of experience
Equipment features	Durability/robustness Appearance User ability Comfort Familiarity Health Type Activities Size Weight Move around in chair
Taking action when there is a problem with equipment	
Approaching involvement	Choice Don't know

I recognised at this point there were too many codes and many were very literal, however I chose not to refine these at this stage as I felt it was more appropriate to complete the remainder of the interviews first.

The key messages noted in my reflexive diary emerging from the remaining interviews included:

Interview	Key message
4	Involvement is a concept that has not been considered Appearance is not important Importance of speaking up when things are not correct Experience and familiarity promote ability to be involved
5	Participant under-valued the value of her own knowledge and experience Despite experience of wheelchair user, health professional valued as expert and final decision-maker Limitations of the NHS
6	Involvement is a concept that has not been considered Impact of equipment on caregiver's individuality
7	Involvement is a concept that has not been considered Environment as a key barrier to access Familiarity of equipment important Choice and appearance of equipment not important

My next step was to immerse myself in the remaining four transcripts and note codes across these that confirmed or contradicted those I had come up with from my immersion in the initial transcripts. I also considered ways to bring the codes into more condensed groups that were more thematic. The codes at this stage included:

Emerging codes	**Possible over-arching themes**
Role of professionals	Roles in decision-making
Role of wheelchair user	
Role of caregiver	
The meaning of ‘involvement’	Facilitators and inhibitors in decision-making
Approaching involvement	
Professional behaviour	
Individuality/independence	Control/power in decision-making
Experience of services/interventions/problems	
Limitations of health service	

At this stage, I chose to re-read some of the literature to see how my thoughts so far fitted in with existing evidence. I was interested to note that some of my quotes seemed to very closely parallel quotes in other papers. This did boost my confidence in what I had done so far but also made me realise I had more to do if I wanted this piece of work to add to current understanding on patient involvement, rather than just confirm what was known.

I then chose to write about each of the above areas, to expand the codes and note how the quotes confirmed or contradicted these. I thought this also might help me determine the focus for discussion, as I know only one final could be included in the discussion. I also returned to the literature and tried writing this into my emerging analysis. Using the literature in this way resulted in my analysis looking like a literature review that was not particularly well developed. I was also having problems with overlap between my codes and trying to work out how to include these in a way that allowed enough detail to be included in the write-up.

Fortunately, at this stage I met with my supervisors who advised me to step back from the literal way in which I was considering the analysis and look at the bigger picture. They suggested that this would assist in overcoming the problem of overlapping codes, as these would likely fit into a broader theme. I wondered at this time how I could match my analysis to my aims and objectives, to which my supervisor replied that my analysis should really lead my aims and objectives, rather than the other way around. I found this an extremely useful tip – it freed me to return to the transcripts to really look at what lay behind the participants words, and not to continue trying to get their words to fit current literature and my aims and objectives. I returned to reading broader sociological literature and found this to be a more interesting fit with what my participants were saying. I again read the transcripts and returned to my reflexive diary to review the field notes I had made. I was surprised at how my initial reactions to the interview were closer to the more abstract concepts I was now exploring than the literal coding I had developed along the way.

This led me to develop my final themes and sub-themes, which I found much easier to write about, which suggested to me that I had reached analysis that fitted with what my participants had been trying to convey.

Appendix 16: Participant demographics

Participant code	**W1**	**W2**	**W3**	**C1**	**C2**	**C3**	**W4**	**C4**	**W5**	**W6**
Wheelchair user	X	X	X				X		X	X
Caregiver:										
Paid				X	X					
Family						X		X		
Diagnosis	MS (progressive)	Stroke	Spinal cord injury	Provides care for W3	Provides care for W3	Provides care for user with a series of strokes	MS	Provides care for W5	Stroke	Stroke
Age	63yrs	47yrs	57yrs	54yrs	35yrs	38yrs	63yrs	55yrs	58yrs	63yrs
Male	X	X	X			X			X	
Female				X	X		X	X		X
Ethnicity	White British	White Irish	Black African	Black African	Black Caribbean	Filipino	White British	Algerian	Algerian	White British
Length of time using a chair	14yrs	3yrs	3yrs	N/A	N/A	N/A	28yrs	N/A	10yrs	7yrs

Type of wheelchair currently used	Manual self-propel	Powered indoor-outdoor	Manual self-propel/powered indoor-outdoor wheelchair	Provides care for W3	Provides care for W3	Provides care for user with attendant propelled chair	Manual self-propel	Provides care for W5	Powered indoor-outdoor	Powered indoor-outdoor/ manual attendant propelled
Length of time caring for this wheelchair user (other wheelchair users)	N/A	N/A	N/A	3yrs (10yrs)	Not answered (no previous experience with wheelchair users)	15yrs (no previous formal experience)	N/A	9yrs (no previous experience)	N/A	N/A