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What are the characteristics of patients with a stroke who are believed to need a pre-discharge home visit by occupational therapists?

Phillip James Whitehead

Thesis submitted to the University of Nottingham
for the degree of Master of Philosophy,
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Abstract

Pre-discharge home visits are commonly completed by occupational therapists as part of the stroke rehabilitation care pathway. However, wide variations have been reported between stroke units in the number of home visits completed (Drummond et al 2012a; Royal College of Physicians 2006). This research aimed to identify the characteristics of those patients who are believed to need a visit by occupational therapists. Such a study is important as there is currently limited guidance to indicate when a home visit should be completed, or which particular patients should have a home visit. This has implications in terms of standardising practices between occupational therapists and provision of equitable services to patients.

The research for this study combined qualitative and quantitative approaches. The qualitative research consisted of twenty interviews with senior occupational therapists working in in-patient stroke care across the United Kingdom. The interviews explored their views as to the types of patients who would and would not require a pre-discharge home visit. For the quantitative component, a comparative analysis was conducted on the characteristics of two groups of patients from a larger feasibility randomised controlled trial of Home Visits after Stroke (HOVIS). This analysis compared the characteristics of those patients whom the occupational therapists believed a home visit was 'essential' (n=33) and those for whom they did not (n=93). It also analysed the occupational therapists reasons for stating that a home visit was essential for each patient.

Four key patient characteristics were identified as being particularly influential in the occupational therapists' decision making process. These were: moderately severe physical disabilities, mild to moderate cognitive impairments, cortical strokes and living

alone. Occupational therapists sought to balance characteristics relating to the patient's level of ability to manage activities with details of the patient's home environment, including the availability of support within the home environment. Although the presence of physical and cognitive impairments were important factors in the occupational therapists' decision making, the findings suggest that they did not believe that the most physically and cognitively impaired patients were the most likely to need a visit.

The main conclusion from this programme of work was that the home visit is multifaceted and individually reasoned for each patient, but that the four key characteristics outlined above are considered to be major factors in the decision making process by occupational therapists. It is suggested that future research on home visits for patients with a stroke should focus on those with moderately severe physical disabilities and on the role and importance of a patient's cognition in occupational therapists' reasoning process. A focus on the interactive relationship between these components would be fruitful. It is also recommended that future clinical guidelines should incorporate consideration of environmental and cognitive factors.

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The Home Visit after Stroke (HOVIS) Study and the MPhil Study

Phillip Whitehead's Role

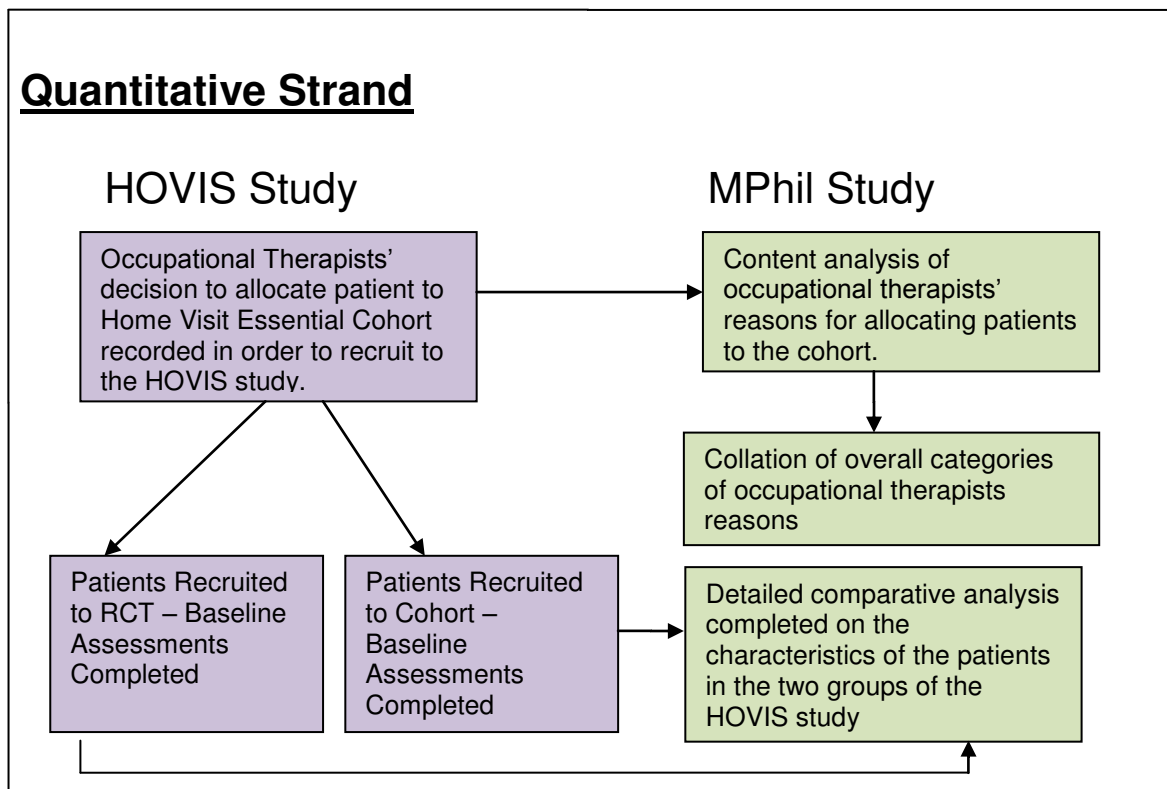
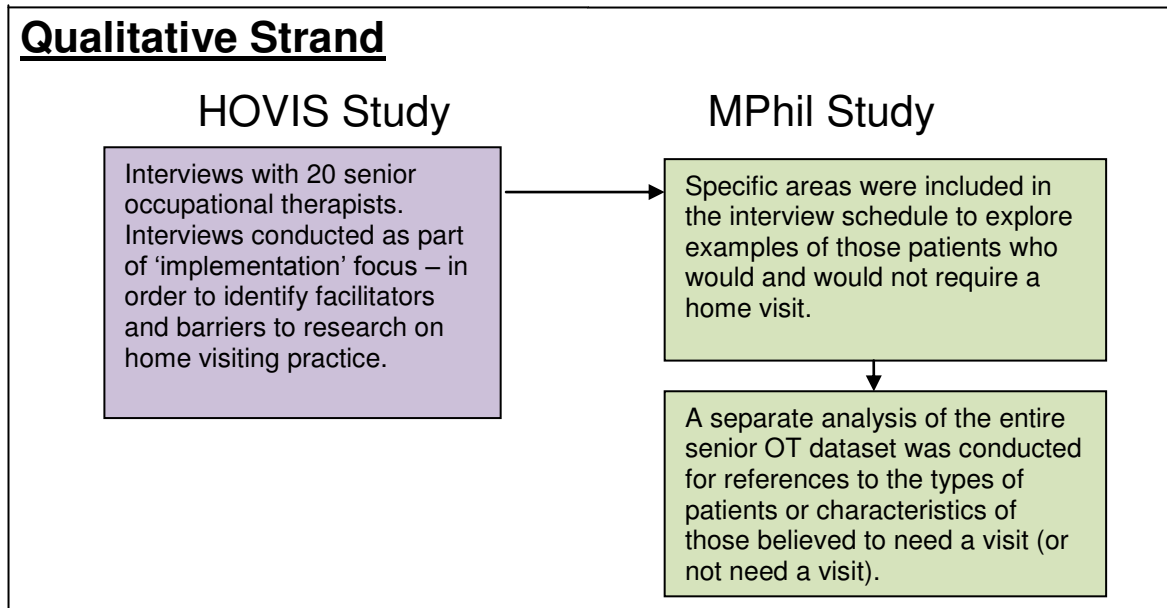
This MPhil was conducted concurrently and under the umbrella of the Home Visit after Stroke (HOVIS) study (Drummond et al 2012b). This study incorporated data gathered as part of the HOVIS study to answer the research question for the MPhil. Figure i depicts the overlap and distinctions between the two.

In addition to studying for the MPhil, Phillip Whitehead worked as Research Associate on the HOVIS study where he was jointly responsible for recruitment of participants (both patients and occupational therapists) and was jointly responsible for collecting all of the data on which the MPhil was based. The specific roles he undertook with regard to the MPhil were:

- Carrying out the literature review including: defining the search terms, conducting the searches, retrieving the articles, and critically appraising and synthesising the literature.
- Contributing to the design of the qualitative study with the HOVIS research team including: designing the topic guides, recruiting the interviewees and conducting the interviews. He conducted five of the 20 interviews. He took the lead role in arranging the research governance approvals for the interview study and was lead author on a letter and opinion article on this subject (Whitehead et al 2010; 2011). Phillip independently, conducted a separate, specific analysis of the dataset gathered from the senior occupational therapists with regard to the characteristics of patients with a stroke who were believed to need a home visit.
- Carrying out the content analysis of i) reasons for each patient being entered into the 'Home Visit Essential' cohort and ii) the categorisation of overall reasons for patients in the cohort

- Designing the database (data entry was shared with another researcher to ensure accuracy).
- Conducting the comparative analysis of the baseline characteristics of those patients in the 'Home Visit Essential cohort' and those patients in the RCT.

Figure i: Relationship between HOVIS and MPhil Studies



Thesis Overview

The overall aim of this research was to investigate the characteristics of patients with a stroke who are believed to need a pre-discharge home visit by occupational therapists. This section provides an overview of the structure of this thesis and explains the layout and content of the separate chapters. There were three strands to the research programme, which were:

1. A review of the literature on pre-discharge occupational therapy home visits, with a specific focus on the characteristics of patients with a stroke who have home visits.
2. Interviews with senior occupational therapists working in in-patient stroke care services focusing on examples of patients with whom they would and would not complete pre-discharge home visits.
3. A quantitative analysis comparing the characteristics of patients in the home visit after stroke (HOVIS) study who were deemed to need a home visit by an occupational therapist, with those who were not.

This thesis is presented in five chapters. The first chapter provides an overall introduction to this study. The literature review, qualitative interviews with occupational therapists, and the quantitative analysis of the patients in the HOVIS study are then presented in individual chapters. The final chapter synthesises the findings from each of the three strands into a broader discussion and provides a conclusion to the research.

Chapter One
Introduction

1.1. Introduction

“Occupational therapy assists people of all ages to achieve health and life satisfaction by improving their abilities to carry out the activities that they need to do or choose to do in their daily lives” (College of Occupational Therapists 2009).

Occupational therapists aim to support people to maximise their ability to carry out every day activities independently and safely. Occupational therapy practice is varied both in terms of the breadth of assessment and treatment media used and in terms of the range and diversity of the settings in which occupational therapists work. In the acute hospital setting a key role for occupational therapists is to assist people to return home to the community safely, and to optimise their ability to function upon their return to the home environment. Discharge planning is a process which aims to facilitate a coordinated discharge from hospital and also reduce length of stay and avoid unplanned readmissions to hospital (Shepperd et al 2010). One core component of discharge planning is the occupational therapy pre-discharge home visit.

A home visit involves the occupational therapist accompanying the patient to his or her home for a period of assessment and treatment, following which the patient returns to the hospital with the therapist (College of Occupational Therapists 1990). A home visit allows the occupational therapist to provide assessment and/or treatment for the patient in the home environment and to implement appropriate actions to facilitate the discharge process. Home visits are believed to increase safety for the patient on

discharge, and increase ability to cope at home (Lannin et al 2007; Johnston et al 2010).

Patients who have a stroke are likely to experience a sudden and rapid deterioration in their ability to function as a result of the physical, cognitive and/or perceptual impairments associated with stroke (Edmans et al 2010). Therefore, some patients will return to their home environment with new and significant barriers which impede their ability to participate in everyday activities. A pre-discharge home visit may assist with overcoming some of these barriers and ease the transition from the hospital to the community (Durham 1992). However, it is not clear which particular patients with a stroke should have a pre-discharge home visit. Should they be completed for all patients? Should they be completed only for a certain subset of the stroke patient population? If so, which patients? What factors influence occupational therapists' decisions as to when a home visit is needed with a particular patient? This study aims to explore the characteristics of patients with a stroke who are believed to need a pre-discharge by occupational therapists.

This chapter will provide introductory background and context to the research. It will provide a definition of stroke and outline the impact of stroke. It will then present an introduction to acute and rehabilitation stroke care, and critically discuss the evidence for occupational therapy intervention within stroke rehabilitation. This will be followed by a more detailed definition of the term 'pre-discharge home visit' and will explain the relevance of this for patients with a stroke, highlighting how practice may vary across different stroke units in the United Kingdom. The chapter will end by outlining the aims, objectives, and plan of investigation for the research.

1.2. What is a stroke?

A stroke has been defined by the World Health Organisation (WHO) (1978) as:

“rapidly developing clinical signs of focal (or global) disturbance of cerebral function, with symptoms lasting 24 hours or longer or leading to death, with no apparent cause other than of vascular origin”

A stroke occurs when there is an interruption to the blood supply to the brain. This interruption could occur within the structure of the brain, or elsewhere within the vascular system, resulting in damage to the tissue within the brain. When the brain tissue is damaged this leads to the onset of the symptoms of stroke. The most common symptoms are sudden weakness or numbness of the face, arm or leg. The particular effects of stroke on the body are peculiar to the specific area of the brain in which the stroke occurred, but they most commonly affect one side of the body (World Health Organisation 2012).

There are two main causes of stroke: ischaemia and haemorrhage. Ischaemic strokes occur when the blood supply to any part of the brain is impaired. This may manifest due to occlusions of the arteries or embolus (clots) migrating to the cerebral arteries (Edmans et al. 2010). Haemorrhagic strokes occur due to bleeding of a blood vessel supplying the brain. Approximately 80-90% of strokes are ischaemic in origin and the remaining 10-20% are haemorrhagic (Mant 2011). Over half of ischaemic strokes are caused by embolus and approximately a quarter are due to small vessel occlusion (Mant 2011).

Globally, it is estimated that there are 4.5 million deaths a year from stroke and over 9 million stroke survivors, with stroke being the leading cause of adult disability (Wolfe 2000). In the United Kingdom, it is estimated that 150,000 people have a stroke each year (The Stroke Association 2012). Stroke is the third most common cause of death in the UK, behind heart disease and cancer. Approximately one third (53,000) of people who have a stroke will die, approximately one third will make a full recovery, and one third will be left with residual disabilities (The Stroke Association 2012). Thus, stroke presents a significant economic cost to the NHS and the carers of people with stroke (Youman et al 2003). A large proportion of this cost is the burden of managing the ongoing disabilities resulting from the stroke.

Given the heavy economic, physical, social and emotional burdens of stroke it is important that all patients are provided with the opportunity to maximise their recovery and limit the residual difficulties they will face following their stroke. Optimising a patient's recovery usually involves a period of stroke rehabilitation, following the stabilisation of the acute stage of the condition.

1.3. Acute Stroke Care and Stroke Rehabilitation

The *National Clinical Guideline for Stroke* recommended that all people who have symptoms which are suggestive of a stroke should be admitted “as an emergency requiring urgent transfer to a centre with specialised hyperacute stroke services” (Intercollegiate Stroke Working Party 2012: 19). The recommendation that all patients with a stroke should receive their treatment on a specialist and dedicated stroke unit is based on robust research evidence of improved outcomes for these patients (Langhorne et al 1993; Stroke Unit Trialists' Collaboration 1997). This systematic review

evidence confirms that patients with a stroke who are treated on general wards have a 14-25 percent higher mortality level than those who are treated on specialist stroke units. Thus, stroke units have been shown to save lives. It is recommended that *all* people who have a stroke should be admitted to hospital for assessment and treatment (Donnan et al 2006).

Furthermore, it is recommended that those patients who require ongoing rehabilitative treatment should received this from a multidisciplinary team who have specialist knowledge and experience of stroke and neurological rehabilitation. Where this is provided on a stroke unit this should be by a single team of staff (Intercollegiate Stroke Working Party 2012). Rehabilitation is defined as:

- “1. the restoration of normal form and function after illness or injury
2. the restoration of the ill or injured person to optimal functional level in all areas of activity” (Dorland 2007).

Rehabilitation is therefore concerned with assisting the person to return to their normal function and manage activities which they were previously able to manage. If this goal is not realistically achievable, then rehabilitation should focus on assisting the person to regain the maximum amount of function that is attainable. If regaining ability is not achievable or realistic, then rehabilitation may focus instead on maintaining an individual’s level of function.

However, stroke rehabilitation is not limited to rehabilitation units: if a patient has ongoing needs then rehabilitation should continue after the patient has been discharged from the hospital. A systematic review of randomised controlled trials of stroke

rehabilitation for patients living at home was conducted by the Outpatient Service Trialists (2004). They used Cochrane collaborative methodology to complete a systematic review of 14 trials which included 1617 patients. They reported that community therapy services could reduce the odds of the patients deteriorating in their ability to carry out personal activities of daily living.

As part of the stroke rehabilitation care pathway, some patients may have their care transferred to the home environment early, with an Early Supported Discharge (ESD) scheme. These services provide specialist rehabilitation support in the home environment which is often more acceptable to patients than an extended hospital stay (Walker 2011a). A Cochrane Review of trials of ESD services identified 11 trials and extrapolated outcome data from 1157 patients (Langhorne 2005). This review reported that ESD services are appropriate for 40 to 50% of patients with a stroke who have mild to moderate levels of impairment. Users of ESD services were reported to have reduced levels of dependency and admissions to institutional care, in addition to significantly reduced hospital stays. This evidence has further increased the focus of policymakers to deliver certain components of stroke rehabilitation in patients' home environments, where it may be appropriate.

1.4. Stroke Rehabilitation – The Role of Occupational Therapy

Occupational therapists' primary focus in stroke rehabilitation is to assist patients to maximise their potential to manage activities of daily living as independently as possible. Occupational therapists usually begin treatment with basic activities but may progress to more instrumental activities or other occupations which are important to their individual patients (Duncan 2011). The occupational therapist will use his or her

assessment skills to identify areas of occupational dysfunction in particular activities of daily living (Ivey and Mew 2010). They will then develop a treatment plan and set goals jointly with the patient in order to assist and promote that patient's recovery. Treatment may be aimed at restoring function or adapting or compensating for functional impairments to prevent the development of further disability (Steultjens et al 2003). Occupational therapy in stroke rehabilitation is provided across the acute stroke unit, stroke rehabilitation unit and the home environment.

Research evidence has shown that occupational therapy is effective for patients with a stroke. Walker et al (2004) carried out an individual patient meta-analysis of randomised controlled trials of community occupational therapy for patients with a stroke. They completed a comprehensive literature search and identified nine eligible randomised controlled trials and obtained the data from eight of these. This provided data from 1143 patients. Although there was some heterogeneity reported in outcome measures, the meta-analysis showed that community occupational therapy significantly improved personal and extended activities of daily living for these patients. In addition, a Cochrane review of occupational therapy interventions for problems in activities of daily living was carried out by Legg et al (2006). They identified 64 potentially relevant trials and included nine with data from 1258 participants. They reported that occupational therapy prevented patients with a stroke from deteriorating in their ability to perform activities of daily living and reduced the odds of a poor outcome (Legg et al 2006).

Combining the evidence from the Cochrane review (Legg et al 2006) and meta-analysis (Walker et al 2004) provides high quality and robust research evidence that certain occupational therapy interventions can improve participants' performance in basic self

care activities of daily living (such as washing and dressing) and wider community participation (such as accessing community facilities or transport). These results have been derived from a large number of patients across a variety of different research settings. It could therefore be hypothesised that other therapy services which focus on similar components of these interventions in a community setting may have similar effects on performance in activities of daily living. Walker et al (2004) note that in a number of these trials the interventions were provided by research therapists who may have been particularly motivated when providing the therapy. Research is needed which replicates these results based on interventions provided by therapists working in clinical settings who simultaneously hold a clinical caseload. Furthermore, there is a large degree of overlap in those trials which were included in the Legg et al (2006) and Walker et al (2004) analysis. Thus outcomes from a number of the same patients have been included in both reviews.

Nevertheless, it is clear that various components of occupational therapy interventions have been shown to improve certain clinical outcomes for people who have had a stroke; enabling them to increase or sustain independence in basic and extended activities of daily living. However, because occupational therapists use a wide range of treatment media and interventions with patients who have had a stroke, Legg et al (2006) have commented that the exact nature of the occupational therapy intervention needs to be clearly defined in research. It is important that future research can establish which particular occupational therapy interventions are both clinically and cost effective and which are not. This will enable services and resources to be targeted appropriately. One particular intervention which occupational therapists may use with patients in an in-patient care setting who are returning to the community is a pre-discharge home visit.

1.5. What is a Pre-discharge Home Visit?

The College of Occupational Therapists (1990) defined a home visit as:

“a visit to the home of a hospital in-patient which involves an occupational therapist/s in accompanying the consumer to assess his/her ability to function independently within the home environment or to assess the potential for the consumer to be as independent as possible with the support of carers” (pg. 1).

In addition to increasing patients' independence, pre-discharge home visits may be completed to identify and reduce the risks of falls due to the presence of hazards within the home environment (Pardessus et al 2002); to increase safety within the home environment (Johnson et al 2010), to ease the transition from the institutional setting (Durham 1992) or to address concerns about a change in functional ability due to the onset or progression of a particular medical condition or disease process (Welch and Lowes 2005). In a rehabilitation setting, they may also be completed as part of an assessment to inform ongoing treatment and rehabilitation goals (Durham 1992).

A pre-discharge home visit is different to an *access* or *environmental visit* in which the occupational therapist visits the patient's property without the patient. Access visits are usually completed to assess the access to the property or space within the property for a wheelchair or other equipment. A pre-discharge home visit is also different to a *discharge visit* in which the patient remains at home following the visit and does not return to the hospital. A discharge visit is usually completed when there are few concerns about the patient returning home and may be considered to be more of a 'check visit' prior to discharge.

1.6. The Pre-discharge Occupational Therapy Home Visit in the Stroke Rehabilitation Pathway

As highlighted earlier in this chapter, there are likely to be significant numbers of patients being discharged from hospitals with new levels of impairment, and new limitations in their ability to manage activities following a stroke. This may pose additional challenges or present new risks for these patients on their return to the home environment. Therefore a home visit with an occupational therapist, before they are discharged from hospital, may be deemed to be an appropriate component of their rehabilitation care.

The *National Clinical Guideline for Stroke* recommends that:

“Before discharge of a patient who remains dependent in some activities, the patient’s home environment should be assessed and optimised, usually by a home visit by an occupational therapist.” (Intercollegiate Stroke Working Party 2012: 27).

However, this recommendation is not based upon evidence from research that has focussed specifically on outcomes of home visits. However, it could be hypothesised, based on the research discussed above, that individuals who receive a home visit as a component of their occupational therapy treatment, may be less dependent in activities of daily living following their discharge home.

In 2006 completion of a home visit before discharge was one of the 12 key clinical indicators for *The National Sentinel Stroke Audit*. This indicated that provision of a

home visit before discharge was considered to be an important area of post-stroke recovery and one of the key areas in which occupational therapy practice was recognised within the national stroke policy. The audit reported that 63% of patients with a stroke, and 73% of those who were admitted to a stroke unit had a visit before discharge (Royal College of Physicians 2006). These figures indicated that although home visits were a common practice in stroke care, there was a great deal of variability reported in the audit between the different stroke unit sites. Some sites reported that they completed home visits with all patients and some reported that they were not completed with any patients, and there was a wide range in between. This is indicative of variation in home visiting practices between stroke units.

However, there were difficulties in collecting accurate data for the audit with some sites including the total proportion of patients who had a home visit, whilst others included only the proportion of those who were considered 'appropriate' to have a home visit. Therefore, since 2006 home visits have not been included in the *National Sentinel Stroke Audit*, and more recent figures on pre-discharge home visits have not been collected routinely.

Drummond et al (2012a) conducted a survey of occupational therapy pre-discharge home visiting practices in stroke units in England. They sent a questionnaire to the lead occupational therapist in each stroke unit in England (184 units). Eighty-seven questionnaires were returned (a 43% response rate). Although the response rate was somewhat low, this is the first time that data on home visits for patients with a stroke has been collected since the 2006 *National Sentinel Stroke Audit*. Drummond et al (2012a) reported that an average of seven pre-discharge home visits were completed in stroke units over a two month period (April and May 2011). However, the number of

visits in this two month period ranged from 0 to 27, which indicated that the variability between different units appears to remain. The authors also reported that more pre-discharge home visits were completed by occupational therapists from rehabilitation than acute stroke units, with an average of 12 and a range from 1 to 27.

Although this survey did not include information about the types or characteristics of patients that had home visits, it would appear that home visits were more likely to be completed with patients with ongoing rehabilitation needs. However, the range reported in the figures for the rehabilitation units (1 to 27 home visits completed in a two-month period) also indicated that there may be some considerable variation between stroke rehabilitation units, and that some patients who remain dependent in some activities *may* be discharged without a home visit.

It is important to identify those patients who occupational therapists think need a home visit. The research for this study will therefore explore the factors on which the occupational therapists base their decisions in order to facilitate an understanding of the issues that impact on decisions about home visiting.

1.7. Background to this Study

This research study was carried out alongside the Home Visit after Stroke (HOVIS) study. The HOVIS study was funded by the National Institute for Health Research (NIHR) under the Collaboration for Leadership in Applied Health Research and Care Nottinghamshire, Derbyshire and Lincolnshire (CLAHRC-NDL) funding stream. The primary aim of the HOVIS study was to examine the clinical and cost effectiveness of pre-discharge home visits for patients with a stroke. A secondary aim of the study was

also to identify barriers to the implementation of research on home visits and barriers to the implementation of the results into clinical practice. Thus, the HOVIS study comprised two distinct strands:

- A feasibility randomised controlled trial (RCT) of pre-discharge occupational therapy home visits for patients with a stroke, and;
- A qualitative investigation and survey of national practice of occupational therapy home visits for patients with a stroke

This study was embedded within the HOVIS project and ran concurrently. It gathered additional data from the participants in the main HOVIS study to answer the research question.

1.8. The Home Visit after Stroke (HOVIS) Study

The feasibility randomised controlled trial aimed to test whether it was practicable and acceptable to randomise patients to receive a home visit or not. The trial was conducted on one stroke rehabilitation unit and eligible patients were randomised to receive either:

- A pre-discharge home visit with an occupational therapist, or;
- A pre-discharge in-hospital interview with an occupational therapist

The pre-discharge home visit was completed by an occupational therapist from the stroke rehabilitation unit. This involved the patient visiting their home, accompanied by the occupational therapist for an assessment and intervention, and then returning to the hospital before the final discharge arrangements were implemented. The in-hospital

interview was developed as an alternative to the pre-discharge home visit. The interview aimed to discuss the patient's home environment in detail, in the hospital setting, without the occupational therapist seeing the patient's home environment prior to discharge.

However, it was not possible to randomise all patients, as the occupational therapists working on the stroke rehabilitation unit who had ultimate clinical responsibility for the patients, were concerned about some patients being discharged without a home visit. A previous feasibility randomised controlled trial of pre-discharge home visits with older people (Lannin et al 2007), failed to recruit successfully due to the concerns of the clinical therapists. Therefore the HOVIS study design also included a 'home visit essential' cohort, which incorporated those patients whom the occupational therapists believed, could not be discharged without a home visit.

All participants in the RCT and the cohort were then followed-up at one week and one month after discharge, by a research assistant from the HOVIS team. The research assistant was masked to the group allocation of participants and collected information on independence in personal and extended activities of daily living; mobility; mood; falls, re-admissions and use of follow-up services; and carer strain.

The qualitative investigation and survey of national practice were conducted concurrently with the feasibility trial. The objective of these components was to collect information on national practices, procedures and opinions regarding home visits for patients with a stroke. The purpose of collecting this information was to place the findings of the feasibility trial into the national context of home visiting, in order to identify issues relating to the practice of pre-discharge home visits which may pose as

barriers to the successful implementation of the findings of the research into clinical practice.

This qualitative strand of the study consisted of interviews with six experts in stroke and/or occupational therapy home visiting; interviews with 20 senior occupational therapists working in stroke care; interviews with the occupational therapists who worked on the HOVIS study; and a national survey of all occupational therapy departments in stroke units in England.

1.9. Aims and Objectives of this Study

This present study aimed to explore the factors that occupational therapists consider to be important and relevant when deciding which patients with a stroke need a pre-discharge home visit. Thus, the research question was: what are the characteristics of patients with a stroke who are believed to need a pre-discharge home visit by occupational therapists?

1.10. Plan of Investigation

For the first part of the study, a literature review was completed in order to identify and critique the available literature on pre-discharge occupational therapy home visits, which particularly focussed on the characteristics of patients who had visits. The aim of the review was to identify the current research evidence and to assess its quality. The literature review is presented in chapter two.

The second component of the research consisted of interviews with senior occupational therapists working in stroke care. The aim was to identify what the occupational

therapists thought about patients who needed home visits. The interviews therefore explored examples of the types of patients whom the occupational therapists would complete home visits with, and examined their reasons for these decisions. This part of the study is presented in chapter three.

The final component of the study analysed the 'home visit essential' cohort of the HOVIS study in detail. The reasons given by the occupational therapists when allocating their patients to the home visit essential cohort were analysed. A detailed comparison of the demographic, medical and baseline characteristics of those patients in the home visit essential cohort with those in the RCT was also undertaken in order to examine the characteristics of those patients whom the occupational therapists would be unwilling to randomise to receive a home visit or not. This part of the study is presented in chapter four.

The final chapter discusses the findings from both the qualitative and quantitative components and relates these findings to the literature on occupational therapy home visits, and an occupational therapy theoretical model of practice. The strengths and limitations of the research are discussed alongside implications for policy and practice. Recommendations for future research are provided.

Chapter Two
Pre-discharge Occupational Therapy Home visits for Patients
with a Stroke: A review of the literature

2.1. Introduction

Although the *National Clinical Guideline for Stroke* recommends that a home visit before discharge should usually be completed by an occupational therapist when a patient remains dependent in some activities, the previous chapter highlighted the apparent variation in the number of patients with a stroke who receive a pre-discharge home visit from different stroke units. This chapter presents a review of the literature on pre-discharge occupational therapy home visits in order to identify relevant factors which may inform which patients have home visits. The aim of the literature review was to identify existing literature on pre-discharge occupational therapy home visits and to extract information which is relevant to the characteristics of patients with a stroke who have visits.

An initial scoping search was conducted which revealed that the literature on home visits for patients with a stroke, and the literature on the types of patients or characteristics of patients who have home visits, was limited. Therefore it was decided that the search would also include literature on pre-discharge home visits which focussed on other aspects of practice and other patient groups (in addition to stroke) in order to extrapolate the findings which might inform occupational therapists' decisions about the need to complete home visits with certain patients. Thus, literature which focussed on one of the following four areas was considered for review:

1. Reported on the characteristics or types of patients who had home visits. This information is directly relevant to the aim of the review.
2. Reported on the outcomes of the home visit for the patient. Evidence of particular outcomes could inform the rationale for the decision to complete

home visits (i.e. if there is evidence they reduce occurrence of falls the patients at risk of falling may be more likely to have a visit).

3. Included occupational therapists' views on home visits. This would provide an indication of occupational therapists' perceptions of the need for or value of home visits.
4. Reported on the prevalence, timing or content of the home visit. This would provide background and context to the need for visits.

2.2. Method

In order to evaluate the information available to date a comprehensive search was carried out using the AMED, Cochrane Library, CINAHL, EMBASE and MEDLINE databases. The searches covered the time periods from 1st January 1990 to 10th June 2011, and were repeated on 9th April 2012 to update the results. It was decided not to search before 1990 as health and social care policies have altered radically since this time. For example, the introduction of the NHS and Community Care Act (Great Britain, 1990) and subsequent legislative changes will have altered the practice context of home visits prior to this period. The following search terms were used 'occupational therap*' AND 'home visit*' OR 'home assess*' OR 'home environment*'. The search terms were intended to be as wide as possible in order not to overlook any potentially relevant articles.

It was the intention to synthesise the findings from the wider literature on home visits within the context of current national stroke policy, and to extrapolate the findings which may be of relevance to an inpatient stroke setting. Therefore, papers were included in the review if they focussed specifically on pre-discharge occupational therapy home

visits from an inpatient setting. Papers which focused on an aspect of the home visit as per the four categories outlined in the introduction to this chapter were included, and papers which used either quantitative and/or qualitative research methods were included. The grey literature was not searched systematically. Due to the limited time period within which to conduct the study, and the limited resources available it was not possible to search the grey literature extensively. However, the reference sections of the included studies were searched for any other relevant literature.

Papers were excluded if they did not focus specifically on pre-discharge home visits (i.e. home assessments to community dwellers, pre-admission or post discharge visits). Papers were also excluded if they focused on the wider discharge planning process and did not distinguish specifically between the outcome of the home visit and other aspects of the discharge planning process. Papers which were not in English were excluded, as funding was not available for translation. Papers were also excluded if they focussed on mental health/learning disability settings, paediatrics, and home visits by other professional groups (i.e. physicians, nurses).

The methodological quality of the papers was assessed using the criteria recommended by Critical Appraisal Skills Programme (CASP) (Solutions for Public Health, 2011), as an overall frame of reference. However, due to the breadth of research methods included in the literature it was anticipated that it would not be possible to use the CASP tools to compare papers directly with each other; instead the intention was to use the CASP tools as a general guide for reviewing the papers and assessing methodological quality.

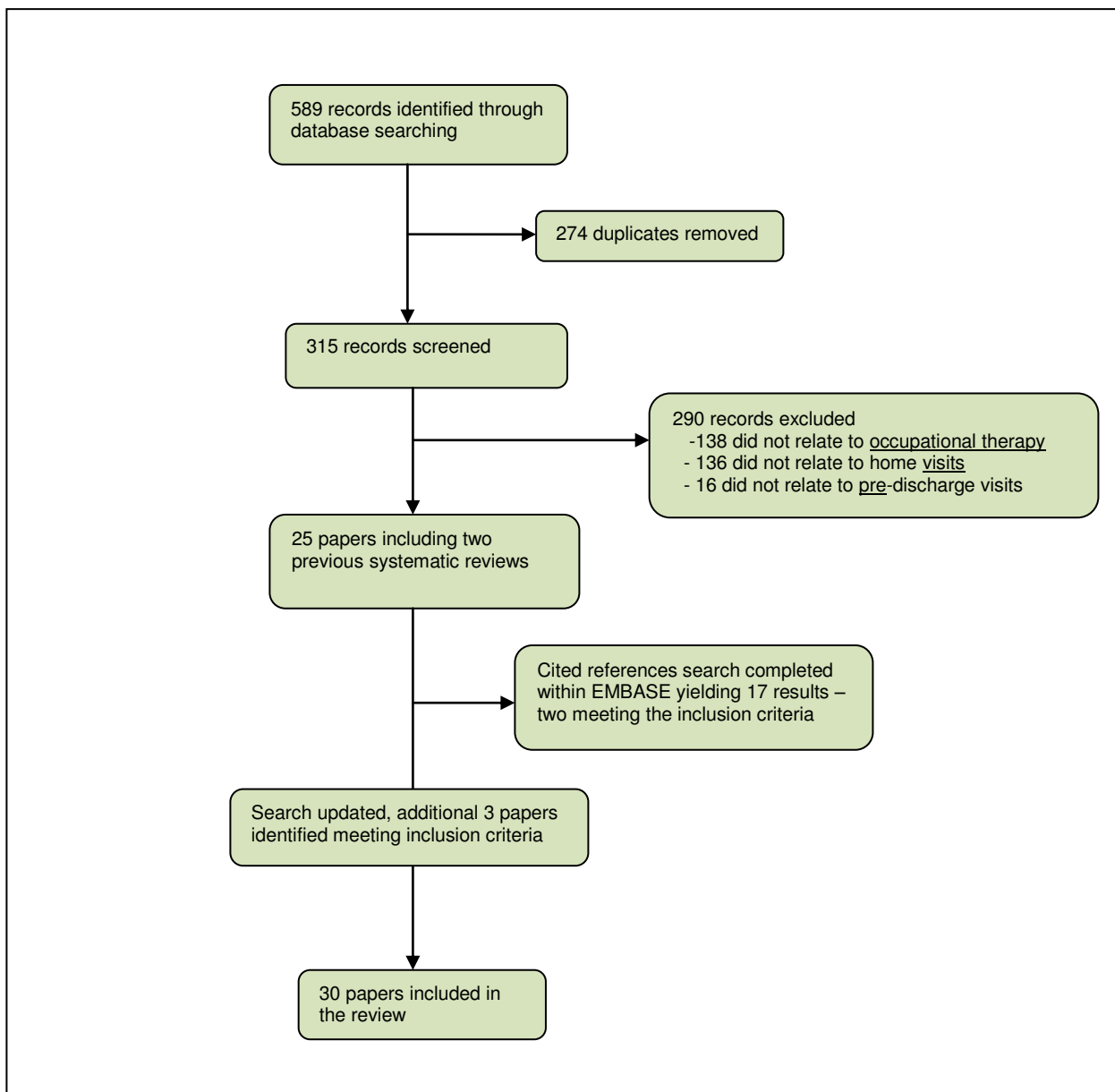
2.3. Results

2.3.1. Papers Identified

The search process is summarised in Figure 1. The search identified six review papers. These will be presented first. The remaining 24 papers have been grouped into the four categories based on the aims outlined in the introduction to this chapter: characteristics of patients who have home visits; patient outcomes; occupational therapists' views; and prevalence, timing and content of visits. Three papers contained information on more than one category and only three papers focussed specifically on stroke. Summary information on the included papers is shown in Table 1, including the author(s) aim and method and the category of the paper.

The initial search identified 589 papers. There was a large amount of overlap between the different databases with 274 papers duplicated. Of the 315 remaining, 290 papers did not meet the inclusion criteria. One hundred and thirty-eight were not focussed on occupational therapy, 136 focussed on the home environment but not home visits, and 16 did not focus on *pre*-discharge visits. This left a total of 25 papers including two previous systematic reviews. A 'cited references' search was then completed within EMBASE on the two systematic reviews, in order to identify the most current and up-to-date literature. This identified a further two papers which met the inclusion criteria. The searches were repeated on 9th April 2012 to update the review. This identified a further three papers which were eligible for inclusion (Atwal et al 2011; Atwal et al 2012; Kashiri and Hong 2011). Thus, a total of 30 papers were included in the review.

Figure 1: The Literature Search Process



2.3.2. Reviews

A total of six review papers were identified in the literature search. Two of these papers were presented as systematic reviews. The earliest was completed by Patterson and Mulley (1999) over 12 years ago and identified only five relevant studies and no randomised controlled trials. They concluded that there was little evidence for the effectiveness of pre-discharge home visits and that further research was needed.

The second systematic review was conducted by Barras in 2005. Barras included both pre and post-discharge home visits in the analysis, and identified only one randomised controlled trial of pre-discharge home visits. The aim of Barras' review was to identify the effectiveness of occupational therapy home assessments on a range of outcome measures. Seven outcome measures were identified including: personnel present, cost, frequency and when a home assessment was completed, readmission to hospital, stakeholder perspective and use of standardised assessments. However, it is not clear how some of these categories have been defined as outcomes. For example the category 'personnel present' reports on a core body of individuals being present on home visits, with no set regime for whom should be present. This is not linked to any measure of 'effectiveness' of the home visit.

Kashiri and Hong (2011) carried out a review of randomised controlled trials of occupational therapy home visits for falls. Like Barras (2005), they included both pre and post discharge visits in the analysis. Of the five RCTs included, four of these focussed on post-discharge home visits and visits to community dwellers. Kashiri and Hong (2011) reported that whilst visits were effective in reducing falls for people who had a history of falling, overall the results were inconclusive.

Table 1: Summary of Papers Included in the Review						
Study and country of research	Study Type	Aims	Research Method	Number of participants included	Category	Stroke
Barras (2005) (Australia)	Systematic Review	Assess findings of literature on OT home assessments.	Systematic review	12 papers.	Review	No
Patterson and Mulley (1999) (UK)	Systematic Review	Evaluate effectiveness of pre-discharge home assessment visits	Systematic review.	4 papers.	Review	No
Welch and Lowes (2005) (UK)	Descriptive Review	Review and discuss literature on pre-discharge home visits within the acute setting.	Literature review.	Not applicable.	Review	No
Mountain and Pighills (2003) (UK)	Descriptive Review	Review literature on pre-discharge home visits for older people.	Literature review.	Not applicable.	Review	No
Kashiri and Hong (2011) (UK)	Editorial Review	To review whether home assessments by OTs reduce falls	Literature Review	Not Applicable	Review	No
Atwal et al (2012) (UK)	Qualitative Synthesis (Review)	To critique the qualitative literature on older adult's experiences and perceptions of home visits.	Literature Review	Not Applicable	Review	No
Clarke and Gladman (1995) (UK)	Descriptive	Examine the use of pre-discharge home visits for stroke patients within one hospital.	Retrospective notes audit	297 149 had a home visit	Characteristics	Yes
Luker and Grimmer-Somers (2009) (Australia)	Descriptive	Investigate whether staff compliance with discharge planning is related to patient experiences post-discharge	Retrospective notes audit combined with semi-structured interviews	50 18 had home visit	Characteristics & Outcomes	Yes
Johnston et al (2010) (Australia)	Cohort	To describe relationship between pre-discharge home visits and falls in patients with a range of conditions.	Cohort study – follow-up interviews	342 27 neuro patients	Characteristics & Outcomes	No
Renforth et al (2004) (UK)	Descriptive	To examine the characteristics of patients who had a home visit from one community hospital and analyse the process of the home visit.	Prospective audit.	388 admissions 118 had home visit 79 in study group	Characteristics	No
Hale (2000) (UK)	Descriptive	Investigate factors influencing the occurrence of pre-discharge home visits	Survey and Interviews	Actual numbers not stated; 81% response rate	Characteristics	No
Blakely and Flanagan (1993) (UK)	Descriptive	Describe practice of home visits in one geriatric medical unit.	Retrospective notes audit	340 notes 58 had home visit	Characteristics	No
Lannin et al (2007) (Australia)	RCT	Investigate feasibility of RCT for pre-discharge home visits for older people	RCT Home visit vs. in-hospital interview	10	Outcomes	No
Pardessus et al (2002) (France)	RCT	Investigate whether pre-discharge home visit by OT reduces risk of falling in older patients	RCT Home visit vs. routine care.	60	Outcomes	No

Table continues on page 26

Study and country of research	Study Type	Aims	Research Method	Number of participants included	Category	Stroke
Nygaard et al (2004) (Sweden)	Descriptive	Illuminate client and therapist perspectives on pre-discharge home visits with older people.	Semi-structured interviews (clients) and group interview (OTs).	23 Clients 9 OTs	Outcomes & OT Views	No
Clark and Dyer (1998) (UK)	Descriptive	Investigate older peoples' responses to recommendations made on pre-discharge home visit.	Semi-structured interviews	50	Outcomes	No
Atwal et al (2008a) (UK)	Descriptive	Explore older adults' and carers' perceptions and involvement in decisions relating to home visit.	Semi-structured interviews	15 Older people 7 Carers	Outcomes	No
Hibberd (2007) (UK)	Descriptive (Audit)	Evaluate the home visiting service within in-patient intermediate care service.	Notes audit Patient Interviews Cost evaluation	20 Notes audited 4 Interviews 3 Cost evaluations	Outcomes	No
Bore (1994) (UK)	Descriptive	Investigate whether patient, therapist and carers' concerns regarding discharge were addressed by the pre-discharge visit	Questionnaire	18 Patients 7 Carers 18 Therapists	Outcomes	No
Atwal et al (2008b) (UK)	Descriptive	Explore occupational therapists' perceptions of home visits with older adults.	Thematic analysis of reflective diaries	15	OT views	No
Durham (1992) (USA)	Descriptive	To determine occupational therapists' and physiotherapists' perceived benefits of home visits	Reflective survey	14 therapists	OT views	No
Chibnall (2011) (Australia)	Opinion	Review literature and express opinion.	Literature review and opinion.	Not applicable.	OT Views	Yes
Mason (1999)(UK)	Opinion	Express opinion.	N/A – Letter	Not applicable.	OT Views	No
Patterson et al (2001) (UK)	Descriptive Survey	Investigate practice of pre-discharge home visits for older people nationally.	Questionnaire	239 (90% response rate)	Prevalence of Visits	No
Lannin et al (2011) (Australia)	Descriptive Survey	To describe home visit practices in occupational therapy departments in Australia.	Questionnaire	53 (25% response rate)	Prevalence of Visits	No
Harris et al (2008) (Australia)	Descriptive	Investigate practice of pre-discharge home visit in a rehabilitation ward.	Retrospective notes audit	227 notes 124 had home visit	Prevalence and Timing of Visits	No
Dove (1999) (UK)	Descriptive (Audit)	To audit the time involved in organising a home visit to develop a standard.	Audit	23 therapists participated	Timing of Visits	No
Franklin (1997) (UK)	Descriptive (Audit)	Carry out clinical audit of home visit reports within one hospital setting.	Audit	30 reports	Timing of Visits	No
Barras et al (2010) (Australia)	Descriptive	Establish 'core/essential' and 'ideal world' elements of home visit intervention.	Delphi-style consensus	81 therapists	Content of visit	No
Atwal et al (2011) (UK)	Descriptive	To evaluate the use and quality of OT home visit information leaflets	Survey	5 leaflets analysed	Content and use of leaflets	No

Two descriptive reviews were also identified which provided a broad based discussion of home visits in the acute setting (Welch and Lowes 2005) and with older people (Mountain and Pighills 2003). The review by Welch and Lowes (2005) appeared to be somewhat haphazard and the authors included information on pre-discharge and post-discharge visits but they did not make this clear or extrapolate the relevance of the post-discharge visit to the acute setting. The review conducted by Mountain and Pighills (2003) was part review and part opinion piece, the authors argued that pre-discharge home visits are often completed to ensure a safe discharge rather than being in the interests of older people. They argued that a review of home visiting practice was needed on the basis of lack of evidence. None of these five reviews made the inclusion/exclusion criteria explicit.

The most recent review was completed by Atwal et al (2012) and comprised a 'systematic thematic synthesis' which aimed to gather and critique the literature on older adults' experiences and perceptions of home visits. Only three qualitative research papers were included. Atwal et al (2012) concluded that older adults are generally satisfied with home visits, but in some cases they may be unprepared to go on them and find them anxiety provoking.

Each of these six reviews concluded that further research was required into the effectiveness of home visits and outcomes for patients. Although each review had a slightly different focus and aim, none focussed specifically on pre-discharge home visits for patients with a stroke. The reviews concentrated on the lack of evidence for particular outcomes from home visits and none focussed on the characteristics of the patients who had home visits. This indicates that although pre-discharge home visits have received some level of attention in the research literature (six review articles), the

characteristics of patients who have home visits appears to have received much less consideration.

The results of the literature review will now be presented in four sections based on the four sections of literature eligible for inclusion that were highlighted in the introduction.

2.3.3. Characteristics of patients who have pre-discharge home visits

Six papers were identified in the search which contained information about patient characteristics (as show in Table 1). Five papers compared the characteristics of patients who had home visits with patients who did not, and one paper reported only on those patients who had home visits. These will now be discussed separately below.

Clarke and Gladman (1995) completed a retrospective audit and examined the medical records of 297 patients with a stroke, from a large hospital in England. They collected information on those who had and did not have a home visit and carried out statistical analysis. They compared the patients' ages, living situations, Barthel Index scores, length of hospital stay (days) and the type of ward the patient was on. One hundred and forty-nine (50%) of the patients received a home visit before discharge. Clarke and Gladman (1995) reported that there were no significant differences in terms of age, or living alone. However, they did report that home visits were more likely to be carried out with patients on the stroke unit ($p < 0.001$), those who spent longer in hospital ($p < 0.001$), and those who had lower Barthel Index scores ($p < 0.001$) (i.e. the most dependent patients). The difference in the length of stay was particularly apparent: the mean stay in hospital for those who had a home visit was 72 days compared with 24 days for those who did not have a visit.

Luker and Grimmer-Somers (2009) carried out a study to investigate the relationship between staff compliance with discharge planning guidelines and the post-discharge experiences of patients with a stroke in Australia. They reported using a systematic sampling method until they had recruited 50 participants, although they do not provide further details of the sampling approach that they adopted. Eighteen of the patients they recruited had a home visit before discharge. Luker and Grimmer-Somers (2009) compared the characteristics of those patients who had a pre-discharge visit with those who did not. They reported that having a home visit was *not* significantly associated with length of stay or level of independence in activities of daily living (as measured by the Functional Independence Measure (FIM) and Functional Assessment Measure (FAM) on admission and change scores during hospitalisation). In contrast to the finding by Clarke and Gladman (1995) this study indicates that home visits were not more likely to be completed with the most dependent patients, or those who spent longer in hospital.

Johnston et al (2010) carried out a cohort study in a metropolitan hospital in Australia. They recruited 342 patients into the study with a range of diagnostic conditions. Their aim was to follow the participants for one month post-discharge in order to monitor the association between the pre-discharge home visit and post-discharge falls (this aspect will be presented in the outcomes section below). However they also reported the characteristics of those participants who received a pre-discharge home visit and compared them with those who received no visit. Two hundred and twenty-three of the participants in the sample had a home visit, compared with 119 who did not. The researchers found no differences between the groups in terms of age, gender, living arrangements or length of stay. However, they did report that patients with a higher risk of falling (as measured on the Falls Risk Assessment Scoring System) and lower

functional independence (Functional Independence Measure scores) on admission and discharge were more likely to have home visits. These differences were statistically significant at $p < 0.05$ level and the FIM score on discharge was significantly lower in the home visit group at $p < 0.0001$. Johnston et al (2010) also reported that patients with orthopaedic trauma or undergoing orthopaedic joint surgery were statistically more likely to have a home visit than not ($p = 0.0002$ and $p < 0.0001$ respectively). However, as these results were derived from one hospital only, they may be reflective of practices which are adopted by individual therapists.

Renforth et al (2004) carried out a prospective, descriptive analysis of pre-discharge home visits from a community hospital in the Northeast of England. They aimed to describe the characteristics of patients who had home visits and analyse the home visit process. Renforth et al (2004) reported that there were no significant differences in age and gender of the patients who had ($n = 118$) and did not have ($n = 269$) a home visit in their sample. In addition to examining difference in age and gender Renforth et al (2004) also reported that of the participants in their study who had home visits: fifty-eight (73%) lived alone, 78 (99%) had a carer (professional or non-professional) and 72 (91%) were discharged to their own homes, although they did not report any statistical analysis of these variables.

Hale (2000) completed a postal survey with members of the College of Occupational Therapists Specialist Section for Elderly People, in order to identify factors influencing the decision of occupational therapists to carry out pre-discharge home visits with older people. She included both open and closed questions in the survey and quantified the data from the closed questions for analysis, whilst using a qualitative approach to analyse the open questions. She reported that patient diagnosis did not affect the

occupational therapists' decisions to complete a home visit, but that staff absences and availability of transport did. Analysis of the open questions also revealed that occupational therapists sometimes felt that they had completed a home visit inappropriately (i.e. when it had not been needed) and this was commonly due to pressure from other people.

A further paper was identified which reported on the characteristics of those patients who had a home visit, but did not compare these with patients who did not have a home visit (Blakely and Flanagan 1992). Blakely and Flanagan (1992) carried out a retrospective analysis of home visits in an elderly care medical unit, in a hospital in Northern Ireland. Of the 340 patients discharged during the study period, 58 (17.1%) had a home visit. The authors described the characteristics of those who had home visits. Sixty seven percent were female and 53.4% lived alone. The mean age was 79.2 years, with a range from 56-92 years. Barthel Index scores ranged from 4-19 and the mean was 13.7. The mean 'mental test score' was 7.6, range 2-10. However, as the authors did not compare these characteristics with those patients who did not have home visits, it is not possible to determine the relevance of this information to the home visit.

In summary, these papers did not report any significant differences in the demographic characteristics of patients who had home visits, including whether they lived alone or with other people. The earliest research paper by Clarke and Gladman (1995) reported that home visits were more likely to be completed with the most dependent patients (lower Barthel Index scores) and this has been supported more recently by Johnston et al (2010). However, Luker and Grimmer-Somers (2009) reported that this was not the

case and that home visits were not more likely to be completed with more dependent patients.

2.3.4. Outcomes for Patients

Nine papers were identified in this literature search which reported on patient outcomes, and two of these papers were also included in the previous section on characteristics (Luker and Grimmer-Somers 2009; Johnston et al 2012). Patient outcomes were identified in the following six areas: *Independence in Activities of Daily Living (ADL)*; *Falls*; *Readmissions*; *Compliance with Recommendations*; and *Post-discharge Support*. These will now be discussed separately:

Independence in Activities of Daily Living

Two randomised controlled trials (RCT) were identified which were completed with groups of older people (i.e. not stroke specific). One of these was a feasibility randomised controlled trial conducted in Australia (Lannin et al 2007) and recruited ten participants; the other was conducted in France (Pardessus et al 2002) and included 60 participants. In these studies, participants were randomised to either have a pre-discharge home visit or not, and then followed up post-discharge for 12 months (Pardessus et al. 2002) or three months (Lannin et al. 2007). Lannin et al. (2007) reported that participants who had a home visit were more independent at two week and two month follow ups than those in the control group, as measured by the Nottingham Extended Activities of Daily Living (NEADL) (Nouri and Lincoln 1987). The differences were statistically significant (p-values .012 and .003 respectively) but had wide confidence intervals as they were based on only eight participants (two participants were lost to follow-up). Pardessus et al. (2002) used three 'autonomy' scales and reported that overall the participants' autonomy decreased during the 12

month follow-up period. In the control group this loss of autonomy was significantly greater, which led the authors to conclude that occupational therapy home visits can preserve patients' independence after discharge from hospital.

Falls

In both RCTs there were no significant differences between the groups in the number of falls reported during the follow-up period. It is important to note the potential paradoxical effect of the interaction between increased independence and falls, which Pardessus et al. (2002) note. If the pre-discharge home visit intervention was successful at maintaining individuals' mobility and independence in the home environment, then this may place the home visit group at increased risk of falling as a consequence of them being more mobile and taking more risks.

In the cohort study by Johnston et al (2010) (discussed earlier), they investigated the number of falls reported by the participants (n=342) during the first month after discharge. They reported that 23% of those who did not have a home visit reported a fall during the follow-up period, compared with 10% of those who did have a visit. This difference was significant ($p=0.003$). The researchers also controlled for potential confounding factors (diagnostic group, living arrangements FRASS and FIM scores) and the difference remained significant. They concluded that not having a home visit before discharge increased the risk of falling. However, for the neurological patient group this risk was not mitigated by a home visit. The researchers report that as neurological patients are at particularly high risk of falling, and they have specific risk factors (i.e. visual-spatial neglect), that the home visit may not be sufficient alone to mitigate these risks. The evidence from this study is methodologically weak as only 27 neurological patients were included in the study, and there is the potential that the

results may be biased due to the characteristics of those patients who were selected for a home visit by the therapists (i.e. they were not randomly allocated to have the visit or not).

Readmissions

In the study by Pardessus et al (2002) nine participants in the home visit group were readmitted to hospital during the follow-up period, compared with six in the control group. In the Lannin et al (2007) study, one participant in the control group was admitted (twice) to hospital within the follow-up period. These differences were not statistically significant. The data on readmission rates following home visits is extremely limited. Whilst home visits are widely reported to increase safety following discharge (Johnston et al 2010), no evidence was identified to indicate that home visits have any effect on readmission rates.

Compliance with Recommendations

Two studies (Nygard et al 2004; Clark and Dyer 1998) interviewed 'older people' post-discharge about the interventions that were provided on the pre-discharge home visit. The participants in Nygard's study were aged over 68, although it is not clear how Clark and Dyer defined 'older people'. Nygard et al (2004) concluded that pre-discharge visits were needed, as the participants were predominantly satisfied with the interventions that had been provided. They elicited 130 statements from the older people and in 41 of these the participants had selected their own alternative solution to the problem, rejecting the suggestion of the occupational therapist. Similarly, Clark and Dyer (1998) found that the participants sometimes refused the equipment and adaptations recommended for them by the occupational therapist. In some cases, the older people were persuaded to accept the recommendations in order to facilitate discharge home.

Some of these older people later reported that they were 'glad' that they had accepted the equipment, whilst others still refused to use it after returning home.

Post-discharge Support

Luker and Grimmer-Somers (2009) (in the study presented earlier), also interviewed 18 patients with a stroke who had had a home visit before discharge. They reported that those patients who had a visit were significantly more likely to be discharged home directly from the acute stroke unit. However, this may be because the occupational therapists were more likely to carry out home visits with those who were most likely to go directly home, rather than the home visit being effective at facilitating a return home. Thus, this should not be considered to be a causal effect. Luker and Grimmer-Somers (2009) also identified that patients were 5.3 times more likely to avoid unpredicted support needs at home if they had had a home assessment visit prior to discharge.

Patient/Carer Satisfaction

Three papers reported on patients' experience of pre-discharge home visits (Atwal et al. 2008a; Bore 1994; Hibberd 2007). Semi-structured interviews were used by Atwal et al (2008a) with older people in an acute hospital (n=15) and Hibberd (2007) with patients in an in-patient intermediate care setting (n=4). Atwal et al. (2008a) used semi-structured interviews to investigate patients' and carers' experiences, based on 15 and seven interviews respectively. They reported that whilst the carers found pre-discharge home visits reassuring, the older adults they interviewed were not always ready and prepared to go on a home visit. Some found the process daunting and anxiety provoking and perceived it to be a 'test' which they could either pass or fail. Atwal et al (2008a) concluded that home visits should not be completed until the patient had reached the optimum level of functioning in order to maximise the effect of the home

visit, but do not indicate at which point this might be or how it might be determined. Hibberd (2007) carried out four patient interviews as part of her evaluation of an in-patient intermediate care service. Hibberd reported that overall the patient feedback was positive, but that one participant stated that she was worried about whether she would 'get things right' on the visit.

Bore (1994) used a questionnaire to gauge whether patient (n=18), carer (n=8) and therapist (n=18) concerns were addressed effectively on the pre-discharge home visit. Overall the results showed general agreement between the patient and the therapist as to the content of the visit. Bore also reported that two patients commented that the home visit was 'overwhelming'. However, she did not report on the patients' level of dependence or medical diagnosis and it is therefore unclear whether these factors were related to the patients' experiences on the visit.

Atwal et al (2008a) and Bore (1994) also investigated carer experiences of home visits. Whilst Atwal et al (2008a) reported that home visits provided reassurance to carers, conversely Bore (1994) found that carers were not as reassured by the home visits as the therapists had thought they would be. However, the sample of carers was very small (n= 8) and Bore included limited details about this aspect.

To summarise, the research evidence on outcomes of home visits is limited and heterogeneous. There is a trend towards home visits leading to increased independence in two small randomised controlled trials and reduced number of falls in a cohort study. However, these studies are based on relatively small numbers of patients and much larger studies in different clinical settings would be needed to provide definitive evidence. There is also an indication that home visits may reduce post-

discharge support needs but that patients may not necessarily adhere to the recommendations that are made on the visit or indeed be satisfied with the outcomes.

2.3.5. Occupational Therapists' Views

Three research studies have investigated occupational therapists' perceptions or views on pre-discharge home visits using interviews (Durham 1992), reflective diaries (Atwal et al 2008b) or a focus group (Nygard et al 2004). In these studies the occupational therapists were reported to: conclude that home visits were important for clients' safety (Nygard et al 2004); believe home visits eased the patient's transition from hospital to home (Durham 1992) and be mostly satisfied with the outcomes of the home visits (Atwal et al 2008b). Overall, the comments from the occupational therapists were positive about the benefits of undertaking home visits.

An opinion article was also identified in which Chibnall (2011) carried out a limited review of the literature. She argued from her own clinical perspective that home visits following stroke should continue, whilst occupational therapists carry out further urgent research into their apparent benefits. In a letter to the *British Journal of Occupational Therapy*, Mason (1999) argued for an examination of the role of the occupational therapist in home visits and contended that given the time they take, occupational therapists need to ensure that they are effective.

Thus, no negative views were identified from the occupational therapists in contrast to the patients. However, in the opinion pieces it was argued that further research evidence is needed.

2.3.6. Prevalence, Timing and Content of Home Visits

A number of papers were also identified in the search that provided background detail and additional context for the practice of pre-discharge occupational therapy home visits. These studies will now be presented below.

In addition to the survey of stroke units completed by Drummond et al (2012a) as part of the HOVIS study, two other surveys were identified which have reported on the prevalence of home visiting practice with older people (i.e. not stroke specific): in Britain (Patterson et al 2001) and in Australia (Lannin et al 2011). Patterson et al (2001) reported that 65% of the 283 NHS Trusts surveyed completed between 11 and 40 visits per month. Eleven percent of trusts completed more than 60 visits per month. Lannin et al (2011) gained responses from 53 (25%) of the 215 hospitals they surveyed. These hospitals completed approximately 13 pre-discharge home visits per month (range 1 to 60). In 40 of these departments home visits were completed with over half of all patients. Three other papers have also reported on the prevalence of home visiting practice within individual service settings. These reports stated that home visits were completed with: 55% of patients in a rehabilitation hospital in Australia (Harris et al 2008); 30% of patients in a community hospital in the Northeast of England (Renforth et al 2004); and 17% of patients in a geriatric medical unit in a Northern Ireland hospital (Blakely and Flanagan 1993).

Three studies reported the timing of home visits at: a mean of 15.5 days (SD 27.5) (Renforth et al 2004); a median of 12 days (range 1 to 146) (Clake and Gladman 1995); and a median of 11 days (range 0-267) (Harris et al 2008) before discharge. Whilst the averages and mid-points of these figures are broadly consistent, the ranges and

standard deviations demonstrate that there is a wide degree of variation. Thus for some patients home visits are well beyond the average of 11 to 15 days before discharge.

Three audit reports were identified (Dove 1999; Franklin 1997; Hibberd 2007) which provided details on the timescales to implement home visits and recording of home visits. Dove (1999) reported that 88% of visits in in-patient elderly care were completed within five working days and that 60% of those visits that were not completed within this time were due to factors outside the occupational therapists' control. Hibberd reported that only 35% of visits were completed within 8 working days of the decision by the multidisciplinary team that a visit was needed, in an in-patient intermediate care service. Visits were delayed because the patient was medically unfit or required additional therapy prior to the visit. Franklin (1997) reported that only 43% of home visit reports were filed in the medical notes, within one hospital setting. These audits of practice indicate that home visits are completed at different stages in a patient's hospital stay and that external factors may impact upon their timing and recording.

Barras et al. (2010) used a Delphi consensus to establish 'core/essential' and 'ideal world' elements of pre-discharge home visits. They sampled 81 occupational therapists from acute rehabilitation settings in Australia about the items which they believed should be core elements of the content of a home visit. The top five core items with 100% consensus were: safety of patient, equipment provision, home layout and functional problems, falls hazards, and seating/lounge.

Atwal et al (2011) carried out a survey to ascertain the extent to which occupational therapists used information leaflets to inform older adults about the pre-discharge home visit. They failed to ascertain this as they received only a ten percent response rate.

However, they also obtained five home visit information leaflets and analysed the readability and content of these. Atwal et al (2011) reported that these leaflets failed to provide unbiased, detailed and evidence based information. They also reported that the average reading grade of the leaflets was four grades higher than the recommended level for the general public. However, the authors do not explain what evidence these leaflets should be based on, and do not acknowledge the lack of evidence for the *practice* of home visits in this paper.

In summary, the research and audits discussed in this section of the chapter are indicative that home visiting continues to be a prevalent but variable component of occupational therapy practice for stroke and other patient groups. Variations in the timing, content and practice procedures (e.g. information leaflets) of visits were also reported. These widespread variations may indicate that home visiting practice varies according to the particular practice setting rather than the particular characteristics of patients who are believed to need home visits. However, it is not possible to determine this from these studies and further research is needed.

2.4. Discussion of Literature

The surveys completed by Paterson et al (2001) and Lannin et al (2011) revealed that similar numbers of patients were reported to receive home visits from acute hospitals in Britain and Australia. Thus home visits continue to be a common practice for occupational therapists working with older people and for patients with a stroke (Chibnall 2011; Drummond et al 2012a). Despite these papers indicating that home visits continue to be completed routinely, a dearth of literature was identified which reported on the characteristics of patients who had home visits and compared them

with patients who did not have visits. The literature that was identified suggested that there were no differences in the demographic characteristics of patients who had visits but revealed conflicting results regarding the level of disability or impairment of patients that had visits compared with those who did not.

The papers which were included in the review were from a variety of countries and service settings, completed with a variety of patient groups, and spanned a wide time-period. Several different research methodologies had been utilised across the papers included in this review. Thus, the findings from the literature contained a large amount of heterogeneity in the aims of the investigations and in the research methods utilised. It is therefore difficult to make an overall assessment of the quality of the body of literature because most of the studies have included small samples of participants and, due to the different aims and methods they are not directly comparable with each other.

The most robust form of evidence for the efficacy of a healthcare intervention is usually considered to be a randomised controlled trial (after a systematic review of several RCTs) (Concato et al 2001). In the literature search for this review, only two RCTs of pre-discharge occupational therapy home visits were identified with participants totalling 70 older people. Whilst both of these trials showed a trend towards increased independence in the home visit group compared with the control group, they did not show a statistically significant difference in falls or readmissions to hospital between the groups. However, due to the small numbers of participants in both studies, the results are statistically weak, and must be interpreted with caution. Moreover, Lanin et al. (2007) were attempting only to evaluate the feasibility of the method and therefore conclusions about the value of the intervention would be inappropriate. Furthermore, Pardessus et al (2002) did not report on whether measures were included to prevent

bias (allocation concealment, masked follow-up assessor) and thus it is not possible to evaluate fully the reliability and validity of their findings.

There is a dearth of evidence to indicate whether home visits are effective in improving any of the outcomes which were identified in this literature search. This lack of evidence means that occupational therapists have little to base their decision on other than their own views and clinical experiences. The suggestion in the literature that some patients may be anxious and apprehensive to go on home visits makes it particularly important that occupational therapists make an informed decision about the basis on which a home visit is needed.

2.4.1. What about Patients with a Stroke?

Only three papers were identified which focussed specifically on stroke, highlighting that there is a paucity of information related specifically to pre-discharge home visits with this patient group. Therefore, the results from the other studies will be extrapolated for their relevance to stroke care.

In the cohort study conducted by Johnston et al (2010), the results for the neurological patient group were different to the patients with other conditions. The risk of a post-discharge fall was not mitigated by a pre-discharge home visit for the neurological patient group. This indicates that the issues for patients within neurological conditions, including those with a stroke, may be different to other patient groups. Indeed, Johnston et al (2010) highlight that the neurological patient group experience additional risk factors, such as visuo-spatial neglect, which may increase their risk of falling after discharge from hospital and that there may be other factors which distinguish them. This finding is indicative that studies which combine pre-discharge home visits for

patients with a stroke with patients with other conditions are unlikely to produce results that are generalisable.

The majority of the studies identified in this literature search focussed on home visits with older people. However, approximately 25% of people who survive a stroke are under the age of 65 (Walker 2011b) and the population of patients with a stroke is likely to be significantly younger than a population of patients from elderly care wards. To further demonstrate this, the mean age of the patients in Clarke and Gladman's stroke specific study was approximately 11 years lower than the mean age in the two RCTs (Lannin et al 2007; Pardessus et al 2002). Thus, a population of patients who are discharged from hospital following stroke are likely to include a higher proportion of younger people than the groups of patients included in most of the studies in this review. The issues addressed on the pre-discharge home visit may differ for people aged under 65 as they may also need to focus on additional activities of daily living which may include aspects such as work or child care responsibilities.

Furthermore, many of the empirical studies identified in this review have largely overlooked cognition as a factor in the pre-discharge home visit process. Both of the RCTs (Pardessus et al 2002; Lannin et al 2007) excluded patients who had a moderate degree of cognitive impairment. However, the prevalence of cognitive impairment after stroke is high, and hospital based studies have shown that this varies between 11 to 56% (Patel et al 2002). Therefore, pre-discharge home visits may be completed by occupational therapists as part of their assessment and treatment of cognitive impairment. From the perspective of stroke rehabilitation it is therefore important that research studies are designed and conducted which explicitly include patients who have cognitive impairment. Evidence which is based on studies which have excluded

patients with cognitive impairment may have limited relevance for stroke rehabilitation practice.

This section has highlighted a number of factors which are both pertinent and distinctive about patients with a stroke, compared with general older patient populations. Evidence which is based solely on findings from research conducted with older people is likely to be unrepresentative of the needs of patients with a stroke. It is therefore important that research on home visits focuses on patients with a stroke as a separate patient group in order to encompass the factors which may be unique to these patients.

The potential impact that a pre-discharge home visit may have on increasing a person's independence in activities of daily living post-discharge is particularly noteworthy for patients with a stroke, as this may assist in reducing the ongoing burden of disability from stroke that was highlighted in the introductory chapter. This may also help to facilitate people with a stroke returning to independence in self care and accessing their wider community and it is important that research is conducted which explores these factors.

2.4.2. Limitations of the review

This review contains a publication bias as due to limited time and resources it was not practicable to search manually for unpublished work. The limited quantity of literature on home visits and the disparities in research methods and patient groups is a further limitation. Therefore comparisons between different studies are difficult to draw.

The majority of the literature identified has been published in the United Kingdom and Australia. However it was not possible, due to resource constraints, to pay for research

articles to be translated into English. Therefore this review also contains a language bias and there may be research published in other languages which has not been included in this review.

2.5. Conclusion

There is an absence of clear and robust research evidence to guide practice decisions as to when a home visit may be indicated for individual patients with a stroke. Occupational therapists must therefore decide which patients receive a home visit on the basis of clinical reasoning, using their own judgement, for each individual patient. However, this literature review has identified that there is also a paucity of literature indicating which particular patients with a stroke may be the most likely to have home visits based on characteristics, outcomes, or occupational therapists' views.

Furthermore, whilst occupational therapists are purported to extol the merits of home visits, there is evidence of conflicting views amongst patients and carers as to their experience of them. Some patients may be anxious about having a home visit, or may be disinclined to adhere to the recommendations made on the visit. There is also limited evidence of effective clinical outcomes to support occupational therapists' belief in their worth.

Chapter Three

Which Patients with a Stroke Need a Pre-discharge Home Visit? The Views of Occupational Therapists

3.1. Introduction

The previous chapter highlighted that there was a paucity of literature relating to the 'types' of patients or characteristics of patients with a stroke who had a pre-discharge home visit, compared to those patients who did not have a visit. The starting point for the research for this study was to investigate the views of occupational therapists working in stroke care about home visits, and to explore examples of those patients whom they considered to need a visit. This chapter will present the first stage of the research programme which consisted of interviews with 20 senior occupational therapists working in stroke care in the United Kingdom. The specific focus of these interviews was to ask the occupational therapists to discuss examples of patients with whom they would and would not complete pre-discharge home visits, and provide details about their reasoning for these decisions.

As part of the Home Visit after Stroke (HOVIS) study, interviews were completed with occupational therapists working in in-patient stroke care, with the aim of identifying facilitators and barriers to the implementation of the findings from the feasibility randomised controlled trial (and any subsequent home visit research). The aim of the interviews in the HOVIS study was to ask occupational therapists about a range of different components of the pre-discharge home visit in order to identify and explore factors which may aid the uptake of the research findings from the main HOVIS study and aid the implementation of the findings of research into clinical practice. As part of this study, specific emphasis in the HOVIS interviews was placed upon asking the occupational therapists to provide and discuss examples of patients who had home visits, patients who did not have home visits and patients whom the occupational therapists would feel uncertain about whether a visit was needed or not.

In this chapter the method will outline how the research was carried out and this will be succeeded by the findings from the interviews. The findings will be presented in three themes.

3.2. Method

3.2.1. Rationale for a Qualitative Approach

Qualitative research methodologies aim to gain insights into behaviours or phenomena (Barbour 2008). The goal of most qualitative research is to attain a depth of understanding of a situation (Patton 1990) and to explore subtleties, complexities, meanings and interpretations (Hansen 2006). Therefore qualitative approaches are usually used when the overall aim of the research question is *exploratory* and the objective is to generate new ideas or insights. Thus, qualitative methods are often used to answer research questions which begin with 'what' or 'how' because they can be used to generate data with sufficient depth and detail to answer these types of questions.

One of the principal strengths of qualitative research is that participants are encouraged to express their views, opinions, beliefs and experiences in their own words (Patton 1990). There are therefore fewer assumptions placed on the data at the outset of the research. The data which is generated in a qualitative enquiry is less constrained by the researcher's pre-conceptions and ideas (Patton 1990) and can be considered to be generated by the research participants themselves.

In contrast, the objective of most quantitative research is *confirmatory* and aims to answer questions which focus on 'how much' or 'how many', or to test the existence or strength of a relationship between variables (Barbour 2008; Broom and Willis 2007). The aim may also be to determine how prevalent a particular phenomenon is in the population which is being studied (May 2001). For example, a questionnaire or survey can be a useful method to quantify the extent of a viewpoint, belief or practice because it can be targeted at a wide sample and can cover a wide geographical population. However, surveys do not readily allow for exploration or examination of a particular viewpoint in detail as they are limited to questions which have already been determined by the researcher's own presuppositions (May 2001). Furthermore, in a questionnaire or survey it is not possible to ask additional questions to explore a new area of interest which may arise during the research, without sending out an additional questionnaire. The depth of the interpretation of quantitative research is therefore much more limited than in qualitative research.

In order to investigate the factors which occupational therapists take into consideration when deciding whether or not to complete a pre-discharge home visit with a patient who has had a stroke, a qualitative approach was deemed to be the most appropriate. A quantitative approach was not considered to be suitable to answer the research question, as it would depend primarily on questions derived by the researcher. As discussed in chapter two, there were no papers identified in the literature search which specifically asked occupational therapists about the types of patients whom they would and would not complete pre-discharge home visits with and there is little published literature which has addressed this topic. Therefore there is little to inform a hypothesis for a quantitative research question.

A qualitative approach was therefore selected as a starting point for this study in order to begin to identify and explore the factors which occupational therapists consider important when making a decision whether a patient needs a pre-discharge home visit or not. This would allow new ideas and topics to be engendered, which could then form the basis for further research. Pope and Mays (2006a) stated that qualitative methods can also provide a useful starting point for studies which will later use quantitative methods to substantiate the findings.

3.2.2. Phenomenological Perspective

When using a qualitative approach a researcher may be informed by one or more theoretical perspectives. This is in contrast to quantitative research which has a more narrow theoretical foundation based upon statistics and mathematics (Hansen 2006). A qualitative researcher may utilise a particular theoretical perspective which then fundamentally and implicitly informs the selection of the research method used (Patton 1990). Alternatively, a researcher may be largely 'method driven' and select a specific approach based upon the appropriateness of the method to the particular research question (Hansen 2006).

Phenomenology can be viewed as both a theoretical perspective and a research method (Patton 1990). As a theoretical perspective, phenomenology is concerned with understanding a phenomenon rather than explaining it and is the study of meaning and experience from the individual's perspective (Lester 1999; Sadala and Adorno 2002). The central tenet of phenomenology is its focus on the meaning of human experiences (Walton and Madjar 1999). Research within the phenomenological approach recognises the subjective context of individual experiences and emphasises the subjective reality of these experiences (Walton and Madjar 1999). Researchers then offer an interpretation

of this reality based upon their analysis of the dataset. Qualitative research methods used within the phenomenological approach are recognised as providing a richness and depth to data which can facilitate the understanding of the phenomena of study because the approach explicitly acknowledges the subjective context of the participants' experiences.

In this study, the aim was to explore the occupational therapists' practice and ask them to draw on examples of their own experiences of working with patients who would and would not require a pre-discharge home visit. The focus was to understand the factors which occupational therapists considered to be important in the context of their practice within their individual stroke units, from their own subjective standpoints. The intention was to then discuss these findings in relation to occupational therapy theoretical models of practice. This aim is consistent with a phenomenological perspective as Hansen (2006) stated: "Research projects conducted using a phenomenological perspective aim to develop a narrative account ending with theoretical propositions" (pg. 62).

However, although a phenomenological perspective informed the research, the primary rationale for a qualitative approach was largely method driven, based upon the rationale of a qualitative method being most appropriate to answer the research question. The selection of the research method will be presented in the next section.

3.2.3. Research Method

Several possible qualitative research methods were considered for their appropriateness to use in this study. These will be discussed below.

Participant Observation

Participant observation is a method in which a researcher becomes a participant member of an organisational structure or society, and actively observes how individuals behave within that structure. Observations of interactions between individuals are systematically recorded by the researcher and these observations then form the dataset (Pope and Mays 2006b). This method allows the researcher to observe actual behaviour and practices as they occur within a specific context. However, due to the time involved in carrying out such an in-depth approach, observational studies are primarily used for investigating one organisational structure in detail. Such studies are therefore only representative of one particular setting and do not readily lend themselves to drawing comparisons between participants or sites (May 2001). In this study, participant observation would have facilitated an exploration of home visiting practice in one stroke unit only, thus limiting the generalisability of the data.

Focus Groups

A focus group or group interview is a method used to collect information from several participants at one time. One of the main advantages of using focus groups is the convenience of collecting data from participants at the same time. Proponents of focus group methods state that they can generate new ideas and information as participants can share thoughts and ideas with each other, which have the potential to spark novel and creative ideas to take the research into new and unexpected directions (Kitzinger 2006). Participants in a focus group may feel more empowered to express their views than in a one-to-one interview with a researcher (Green 2007). However, there are potential disadvantages of using group interviews in exploratory research. The principal disadvantage is the potential for 'groupthink'. Groupthink is a social phenomena initially proposed by Janis (1982) in which the members of a group try to reduce conflict within

the group by reaching a consensus, potentially prematurely, before considering alternative viewpoints. A potential consequence of groupthink in group interviews is that one or two members may dominate the interview, and that group members who hold alternative views to the majority may be reluctant to express these within the group. Therefore group interviews may not be appropriate for research which seeks to explore differences and alternative viewpoints and behaviours.

Interviews

Interviews are a widely used research method for gaining a detailed account of a participant's experiences, beliefs and understanding of a situation (Gerson and Horowitz 2002; Britten 2006; Silverman 2010a). They are commonly used within the phenomenological perspective as they allow participants to describe what is meaningful and important to them, using their own words (Britten 2006). They are also considered to be a reliable method for gaining data on participants' views and experiences (Hansen 2006). Interviews allow researchers to use their own flexibility and apply their knowledge and skills to probe interesting ideas which are revealed during the course of the interview. Interviews are also a useful way to compare the views and experiences of different research participants. However, one of the principal criticisms of interview studies is that they provide only the participant's own account of their experience, behaviour or in this case, their clinical practice (Silverman 2010b). This account may not be representative of the participant's actual behaviour or practice in reality. Another criticism is that interviewees may tell the researcher what they think he or she wants to hear and seek to project themselves in a particular way (Silverman 2010b).

The overarching aim of this part of the study was to obtain the occupational therapists' views and to identify the factors which they considered to be important when making

decisions about which patients need a pre-discharge home visit. Occupational therapists working on different stroke units may have different views and practices and therefore it was considered to be important to obtain a range of views from therapists across several stroke units. Using one-to-one interviews would allow the researchers to probe the views of the individual occupational therapists which would not be possible within a focus group setting. Thus, interviews were selected for use in this study in order to explore the views and experiences of occupational therapists practicing in different locations in the United Kingdom.

3.2.4. Type of Interview

As interviews were to be used to answer the research question, it was then necessary to decide upon the type of interview. There are three main types of interview style which are commonly used in qualitative research. These are: structured, semi-structured and in-depth interviews (Hansen 2006). Structured interviews follow a highly prepared schedule which should be administered in a set manner without deviation, thus the format for the interview is highly prescribed. Semi-structured interviews have a pre-prepared schedule which should be followed closely (which often includes a series of additional prompts) but the interviewer has freedom to deviate from the schedule and explore or probe points which are of particular interest. In-depth interviews ask only one or two questions and the researcher explores each of these in a great deal of detail. The structure of an in-depth interview is therefore largely determined by the conversation that takes place between the interviewer and interviewee.

Structured interviews would not have been appropriate for this study as a highly prepared schedule would not have allowed interviewees to speak freely and expand on points which were important to them, and would not have allowed the interviewer the

freedom to pursue any topics which arose which warranted further exploration. In-depth interviews would also not have been appropriate as the interview would not have had enough focus and would not have covered all the areas of practice of home visits which the research team wished to know about.

Therefore, semi-structured interviews were chosen for this study, and as interviews were already being completed as part of the main HOVIS study, they could also be used as a basis for this research. In the main study, the aim was to cover a range of issues relating to the practice of home visits as part of the implementation agenda. A structured approach was required in order to ensure that the interview was focussed and covered all the topics required. However, it was also important to retain some flexibility within the interview structure in order to allow respondents to speak freely and expand upon the areas which were particularly important and relevant to them. In a semi-structured interview, the researchers pre-select the topics but the responses given by the interviewee determine the information which is generated and the relative weight of different research questions (Green and Thorogood 2004).

3.2.5. Content of Interview and Topic Guide Design

The interview topic guide was designed to encompass a range of issues related to the completion of pre-discharge home visits in accordance with the main HOVIS research aims. However, specific emphasis for this study was placed on asking occupational therapists working in different settings to provide examples of particular stroke patients whom they would and would not complete home visits with, and also those they would be unsure about. Rather than asking occupational therapists to talk directly about the types of characteristics or types of patients whom they would complete a home visit with, the intention was to ask for examples of particular patients in order to encourage

story-telling and narratives through the use of examples. These examples could then be explored by the researchers in order to analyse the factors which were considered to be important.

A semi-structured interview requires an interview schedule or topic guide to steer the focus of the interview. This topic guide should be theoretically informed and user-friendly in order to facilitate a successful interview (Gerson and Horowitz 2002). An interview topic guide for this study was initially designed over a series of meetings with the HOVIS research team (two occupational therapists and a qualitative researcher). The guide was then discussed and refined through discussions with the rest of the HOVIS research team (the Principal Investigator and a Stroke Consultant). They were also sent to local stroke researchers (n=10) and the HOVIS trial steering group (consisting of the research team plus experienced stroke trialists, statistician, health economist and stroke consultant) for comments. The topic guide was designed based on literature on qualitative research design (Gerson and Horowitz 2002; Britten 2006); and previous literature on occupational therapy home visits (Atwal et al 2008b; Barras 2005; Patterson and Mulley 2001).

Other areas in the topic guide covered: the purpose of home visits, content of visits, report writing following home visits, use of information, and suggestions for ways in which home visits could be improved. These additional issues were intended to add context and depth to the interview, and highlight other aspects of the occupational therapists' practice. Each area within the topic guide had a series of prompts which the interviewers could then use if necessary. This allowed for flexibility in order to facilitate the semi-structured nature of the interview.

The topic guide (Appendix A) began with general demographic areas relating to the occupational therapists' place of work, type of stroke unit and length of experience in stroke care; before moving onto questions about pre-discharge occupational therapy home visits which became more focussed as the interview progressed. The guide was designed based upon recommendations in the literature that it is advisable to begin with questions with which the interviewee will feel comfortable and be able to answer easily (Britten 2006). This allows the interviewee to settle into the interview and feel relaxed and comfortable at the beginning, before moving onto the more fundamental questions which they may then answer more freely. The topic guide was designed so that the interview would last for approximately 30-40 minutes which was felt to be a reasonable amount of time to capture the information without overburdening the interviewees.

3.2.6. Sampling

Having decided upon the type of interview to complete it was then necessary to select the sample of occupational therapists to be interviewed. It is important to select the people who are included in interview research studies carefully (Rapley 2007) although Hansen (2006) highlighted that the numbers of people are less important than they are in a quantitative study. It is still important to give consideration to the range, type and number of people who are interviewed and the basis on which interviewees are selected.

The aim for this study was to interview 20 senior occupational therapists. This number was based on both practical considerations of the time and resources available to collect and analyse the data; and that 20 interviews would be sufficient to answer the research question and achieve data saturation. The tenets of data saturation are that few new concepts are found from analysing data from additional participants (Francis et

al 2010). Green and Thorogood (2004) stated that little new information is usually obtained from interview transcripts after twenty interviews have been completed. Furthermore, other interview studies which have aimed to explore a specific aspect of occupational therapy practice (Guidetti and Tham 2006; Beaulieu 2007; Chard 2006) have interviewed between 12 and 23 therapists, which has been reported as the optimum number for such an exploratory study.

The intention was to obtain a sample of occupational therapists from a range of different sites across the United Kingdom, with a particular focus on encompassing both urban and rural geographical locations. The distance between the NHS site and the patient's home was considered to be a potentially important factor in home visiting practice and therefore the aim was to interview occupational therapists across a geographical spread which encompasses both urban and rural sites. Additionally, the four nations of the United Kingdom (England, Scotland, Wales and Northern Ireland) have different service configurations for their health and rehabilitation services (Ham 2004) and this has the potential to impact upon the views and experiences of occupational therapists. Thus, the aim was to select occupational therapists working in different nations and in different Strategic Health Authorities (SHAs) in England. This was in order to ensure that the sample represented a range of views and perceptions of occupational therapists practicing in different geographical regions across the UK.

In order to identify a national sample of occupational therapists working in in-patient stroke care, an email was sent to all members of the College of Occupational Therapists Specialist Section for Neurological Practice (COTSS-NP) (n= 800, approx) asking for volunteers, who were willing to be interviewed regarding the practice of pre-discharge home visits. To be eligible to participate, volunteers were required to be

senior occupational therapists who were currently working within an in-patient stroke setting. An in-patient stroke setting could be either an acute hospital (acute, hyper-acute, mixed or rehabilitation stroke unit; or rehabilitation unit treating patients with a stroke). In-patient intermediate care settings were not included. Senior occupational therapists were chosen as they would have more clinical experience to draw upon in the interviews and their clinical reasoning skills could be considered to be more advanced. Volunteers were sought as this was considered to be an effective method to identify a range of occupational therapists from across the UK.

The intention was to select the interviewees from those who volunteered, on the basis of a mapping exercise where each volunteer was assigned a sticker on a map of the UK. The map was used to locate the volunteers geographically in the UK, in order to purposively sample them. The rationale for purposively sampling is to select a range of information rich cases (Patton 1990). Silverman (2006) stated that purposive sampling involves a sample being chosen carefully based on a feature of the population which is considered to be important to capture in the sample. Thus, interviewees were purposively selected from those who volunteered in order to ensure that the sample represented coverage of the UK and encompassed both urban and rural settings.

3.2.7. Piloting

Before beginning the main interviews, a pilot interview was completed with a local occupational therapist who worked in neurological rehabilitation. The purpose of the pilot interview was to check whether the topic guide was understandable and useable. The pilot interviewee provided feedback on the relevance and ease of understanding of the interview topic guide and the topics covered in the interview. Minor revisions were made to the topic guide following the pilot interview. The revisions added additional

prompts to individual questions, in particular the question relating to the purpose of doing pre-discharge home visits for people with a stroke with additional prompts being added regarding the value and the time taken. The final topic guide included a total of 13 topic areas (see Appendix A).

3.2.8. Interviewing Procedure

It was decided that interviews would be completed by different interviewers from the HOVIS research team. This was in order to avoid interviewer bias which may result from one individual's own views on home visits. The intention was that four members of the HOVIS research team would complete five interviews each. The interviewers had all undergone training in research methods and had extensive experience of interviewing either as researchers and/or clinicians. The interviewers contacted the interviewee by email as soon as possible after the research governance approval had been obtained for the NHS site in which they worked. A convenient time for the interview was arranged by email. Interviewers then contacted the occupational therapists by telephone at the time the interview had been scheduled. All interviews were completed via the telephone at a time to suit the interviewee. The occupational therapists were given the option of completing the interview in their own time or within their working day. Interviews were audio recorded, using a digital voice recorder, and informed verbal consent was obtained and recorded from each occupational therapist at the start of each interview.

3.2.9. Transcription

After the interviews were completed they were transcribed verbatim by a professional transcription service. The member of the research team who had carried out the interview then checked each transcript for accuracy against the audio recording. Any inaccuracies which were identified by the researchers were corrected. The researchers

also anonymised the transcripts by removing the names and workplaces of the occupational therapists, and any other references in the text which could potentially identify the participant. The anonymised and corrected versions of the transcripts were then used in the analysis.

3.2.10. Data Analysis

The demographic information obtained from the occupational therapists regarding their experience and workplaces was used in this study in order to provide a description of the sample. Data collected were: NHS pay band, type of stroke unit, number of beds on stroke unit, and the number of patients on the occupational therapists' caseload.

The rest of the dataset was analysed using thematic analysis. Thematic analysis is a suitable way to analyse the data when the aim of the research is exploratory and inductive (Pope et al. 2006). Braun and Clarke (2006) stated that thematic analysis is a method for analysing, interpreting and presenting qualitative data which is independent of theoretical assumption and does not require the researcher to adopt a particular philosophical perspective. It was therefore selected for use in this study which was method led and inductive rather than being based within a particular theoretical paradigm. However, as highlighted earlier in this chapter some of the principles of phenomenology were used to inform this analysis.

Thematic analysis enables researchers to provide a detailed and complex account of data (Braun and Clarke 2006) and thus, the dataset for this study was analysed using a thematic analysis approach. The entire interview transcripts were analysed and any references to the characteristics or 'types' of patients whom the occupational therapists would complete home visits for, were coded and included in the analysis. The analysis

took place in six stages, as based on the processes outlined by Braun and Clark (2006).

The first stage of the analysis involved becoming familiar with the data by reading and re-reading the transcripts and by listening to the audio recordings. The transcripts were initially read several times in full to become familiar with the data, and then subsequently with particular focus and emphasis on question number five. The audio recordings were also listened to, in order to capture the specific emphasis and meaning of the texts.

In the second stage, the entire dataset was coded and all items relevant to the research question were given a code. As part of the coding process, there were a series of meetings with the other members of the research team who were working on the full transcripts to answer different research questions. These meetings were intended to increase rigor and ensure consistency in coding procedures between the researchers who were all familiar with the interview transcripts. The initial codes were checked and cross referenced with the other research team members.

The third phase involved searching for patterns within the codes and grouping similar codes together to form initial themes. Meetings with other research team members were completed to discuss the grouping of codes and to check that items were being grouped in a manner consistent with the content of the transcripts. Where there was a disagreement consensus was reached by discussion and by a majority decision amongst the team members.

In the fourth phase the themes were reviewed and checked in relation to the coded extracts. The fifth phase involved defining and naming the themes. The sixth and final phase involved writing-up the report and the final analysis and ongoing refining of the themes. The final three stages did not involve the other research team members, as these stages related specifically to the research question for this study. The other researchers were working on different aspects of the data and due to the different research questions collaboration in these final stages of analysis would not have been appropriate. However, during the final three stages the other research team members were consulted on the development of the themes and were in agreement that the themes were an accurate reflection and interpretation of the data contained within the interview transcripts.

3.2.11. Research Ethics and Governance Approvals

Before the interviews could be completed it was necessary to obtain research governance approval from each of the NHS sites where the interviewees worked. This approval was required because the occupational therapists were participating as NHS employees and would be discussing the home visiting practices of their particular NHS organisation. The organisations therefore had to issue approval for the occupational therapists to participate in the research. The procedure for obtaining the individual research and development approvals for this stage of the study was complex and time consuming. In order to obtain the necessary approval a separate fourteen-page site-specific information (SSI) form had to be submitted to each of the sites where the occupational therapists worked.

The process of obtaining approval was different for each of the four UK nations. In England, the SSI forms were submitted via the online Integrated Research Application

Service (IRAS). In Wales, Scotland and Northern Ireland, there was no centralised process and SSI forms were submitted through a different route in each nation. A member of the research team had to contact each site individually to find out to whom the form should be submitted.

Before issuing their approvals, some sites raised numerous queries, whilst others did not raise any. Queries included: requests for signed copies of researchers' curriculum vitae; requests for patient information packs which were not relevant for this stage of the study; and disclosure of the name of the occupational therapist taking part in the interview (which the research team did not disclose as this would have been in breach of the participant's confidentiality). The time taken to obtain approvals ranged from six to 197 days. This impacted on the timing of the interviews as they could not be completed until approvals were obtained. The process of obtaining the research governance approvals for this stage of the study has been discussed in detail elsewhere by Whitehead et al. (2010; 2011).

3.3. Findings

The findings from the interviews will now be presented. The findings section will begin with demographic details about the sample of senior occupational therapists who were interviewed. This will be followed by a general overview of the main themes which were developed in the analysis. Each main theme has been divided into two sub-themes. Each theme and sub-theme will be presented in detail, with quotations from the occupational therapists provided to illustrate the core components of each.

3.3.1. Sample

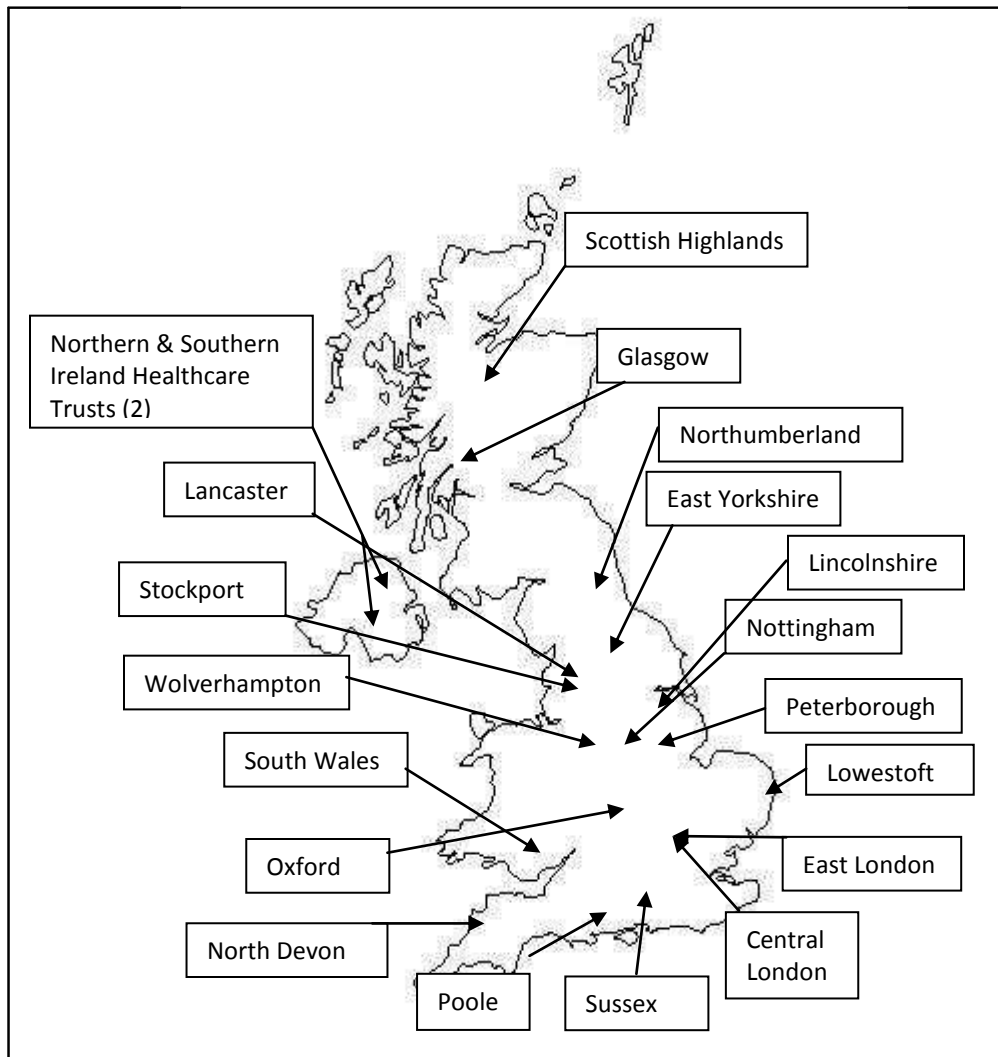
Seventy-five occupational therapists responded and volunteered to take part in the interviews. The 20 interviewees were selected on the basis of the mapping exercise described in the method section, and Figure 2 shows their geographical distribution across the UK. Table 2 shows the demographic details of the occupational therapists in the sample including: their NHS band level, the type of stroke unit where they worked, and the number of patients on the occupational therapists' caseload. The number of patients on the occupational therapists' caseloads has been grouped into categories to preserve the anonymity of the interviewees. The occupational therapists were from a range of hyper-acute, acute, rehabilitation and combined stroke unit settings and one occupational therapist was from a community hospital with designated stroke rehabilitation beds. They were all senior occupational therapists: five were band 6, twelve were band 7 or above (three did not give their band level). There was a range in the size of the stroke units where they worked, and the staffing levels of the stroke units. The number of patients on the occupational therapists' individual caseloads ranged from 3 to 19. This demonstrates that the sample represented a range of seniority, experience and caseload mix. The occupational therapists were all female.

3.3.2. Completion of Interviews

In total, 20 interviews were completed by telephone by members of the HOVIS research team; six by one team member, two completed five each, and one researcher completed four interviews. The interviews ranged from 17 to 67 minutes, with an average time of 40 minutes. As the interview schedule was pre-prepared, the variability in the time taken for the interviews was directly related to the length of the responses given by the occupational therapists and by the details they provided in their examples.

This suggests that some occupational therapists were able to provide more detail and examples than others.

Figure 2: Geographical Location of Interviewees



On the whole, the occupational therapists were able to give clear and detailed examples as to the patients for whom they would and would not complete home visits. In some cases, they provided examples of patients from their current caseload or patients whom they had worked with in the past. Some of the occupational therapists spoke more broadly about the ‘types’ of patients who they would provide home visits

for. In general, the occupational therapists appeared to find it more difficult to provide an example of a patient with whom they would be unsure about whether or not to complete a home visit. Four of the occupational therapists stated that they would never be unsure about completing a home visit with any patient, indicating that their decisions as to whether to complete a home visit or not were very clear cut.

Table 2: Details of Senior Occupational Therapists

NHS Band Level	Type of Stroke Unit	Number of Patients on OT caseload	Number of OTs
Band 6	Acute	6 - 10	1
Band 6	Rehabilitation	≤ 5	1
Band 6	Rehabilitation	6 - 10	2
Band 6	Mixed**	11 - 15	1
Band 7*	Hyper acute	6 - 10	2
Band 7*	Rehabilitation	6 - 10	2
Band 7*	Mixed**	≤ 5	1
Band 7*	Mixed**	6 - 10	4
Band 7*	Mixed**	≥ 16	1
Band 7*	Not specified	11 - 15	1
Band 7*	Not specified	Not given	1
Not given	Rehabilitation	11 - 15	1
Not given	Acute	≥ 16	1
Not given	Rehabilitation	11 - 15	1
			20 (total)

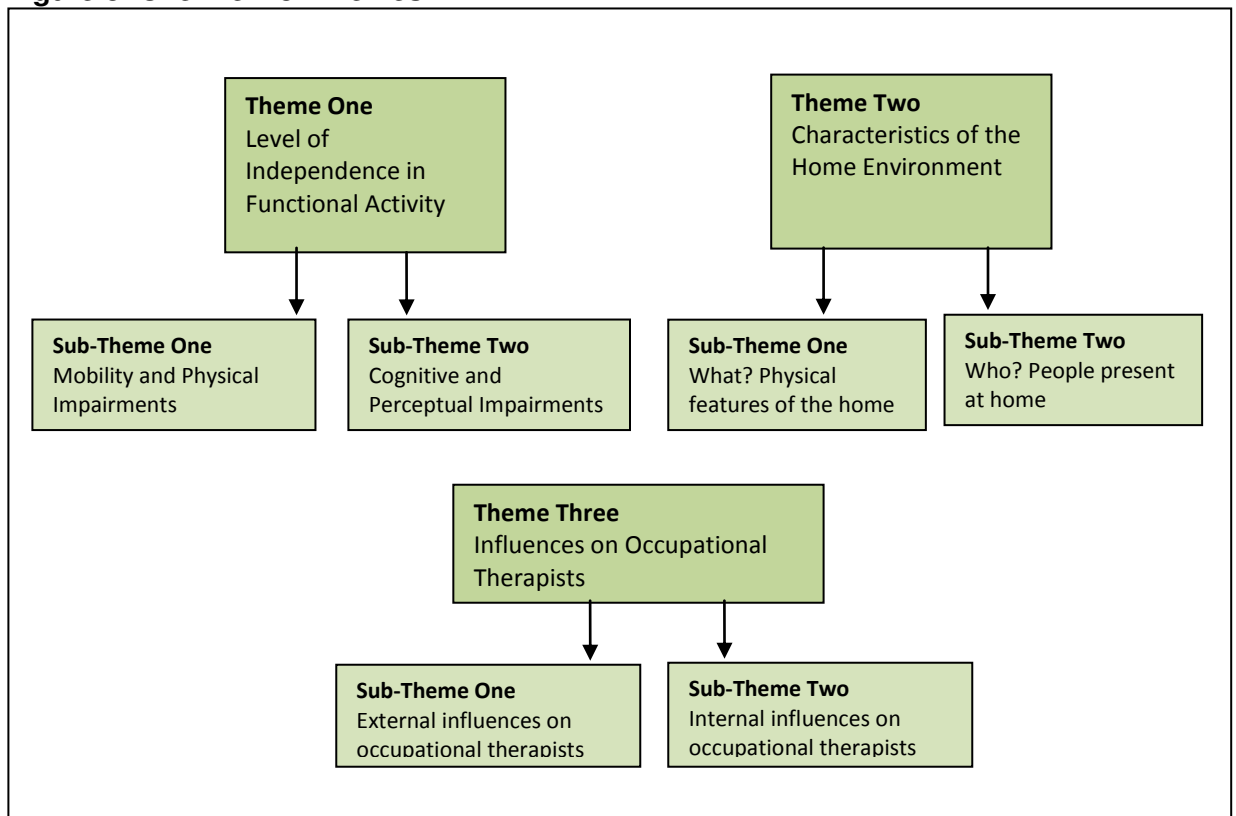
*Band 7 or higher

** Refers to a combined unit with both acute and rehabilitation beds

3.3.3. Introduction to Themes

Three themes were developed in relation to the research question. These themes were derived using the six stages of thematic analysis which were outlined in the method section of this chapter. The first three stages of the analysis involved all four interviewers from the HOVIS research team comparing their codes. The final three stages were completed solely by the author as they related specifically to this study. The three themes were: *Level of Independence in Functional Activity*; *Characteristics of the Home Environment*; and *Influences on Occupational Therapists*. Each of these main themes was divided into two sub themes. Figure 3 shows the themes and sub-themes.

Figure 3: Overview of Themes



Level of Independence in Functional Activity referred to the degree to which the patient had been affected in his or her ability to manage activities of daily living (e.g. personal

care, transfers, meal preparation) independently. This theme was divided into ‘mobility and physical impairments’ and ‘cognitive and perceptual impairments’. The second theme, *Characteristics of the Home Environment*, was sub-divided into ‘What? Physical features of the home’ and ‘Who? People present at home’ which respectively referred to the layout and physical composition of the home, and the people present within the home environment to provide support. The final theme, *Influences on Occupational Therapists*, encompassed the issues which occupational therapists referred to that influenced their decision to complete a home visit with a particular patient, which did not relate directly to the patient or the patient’s home environment. This theme was divided into ‘external influences’ and ‘internal influences’.

Each of these themes will now be presented separately, beginning with a general introduction and moving onto each of the two sub-themes.

3.3.4. Theme 1: *Level of Independence in Functional Activity*

The occupational therapists spoke extensively about a patient’s ability to manage functional tasks independently as being a determining factor in the decision to complete a home visit or not. They talked about the patient’s ability to manage activities independently, in relation to that person’s pre-morbid level of functional ability:

“[He was a] previous plasterer, obviously independently mobile and fully independent with all ADLs” [OT 16]

“...as I say he was very independent before [his stroke]” [OT17]

In general, the occupational therapists reported that home visits would be completed for patients whose functional abilities were significantly different to their pre-morbid abilities:

“Okay, so somebody that I would do a home visit for, would be somebody who'd had quite a change in their level of function since their stroke” [OT 2]

There was also a strong degree of consensus that patients who had recovered very quickly, who had previously been independent and returned to their pre-stroke level of independence, would not require a home visit. Also, patients who had had a significant level of impairment prior to their stroke, resulting from co-morbidities and pre-existing medical conditions, and had returned to their pre-morbid level of function would generally not be offered a home visit by the occupational therapists:

“You know the patient seems to have made a remarkable recovery in quite a short time, back to normal levels of functioning and fine and as far as everybody is concerned there is no need to do a visit.” [OT 3]

When discussing the examples of patients whom they would and would not complete a home visit with, the occupational therapists considered how that patient's level of independence had been affected by either physical impairment, cognitive impairment, or a combination of both:

“I would [complete a home visit] I think for patients who've had significant physical or cognitive difficulties following a stroke” [OT18]

Physical, cognitive and perceptual impairments were all discussed at length by the occupational therapists. The crucial issue appeared to be the *level* of this impairment and how this affected the patient's ability to manage activities safely and/or independently. However, the issue regarding the level of the impact on independence which would warrant completion of a home visit was complex and not straightforward. A range of examples were given regarding patients' level of impairment and these ranged from near independence to high degrees of dependency. Some occupational therapists alluded to the fact that home visits would generally be completed with the most impaired patients:

“So we do tend to get a lot of the more impaired patients physically and cognitively. So by default we end up doing home assessments on most of those patients because they do tend to be the patients that fall into the most impaired brackets” [OT 7]

However, it was not unanimously the case that the most physically and/or cognitively or perceptually impaired patients would be believed to need a home visit and there was a great degree of variability within the examples which were given. One occupational therapist gave an example of a patient who was managing independently on the ward. She reported that she still felt the need to complete a home visit in order to 'see' how he would manage at home:

“...but we will do a home visit with him even though he's independent on the ward, just needs minimal assistance and the reason for that is the same as I said before, it's really to see how he's going to manage around his own home.” [OT 13]

Another occupational therapist offered an example of a patient who had not 'hugely' been affected by her stroke. However, she felt that a home visit was indicated for this patient because the stroke had exacerbated a pre-existing visual problem which may affect her ability to manage independently and safely at home:

“So she's someone I would definitely want to do a visit with, even though, you know, arguably the stroke hasn't affected her hugely... She's not, she's not got a dense hemiparesis or, you know, she's not really got hemiparesis at all, but because the effect on her vision, it's going to be a big determining factor as to whether she can manage at home or not.” [OT 5]

Thus, the *level* of the impairment was a complex factor for the occupational therapists. Overall, it was not possible to determine that those who were the most impaired would be the most likely to need a home visit. 'Level of independence in functional activity' was split into the two-sub themes: 'mobility and physical impairments' and 'cognitive and perceptual impairments'. This was based on stage three of the thematic analysis process, whereby the individual codes were grouped together into similar categories. The occupational therapists reported issues that could be 'grouped' into those which had a physical basis and those which had a cognitive or perceptual basis. Although in some patient examples both physical and cognitive/perceptual impairments were reported, the occupational therapists clearly distinguished between them. Each of these sub-themes will be presented separately.

a.) Mobility and Physical Impairments

The occupational therapists unanimously discussed mobility as a contributing factor in making a decision about a home visit. There was a general, but not unanimous consensus that patients who were independently mobile before their stroke and had returned to near independent mobility would not require a home visit, when taken into consideration with other issues. The following statements were all made about patients who would not require a home visit:

“If they were independently mobile before and they are back to independent mobility or very close to it” [OT2]

“...they look like they’re totally independent at ward level, they are up, they’re mobilising, they’re self caring, no problems have been identified” [OT 7]

“he was walking about, obviously had some weakness around, his knee was snapping back on the left and things like that, but he was actually quite mobile with the frame” [OT 15]

However, differing views were expressed and different examples were given regarding the level of mobility impairment which would warrant completion of a home visit, and there appeared to be no clear pattern within the dataset regarding what ‘type’ of mobility problem or what level of mobility impairment would necessitate a home visit. In the following examples, the occupational therapists discussed patients who would be considered to need a home visit, and the patients ranged from being independently mobile, to not mobile at all:

“...and I would definitely do a home visit with this gentleman... he’s actually doing really well but he’s quite independent on the ward walking with one stick” [OT 13]

“I’ve got another gentleman who used to walk with a walking stick, he lives alone and he’s now using a walking frame with assistance of one, and he would be somebody I would do a home visit for” [OT 11]

“I would do a visit if a patient has got quite a lot of, still got quite a lot of needs in terms of, if they are maybe not mobile yet particularly” [OT 8]

Some of the occupational therapists reported that they would complete a home visit if a patient had become wheelchair dependent following their stroke. Sometimes this was a ‘blanket’ decision to complete a home visit with all new wheelchair users:

“I will always do one if somebody’s had, er, become wheelchair dependent... you’re going to need to know what that’s like... moving around the property in a wheelchair” [OT 4]

Or it may be that home visits would be completed with patients who were returning home with high levels of dependency, particularly wheelchair users:

“...we really need to look at the home environment to see whether it’s going to be suitable for a wheelchair and doing the transfers” [OT 8]

However, again there were differences between the occupational therapists and it was not wheelchair use *per se* which warranted a home visit. This was one of a number of factors which was considered. One occupational therapist gave an example of a patient with high level of dependence and pre-existing memory problems. Since her stroke the patient was using a wheelchair and a hoist to transfer and she was going to return home with a large amount of family support. The occupational therapist reasoned that the patient did not require a home visit, but that an access visit would be sufficient:

“...she’s not going to learn anything from being at home. Anything we need to teach her family we can teach them in the hospital environment and having me seeing her home environment, I can, I can help them to relate it to that home environment without actually having to take her there and, and go through it there, you know, in situ. So she’s someone I wouldn’t do a visit with.” [OT 5]

In addition to mobility, the occupational therapists also commented extensively on physical impairments which affected independence in other activities of daily living, particularly transfers. When discussing examples of patients for whom they would complete home visit, transfers were usually mentioned in relation to an aspect of the home environment:

“...to try various things at home, like the transfers within their own environment” [OT 2]

“Well obviously from the functional point of view, look at is he able to transfer safely at home?” [OT 19]

“...that she is able to walk about the lower floor of her house and get on and off a normal bed rather than a hospital bed” [OT 14]

These examples differed from the examples given below about patients who would not require a home visit, as these patients tended to be the most independent with very minimal or no impairments:

“...she is independently with personal care, kitchen, all that has been assessed here” [OT 16]

However, there were also cases where the occupational therapists felt that a patient may be too dependent to need a home visit because the highly dependent needs could be adequately assessed in the home environment:

“Because they’re... going to be dependent at home and everything that they’re going to be managing at home that you know say if they were able to feed themselves, that you could assess that in the hospital, the home environment’s not going to affect that.” [OT 17]

Concerns were also raised about the abilities of some highly physically impaired patients to cope with the demands of the home visit, in terms of the effort required to sustain sitting out of bed for the time period involved in the home visit:

“...things do come into play about whether or not they can tolerate sitting out long enough.” [OT 2]

Some of the occupational therapists reported that an access visit or environmental visit may be completed without the patient, instead of a pre-discharge home visit with the patient, for those with the highest levels of physical dependency. Issues such as space for hoisting equipment and wheelchair turning were reasoned to be better assessed on a visit by the occupational therapist without the patient, in some circumstances.

Overall, in terms of physical impairment, it appeared that the occupational therapists felt that those patients with very minor impairments would be the least likely to require a home visit. However, this was not unanimously the case and there were exceptions to this, particularly regarding those with the greatest level of dependency, and those that also had cognitive and/or perceptual impairments.

b.) Cognitive and Perceptual Impairments

Whilst there was almost a unanimous agreement amongst the occupational therapists that patients who had returned to their previous level of function, including cognitive function, would not be offered a home visit, differing viewpoints were expressed regarding patients who did have some degree of cognitive impairment. For most of the occupational therapists, a cognitive impairment was a significant factor in the decision to complete a home visit or not.

An important factor for some of the occupational therapists was the consideration that patients with a cognitive impairment may perform functional activities better in the familiarity of their own home environment and that the home visit would provide the patient with the opportunity to demonstrate this ability. The home visit was also reported to provide the occupational therapist with the opportunity to assess how the patient

would perform in a more 'realistic environment'. There were certain aspects of cognitive ability which the occupational therapists reported could not be adequately ascertained within the hospital environment and that aspects of cognition could not always be realistically assessed in hospital. Additionally, home visits were reported to be an opportunity to assess how a patient with a cognitive impairment may manage outside of the safety and structure of a hospital based environment:

"[I would complete a home visit] for somebody who is cognitively impaired and they are struggling on the ward but I think they might be better in a familiar environment. Or they are doing quite well on the ward but I've got concerns about their cognitive impairment when they are not in that structured environment." [OT 20]

A concern expressed by several occupational therapists was that patients with cognitive impairment may not be able to understand the nature and purpose of the home visit, and that it may be distressing for them to visit home and then to return to the hospital:

"Someone who I probably wouldn't do a visit with is someone who's got a cognitive deficit in many ways because of the whole issue of the patient not really comprehending what the home visit is all about and maybe then not wanting to come back. So you can get into the situation of it being, ending up being a discharge visit which is not great at all." [OT 8]

Another example was given about a patient whose cognitive impairment had led to unpredictable behaviour. The occupational therapist reasoned that she would not complete a home visit with this patient because of the level of risk:

“He is agitated and aggressive, he’s very impulsive. His physical abilities vary hugely because of his cognitive impairment... We can’t control how he responds... One minute he’ll be walking and the next minute he might just stop and not move... So, he’s a major risk to staff, to himself, to his family he would be a significant risk, so we’ll not do a visit with him.” [OT 14]

When asked to give examples of patients whom they would be unsure about completing a home visit with, those patients with cognitive impairments were the most common example. Generally the issues were around the patient potentially not understanding the purpose of the home visit, either due to a cognitive impairment resulting from the stroke, or from pre-existing memory problems:

“...so they might not really understand what the purpose of the home assessment is and be able to grasp the concept of what you’re doing so it might be quite distressful to take from home and bring them back again.”

[OT 6]

Patients who lacked insight into their level of impairment were also a cause of uncertainty for other occupational therapists. They questioned whether the home visit might prove to be more distressing than it was actually worth for these patients; or whether to complete a home visit for a patient who lacked insight could actually be beneficial for that patient’s insight.

Overall, there appeared to be a split in the level of cognitive impairment which would be deemed to warrant the completion of a home visit. Those with very minimal or no impairment would be believed not to require a visit (when taken into consideration with

levels of physical impairment). Those with a significant degree of impairment may also not be offered a visit; either because they would be considered not to learn anything from the visit, or because the visit may be considered to be too distressing or risky for the patient, their family or the staff. Thus, it appeared to be those patients falling somewhere into the middle with some degree of cognitive impairment who would generally be considered to require a visit. However, this was also considered alongside other factors relating to the patient's behaviour, insight, ability to comprehend the nature and purpose of the visit, and psychological ability to cope with visiting home and then returning to the hospital following the visit.

The occupational therapists also mentioned issues around perception and vision which would be factors in their decisions to complete home visits. These were sometimes given as part of a list:

"If they have a speech or communication problem or a physical deficit or a perceptual problem, then we definitely would [complete a home visit]" [OT 9]

Or in specific examples:

"She's someone I'd want to see in her own environment because obviously having a, having a pre-existing knowledge of the environment helps you with your orientation to it" [OT 5, speaking about a patient with a visual problem]

"We have one who has neglect so he's one that when it comes to going home he would be a candidate for a home visit" [OT 19]

Anxiety and mood were also highlighted by two occupational therapists as contributing factors in their decisions to complete home visits with particular patients. These were given as potential reasons to complete a home visit if there were concerns about a patient having low mood or heightened anxiety. However, these issues were not discussed extensively by either of the two occupational therapists, or by the rest of the sample. They appeared not to be the principal reasons given for completing the visits but were secondary considerations, alongside other factors.

3.3.5. Theme 2: *Characteristics of the Home Environment*

When considering the factors about the patient's level of independence in functional activity and level of impairment, these were rarely discussed by occupational therapists in isolation and were inextricably linked to factors about the home environment (including the availability of family and care support within the home environment). Characteristics of the Home Environment has been presented here as a separate theme as, although these factors interacted with the patient's level of impairment, they were factors which were external to the patient and the patient's ability to manage activities of daily living independently. Factors related to the home environment could clearly be divided between those physical features of the home and the availability of support within the home environment from other people. Characteristics of the Home Environment has therefore been divided into two sub-themes: 'What? Physical features of the home' and 'Who? People present within the home'. These sub-themes will now be presented separately.

a.) What? Physical features of the home

This sub-theme was small, as the occupational therapists considered these factors alongside the information they had about a patient's level of independence in functional activity. With regard to the physical aspects of the home environment, the occupational therapists referred to using the home visit to identify whether this would be suitable for the level of impairment of particular patients:

"He would be very high risk of falls so really the removal of mats and ensuring the home environment is going to be as safe as possible to reduce falls risk" [OT 16]

"...and looking at the furniture and the home environment because obviously you have to have quite a de-cluttered home environment for someone with neglect" [OT 19]

The occupational therapists also discussed concerns about space within the property, access to the property and stairs. These were all potential factors about the home environment which would contribute to the decisions to complete a home visit:

"...and there was concern about how their frame or wheelchair or whatever would fit in the home environment" [OT 20]

"And there is, I think she said 6 or 7 steps to get into the front door, so in this case obviously the home visit will allow me to look at that access point" [OT 16]

“She’s not safe on the stairs at the moment without close supervision” [OT 14]

Several of the occupational therapists reported that they would complete a home visit as part of the process of checking that the home environment would be suitable for the equipment they wanted to provide to compensate for a physical impairment. When discussing a patient she would complete a home visit for, assessment for equipment was an important factor in the decision to complete the visit for some of the occupational therapists:

“So if he say he needed a chair raiser, raised toilet seat, things like that, then we could look into providing that” [OT 11]

However, when discussing a different patient, whom she felt did not need a home visit, the same occupational therapist reported that if she was able to get someone else to check the equipment she would not need to complete a visit herself:

“The only thing is that they would like a drop down seat in the shower and that may be one that I would consider doing a home visit for, however if I can use the technicians that fit the equipment because they’re trained to actually look and see if the people are safe with bathing equipment then I wouldn’t need to do that but that would depend on their availability to do that check for me.” [OT 11]

Again, this demonstrates that it is not equipment provision *per se* which is important in whether a home visit is required or not. This also depends upon other factors relating to the environment, and availability of other support within the environment.

b.) Who? People present within the home environment

The presence of other people within the home environment was an important factor in the occupational therapists' decision-making about home visits. Availability of support within the home from family members appeared to be an important factor in determining whether a home visit would be needed. Some of the occupational therapists explained that a home visit may be required because of concerns of or about family members. One occupational therapist gave an example of a home visit being provided in order to ease the concerns of a family member as to how the patient may manage at home following discharge. Conversely, another occupational therapist stated that a home visit may be used to demonstrate to a family member the complexity of a patient's needs and to emphasise the difficulties that that family member may encounter as a carer when the patient returns home:

"...his wife was very nervous about having him home because he was really doddering... And, so, again, I wanted to demonstrate to her how the distances in the home are shorter than the distances in the hospital" [OT 4]

"Sometimes the relative perhaps you realise on the first visit has no concept of the problems they're facing so we might go back in another couple of weeks and then do another one" [OT 9]

Home visits were also an opportunity for the occupational therapists to assess how a couple may 'work' together, particularly if the patient has a caring role or other such family responsibilities:

"If they live or seem to be the main carer for somebody else and then quite often that other person we may not have been able to see at ward level so it is a way of going out and seeing how the couple work together" [OT 7]

Other examples were provided where the occupational therapists had completed visits for patients due to the patient having a role as a carer within their home environment. In the example below, the patient had communication problems following his stroke, and he was also the main carer for his wife with dementia. The occupational therapist highlighted that one of the reasons for completing the visit was because:

"...family, friends have raised concerns about how that's going to work. Not only in terms of their own kind of relationship but also the patient's roles and responsibilities. If he can't talk properly how's that going to work?" [OT 3]

However, in some cases, obtaining information about the home environment from family members either in the hospital or on an access (environmental) visit also appeared to help the occupational therapists see how the patient would fit into their home environment on discharge. In some cases, this information enabled them to feel comfortable about not completing a home visit because they could obtain the necessary information from or with the family:

“So because he had an architect son who knew what the environment needed to look like, the wife had certain sort of caring background working with stroke patients... the risks I felt were really low [and a home visit would not be needed] ” [OT15]

“We would definitely have done a home visit with him, but... we checked everything out with just the environmental visit with the family.” [OT 13]

However, this process was also complex and not clear cut. Another occupational therapist gave an example of a patient who lived with her son who had been providing a great deal of support to her prior to her stroke. The patient had almost returned to her previous level of function and the plan was for her to return home with continued support from her son. However, the occupational therapist worried that:

“Will that little bit of difference and slightly worse than, than before be the, the straw that breaks the camel's back, if, if you know what I mean? So she's one that yeah, I, I will be thinking about doing a visit for.” [OT 5]

It appeared that the occupational therapists also made an assessment of the quality of information they had about the home environment, and the sustainability of the existing social support network. There appeared to be a reasoning process relating to the information they were given and whether this was sufficient to not require a home visit:

“And equally, and I don't really know how to put this, but we would only ask family members who we thought were able to do it [obtain details/measurements of the home environment] accurately.” [OT 2]

In the case of occupational therapist 15 whose patient's son was an architect and wife was an experienced stroke carer, this would be sufficient. However, for occupational therapist four who described an anxious wife, and occupational therapist five worried about a son who was already providing a great deal of care, the home visit was felt to be indicated as a tool to address these concerns.

Availability of formal community follow-up services or social care services was also a factor in some examples for the occupational therapists to take the decision not to complete a home visit, if the potential areas of concern could be addressed by the follow-up teams:

“we’ve got a very good community intermediate care team who follow people up very soon after discharge so we, we pass on reports to them and have conversations with them and sometimes they even come and meet the patients before they go, so in those circumstances we probably wouldn’t do a visit” [OT 6]

“...but she will also have a community rehab team follow her up and plus because a tiny little bit of slurred speech will also have SALT follow her up, so she has got that back up at home so that person we will not do a home visit [with]” [OT 13]

Therefore, the availability of family or formal care support could mitigate the concerns of the occupational therapists regarding the patients level of functional impairment and enable them not to complete a home visit for some patients. Conversely, in other

circumstances a home visit was felt to be necessary because of concerns about the carers' ability to manage.

3.3.6. Theme 3: *Influences on Occupational Therapists*

The third theme referred to the other issues that the occupational therapists factored into their decisions about home visits that did not relate directly to the patient or the patient's home environment. These were factors that influenced the occupational therapists' decision as to whether a home visit was needed. In some examples these influences were very strong and could over-ride the occupational therapists' own reasoning as to the factors of the level of independence in activities and the characteristics of the home environment, and persuade them to complete a home visit even though they did not necessarily think it was needed. This theme has been termed 'Influences on Occupational Therapists' and is smaller than the preceding themes. Within the analysis the areas within this theme could be clearly split into two sub themes: 'external influences' and 'internal influences'.

a.) External Influences

Two of the occupational therapists referred to a blanket policy where they would complete home visits with all patients who were going to return home from the unit where they worked. For one occupational therapist [OT 1] it was the policy of the particular unit, that unless the patient had recovered very quickly and returned to pre-morbid function, then a home visit would be completed. If a home visit was not going to take place then a risk assessment was completed to confirm that there were no outstanding issues. Another occupational therapist also completed home visits with all patients who were returning home. It was not clear whether this was the policy of the

particular unit, or her own particular policy as she was the only occupational therapist on the unit where she worked. She was also the only occupational therapist interviewed who was based within a community hospital, and the practice of this unit may be different on the basis of the different structure of this type of setting:

“I mean I will probably do a pre home, discharge home visit with everybody where home is where they’re going to be discharged to or where they want to go and they’ve got capacity” [OT 12]

Some of the occupational therapists also spoke about the influences of other people on the decision to complete a home visit. In these cases, they were clear in their own mind that a home visit was not required, but a third party (either a patient or a relative) was requesting a visit. Alternatively, other staff members had informed patients or relatives that there would be a home visit when the occupational therapists thought that they did not need one. These examples were distinctly different to the examples given above where the occupational therapists themselves were concerned about the carer or relative and had taken these concerns into their reasoning to complete a home visit. These examples below were given as examples of patients whom the occupational therapists would be unsure about completing a home visit with:

“And sometimes you get a patient or relative you know asking for a visit when things seem to be absolutely straightforward, so you know, why are we bothering?” [OT 3]

“And that’s the ones that are the hardest when the family feels a home visit is required... but also we get nursing staff and medical staff telling patients

and families that there will be a home visit prior to us deciding if one's actually needed or not, but then they have this idea in their head that this home visit will have to be done... which then makes it very difficult for us to explain why not when they've already felt that this is part of the process, I think that's the hardest one when I don't think they need one, but other people have told them that they do" [OT 18]

Patient choice was mentioned by one occupational therapist as a factor in the decision to complete a home visit:

"If it seems that there may be some anxiety then we will, just discuss it with them if they do particularly want to visit home" [OT 7]

However, patient choice was not mentioned by the other occupational therapists, as a factor in whether to complete a home visit.

The occupational therapists also highlighted that practical factors may occasionally influence their decisions not to complete a home visit or may contribute to uncertainty as to whether to complete a home visit or not. These reasons included: distance to the patient's home from the hospital, patients being discharged out of area, lack of availability of suitable transport and potential risks to the occupational therapist and accompanying staff.

b.) Internal Influences - 'Gut Feeling'

One occupational therapist spoke about being very clear about some patients who would and wouldn't need a home visit. However, for those she was unclear about she

spoke about this being a 'gut feeling' that a visit was needed, taking into consideration all of the information about a patient's abilities, disabilities and their home environment:

"I mean some patients it's very obvious that you do a visit with and there are ones that it's obvious that you wouldn't but we do get those ones that you're like 'oh I just don't know if I should do a home visit or not'. And it is, although it's not very objective, sometimes it's a gut feeling that you have about someone" [OT 17]

Another occupational therapist also indicated that those whom she was unsure about needing a visit or not probably had something about them which meant that they did actually need one:

"And very few that I struggle whether to do a visit or not, I feel if get to the stage that I'm not sure, that's usually the one I should do a visit with." [OT 7]

In a few cases, it appeared that there was nothing which could particularly be articulated by the occupational therapists about why a home visit was needed, but it was a feeling or instinct that they had about a particular patient.

3.4. Discussion

This section will provide a brief summary discussion of the findings. However, these findings will be discussed in further detail in chapter five of this thesis with the findings from the rest of the study.

3.4.1. Sample

A wide geographical sample of occupational therapists was obtained encompassing both urban and rural localities, as per the aim of the purposive sample. The majority of the occupational therapists were band seven or higher, indicating that they were experienced in their clinical practice. There was a big range in the size of the occupational therapists' caseloads from three to 19, which could be an influential factor in their decision making about home visits. Those with fewer patients on their caseload may have more time with which to spend with their patients and may therefore complete more home visits. It is not possible to determine this from the sample here. Overall, whilst this sample should not be considered to be representative of occupational therapists nationally, it was possible to achieve a sample which covered a geographical spread of the UK.

3.4.2. Level of Physical and Cognitive Impairment

The majority of the characteristics that were identified related to the person (patient) and the principal factor was the person's level of physical and/or cognitive impairment and how this had impacted on their ability to manage activities. This is perhaps unsurprising as providing treatment aimed at increasing independence in activities of daily living, and modifying the home environment to increase independence and reduce risks, are the core skills of the occupational therapist (Hagedorn 2000). However, the issue regarding the *level* of dependency which would warrant completion of a home visit was a complex one.

Overall, the occupational therapists reported that patients who had returned to their pre-stroke level of function would not require a home visit, and the agreement between the occupational therapists was almost unanimous. Those that had not returned to

independence (or near independence) or to their previous level of function were generally felt to require a home visit. However, the main exception to this for some occupational therapists, were patients who had higher levels of physical dependency or cognitive impairment. For these patients a home visit would have to be considered alongside an assessment of whether they would be able to cope with the physical and emotional demands of the visit.

Whilst the general trend within the data appeared to be that physically dependent patients would be the most likely to need a pre-discharge home visit there were clear exceptions to this, such as the example provided by OT 13 whose patient was independently mobile and the occupational therapist wanted to do a home visit 'just to see' how he would manage in home environment. Furthermore, some occupational therapists reported that they could assess everything in the hospital for the most physically dependent patients and therefore there was no need to complete a home visit. This appeared to go against the general trend towards completing home visits with physically dependent patients. With regard to the physical impact on activities of daily living, such as the ability to transfer, level of independence was usually considered in relation to an aspect of the home environment (e.g. to observe the patient transferring on and off their own bed as opposed to a hospital bed). However, some of the occupational therapists also expressed concerns about the ability of highly physically dependent patients to cope with the potential demands of the home visit, and therefore indicated that a home visit may not always be appropriate for these patients.

Furthermore, the level of physical dependency could not be considered in isolation from cognitive and perceptual impairments. A patient's level of cognitive impairment was an important factor for the occupational therapists when deciding whether that patient

needed a home visit or not. There were several factors which contributed to the importance of cognitive impairment: can the patient be adequately assessed in hospital? Will the patient understand the nature and purpose of the home visit? Will it be distressing for the patient to go on the home visit and then have to return to the hospital?

These factors appeared to be combined and considered together in the decision making process. It was reported that patients with cognitive impairment could usually be assessed more appropriately in their home environment. This was felt to offer a more realistic picture of how their impairment would impact on their ability to complete tasks independently. This could be due to either the home being a more familiar environment for the patient; or a less structured (and therefore more challenging and realistic) environment than the hospital. However, again the issue regarding the level of impairment was complex and not clear cut. A higher level of cognitive impairment was a cause for concern for many of the occupational therapists.

The combination of these factors indicates that generally those patients with mild to moderate level of cognitive impairment would be the most appropriate for a pre-discharge home visit. However, this can only be suggested by the data presented here and further research is required to explore this in more detail.

Categorising level of impairment is complex. The occupational therapists spoke in broad terms using words like 'severe' (OT3); 'significant physical or cognitive difficulties' (OT18); 'dense hemiparesis' (OT5) and 'the more impaired patients physically and cognitively' (OT7). Discussing level of impairment was linked to the terms 'independent' and 'dependent' which were used extensively in the examples. However, no formal

process of categorisation was reported and the occupational therapists did not indicate that a particular Barthel Index or Mini-Mental score would indicate that a home visit was necessary; these decisions appeared to be made on the basis of the occupational therapists' own judgements. Further research is required which examines the actual level of independence/dependence of patients who have home visits, in order to investigate whether there are specific levels or scores for patients who are most likely to be considered appropriate by occupational therapists.

Although the occupational therapists referred to patients' demographic details when discussing those patients who would and would not be offered a home visit these factors were not considered to be stand-alone reasons for completing or not completing a home visit but were factors which were considered alongside other information about patients' level of impairment and information about their home environment. There appeared to be no pattern within the data regarding the ages or living situations of patients who would and would not be offered a home visit, which indicates that these factors were not in themselves key influences on the occupational therapists' decisions.

3.4.3. The Person and The Home Environment: A balancing act

The occupational therapists linked the information they had about a patient with the information that they were able to gather about that patient's home environment, including the availability of formal or informal care support within the home environment. They appeared to engage in a process of balancing these two areas of information. For example, a concern about a patient being able to manage a specific functional task could be mitigated by the presence of another family member who was judged to be competent to assist the patient to complete such a task. Alternatively, a concern about the physical characteristics of the home environment could be mitigated by information

from a family member who had knowledge about what the home environment needed to look like.

If the occupational therapist had concerns about an imbalance between the patient's ability to complete daily living tasks independently and the home environment being able to support that ability, then a pre-discharge home visit may be deemed necessary in order to further assess and address this imbalance.

3.4.4. Influences on Occupational Therapists

The factors which were not directly related to the patient or to the patient's home environment had the potential to override all other information about the patient and the patient's home environment. Interestingly, the occupational therapists, in certain circumstances, would complete a home visit despite the fact that they were not concerned about the patient's ability to manage tasks independently or their home environment. Some occupational therapists referred to the influence of third parties such as other ward staff or family members requesting or demanding a home visit which in some circumstances would convince them to complete one, even though they did not feel that it was needed.

This finding is consistent with Hale's (2000) research, which also reported that occupational therapists may complete home visits due to pressure from relatives or professionals. This could perhaps suggest that occupational therapists are not always fully confident of their reasoning as to when a home visit may be indicated, or that they may err on the side of caution when they are faced with pressure from a third party to complete a visit. The lack of evidence to support the effectiveness of home visits and

absence of a clear guideline as to when a home visit should be completed may be a contributory factor to this pressure.

3.4.5. Limitations

There are some limitations of qualitative research methodologies in general, and interview methods in particular. Perhaps the principal criticism of qualitative research is the subjectivity of the analytical process. Rigour in the research process is much more difficult to maintain, demonstrate and assess in qualitative data collection and analysis. In this study, procedures were put into place in order to maintain and demonstrate the rigour. Firstly, interviews were completed by four different researchers, in order to avoid the potential for one interviewer to bias the discussions based on his or her own views on home visits. Secondly, all interviewers read the transcripts and were involved in the initial coding stages. This ensured that the initial codes which were developed were agreed between different researchers and were not purely based upon one individual's interpretations. Finally, following the finalisation of the themes these were discussed with the other members of the HOVIS team who concurred that these themes were an accurate interpretation of the dataset.

The six stages of thematic analysis were adhered to and recorded at every stage of the analysis process. This allowed the researcher to revisit the initial codes, categorisation of codes, and how the themes were developed. This allowed for a process of self reflection and challenge and facilitated a process of checking and rechecking the data to ensure accuracy and rigour.

Specific limitations of this study were that the occupational therapists who were interviewed were all recruited via the College of Occupational Therapists Specialist

Section for Neurological Practice and may therefore represent a group of particularly specialised and knowledgeable therapists, by virtue of their membership of this specialist group. The occupational therapists all volunteered to be interviewed and this may also indicate that they were particularly keen to discuss the topic of pre-discharge home visits or that they may have had particularly strong views on the topic.

These findings are based on the views and opinions expressed by 20 occupational therapists, and although the core themes emerged from the data there were examples of exceptions to these main themes and these have been highlighted. These findings are exploratory research and are not intended to be representative of national home visiting practice.

The findings from this chapter will be triangulated in the next chapter by comparing them with the actual observations which were recorded during the Home Visit after Stroke study at the trial site. This will further enhance the reliability of the results.

3.5. Conclusion

The findings from the interviews with the senior occupational therapists demonstrate that a patient's level of independence in functional activity is a key factor in the decision to complete a home visit with a particular patient. However, this issue alone is not indicative of whether a pre-discharge home visit is believed to be necessary and is inextricably linked to the information the occupational therapists have about the patients' home environment. The occupational therapists appear to balance these factors in order to determine whether a home visit is indicated. Exceptions to this rule

may occur when external or internal influences override occupational therapists' own clinical judgement.

The presence and the extent of a cognitive impairment was also a key factor in the occupational therapists' decision to complete a home visit. Whilst a moderate cognitive impairment may indicate that a visit is needed, a more severe impairment caused concern for a number of the occupational therapists as to whether the patient would be able to cope with the demands of the visit. This is a key finding from this qualitative research study, as cognitive impairment has previously received scant attention in the literature on occupational therapy home visits.

Chapter Four

The HOVIS Study - What were the Characteristics of the Patients in the Home Visit Essential Cohort?

4.1. Introduction

The previous chapter presented the findings from interviews with senior occupational therapists which explored the types of patients with a stroke with whom they would complete home visits. A common criticism of interview research is that it provides only an interpretation of participants' own accounts of their behaviours and experiences, and that these accounts may differ from actual observed behaviours and actions (Silverman 2010). Thus, relying solely on occupational therapists' descriptions of what they say they do would only provide a description of their reasons for completing home visits with certain patients and not with others. As such, interviews alone would provide limited data to answer the research question. Therefore the objective of the second part of the research, presented in this chapter, was to observe decisions about home visits that were made in clinical practice, and compare the characteristics of those patients whom occupational therapists believed to need a home visit, with those whom the occupational therapists were uncertain about. This information was gathered in the context of the HOVIS feasibility randomised controlled trial to identify the characteristics of patients who were deemed to be 'home visit essential' and the reasons the occupational therapists gave for these decisions.

As part of their involvement in the HOVIS feasibility randomised controlled trial, the occupational therapists working on the stroke rehabilitation unit were asked to consider the rationale for the need for a home visit for every patient and whether they felt a home visit was essential or whether there was genuine clinical uncertainty as to whether a visit was indicated or not. The reasons given by the occupational therapists when a pre-discharge home visit was deemed to be 'essential' were systematically recorded by the HOVIS research team. This meant that data on these decisions could be collected by

the research team in a systematic manner. The HOVIS study had two distinct groups of patients: those in the 'home visit essential' cohort study (whom the occupational therapists would not randomise because they believed they 'essentially' needed a visit), and those in the randomised controlled trial for whom there was clinical uncertainty regarding the need for a home visit. Thus, these groups provide the opportunity for a detailed comparison of the characteristics of patients with a stroke whom occupational therapists believe to need a home visit, with those who are not believed to need one.

This chapter will provide background to the HOVIS methodology and outline the method of data collection. The results will be presented in two parts: the first part detailing the reasons given by the occupational therapists and the second part comparing the patient characteristics between the two groups.

4.1.1. Background to HOVIS Methodology: The Control Issue

Randomised controlled trials (RCTs) are consistently rated as the highest level of research evidence, behind a systematic review of a number of randomised controlled trials (Guyatt et al 2000; Concato et al 2001). Thus, randomised controlled trials are considered to be the most effective way to demonstrate the effectiveness of a healthcare intervention, and are often cited as the 'gold standard' of evidence based healthcare (Kaptchuck 2001). Randomised controlled trials are considered to be the gold standard because patients are randomly allocated to the treatment and control groups and the treating clinicians do not have control over which group their patients are allocated to. This limits the possibility for selection bias which is caused by certain patients being actively selected for a healthcare treatment if healthcare professionals think that they will gain from it.

Although randomised controlled trials may be considered to be the 'gold standard' of research evidence, it may not always be feasible for researchers to conduct such a trial. There may be ethical or methodological issues which preclude the implementation of an RCT design. This may be the case particularly for treatments which are established and perceived to be routinely available and therefore cannot be withdrawn. However, there are alternative research methodologies that can be used when investigating outcomes of particular treatments or therapies. A cohort study involves a 'cohort' of people being followed for a set period. In some studies two groups may be compared: one of whom has had the variable of interest and the other group who did not (Mann 2003; Siriwardena 2007). This is a less robust than an RCT method as participants are not randomly allocated to the treatment group. However, cohort studies still enable a particular group of people to be followed up following exposure to a particular treatment.

When investigating outcomes for home visits, cohort studies have been conducted in which patients were followed-up post-discharge to record outcomes. The study conducted in Australia by Johnston et al (2010) which examined the relationship between pre-discharge home visits and falls, reported that participants who had a home visit were less likely to have a fall after discharge than those who did not have a visit. However, the findings from studies in which patients were not randomly allocated to the treatment or control group have limited applicability as the results are potentially biased because the occupational therapists actively selected participants to receive the intervention. Thus, the results may reflect the characteristics of the patients who were selected for the intervention by the therapists, rather than the effectiveness of the intervention itself.

Whilst the findings from cohort studies may have relevance, there continues to be a need for randomised controlled trials to investigate patient outcomes following pre-discharge occupational therapy home visits in order to demonstrate their clinical effectiveness. The literature review in chapter two identified several papers which advocated the need for 'urgent' randomised controlled trials and highlighted the paucity of this level of research evidence for this intervention (Patterson et al 2001; Welch and Lowes 2005; Lannin et al 2011).

One possible reason for the lack of robust research evidence for pre-discharge occupational therapy home visits is that it may be considered unethical to withhold what is perceived to be a routine treatment (Patterson and Mulley, 1999; Welch and Lowes 2005). Home visits are an established component of occupational therapy practice and in order to form the control group needed to conduct a randomised controlled trial, some patients must necessarily not receive a home visit. This has potential implications in terms of obtaining the necessary ethical approvals to conduct the research. National Research Ethics Committees (that have the responsibility of protecting the wellbeing of research participants) may consider it not to be in the best interests of patients to withhold a particular treatment or intervention. Patients and their relatives may also be unhappy with the design of a research study which denies them access to a treatment which is perceived to be routinely available. Furthermore, pre-discharge home visits are often completed by occupational therapists because of concerns about patient safety (Welch and Lowes, 2005), and the occupational therapists themselves may have concerns about certain patients being randomised to the control group and therefore not receiving a home visit.

In the feasibility RCT of pre-discharge home visits conducted by Lannin et al (2007) in Australia, only ten participants were recruited to the study. This was despite Lannin and her colleagues reporting that many more potentially eligible participants were available within the hospital at the time of the research. The study did not have a designated recruiter, and the researchers relied on the ward based clinicians to identify and alert them to those patients who were potentially eligible for the study. This is perhaps indicative of the concerns highlighted above, that clinicians involved in the Australian trial were reluctant to enter patients into a trial where they could be randomised to the control group. Indeed, Lannin et al believed that the therapists on the wards did not enter their patients into the study if they were worried about the possibility that they may be randomised to the control group (and therefore would not receive a home visit).

4.1.2. Zelen's Design

An alternative design for randomised controlled trials which aim to test established, routine or new and novel healthcare interventions was proposed by Zelen (1979, 1990). This method involves potential participants being randomised to either the treatment or control group *before* they are approached for consent to take part in the study. There are then two possible variations on the method (Torgerson and Roland, 1998). The first involves only the participants in the experimental treatment group being asked for consent after randomisation. This method is mainly used for population based interventions and only the participants in the intervention group are aware that an alternative is available. The second variation involves participants in both groups being asked for consent after randomisation. If patients are not happy with their group allocation they may cross-over to the alternative group.

Zelen's randomisation method was considered in the design of the HOVIS study. However, the first variation was not appropriate for the study. This approach requires that participants in the control group are followed-up 'remotely' and researchers would not be able to collect follow-up information directly from the participants.

The second variation was a possible method for the HOVIS study. Patients who were randomised to the control group could have been moved to the intervention group prior to being approached by the research team if the clinicians involved in their direct care were concerned about them not receiving a home visit. However, Zelen's design is not recommended for studies with a high expected crossover rate, as this may lead to a reduction in the power of the study (Torgerson and Roland, 1998). It was anticipated that there could potentially be a high crossover rate from the control group to the treatment group – if the clinicians were concerned about patients' safety. This has the potential to introduce bias into the study as the two groups may end up being very unequal at the end point – i.e. many more patients have been removed from the control group and been given the home visit intervention. Potentially, this could have led to a larger preponderance of patients in the control group whom the occupational therapists considered to be 'minimal risk' when compared to the intervention group. This would have the potential to bias the outcomes of the study.

4.1.3. The HOVIS Alternative: The Home Visit Essential Cohort

The HOVIS research team wanted to investigate whether it was feasible to conduct a randomised controlled trial. However, it was recognised that a conventional randomisation design in which all patients were randomly allocated to home visit (intervention) or control would be unlikely to work. This was due to the issues identified in the literature regarding the ethical difficulties in allocating people to a control group,

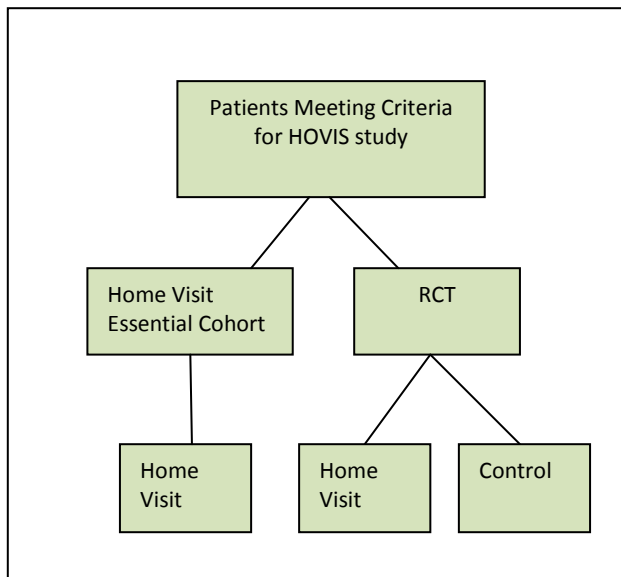
and based on personal communications from the researchers involved in the Lannin et al. (2007) study regarding the potential recruitment difficulties that they encountered. Therefore an alternative methodology was developed which involved the inclusion of a parallel cohort study. The cohort study was established in addition to the RCT and the two randomised groups (home visit group or hospital interview group) to incorporate those patients whom the ward based clinicians would be unwilling to randomise.

The purpose of the home visit essential cohort was threefold. Firstly, it aimed to address the safety concerns of clinicians about randomising certain patients to the control group (no home visit) in that certain patients could be deemed to need a home visit. Secondly, it was intended to increase the overall acceptability of the research to the clinicians working on the ward, in that they could specify when a home visit was indicated for certain patients and that these patients could still be included in the research (i.e. giving the clinicians control over their patients). Thirdly, it enabled the research team to collect data on those patients whom the ward based occupational therapists believed 'essentially' needed a home visit, whom would otherwise be 'lost' to the research if they could not be randomised. Thus, the objective of including the cohort study was to establish whether the researchers could recruit successfully to the RCT whilst concurrently balancing the potential concerns of the clinical therapists (Drummond et al, 2012b).

The occupational therapists working on the stroke rehabilitation unit, in collaboration with the multidisciplinary team, were given the responsibility for deciding whether a home visit was clinically indicated or 'essential' for each individual patient and therefore whether that patient was eligible for recruitment to the cohort study. If there was clinical uncertainty as to whether a home visit was indicated or not then the patient would be

eligible for the RCT and for randomisation to the home visit group or the control (hospital interview) group. Figure 4 shows the two parts of the study and the three possible treatment groups. The home visit intervention was the same for participants in both the RCT home visit group and the home visit essential cohort.

Figure 4: The HOVIS Study



4.1.4. Development of the Home Visit Essential Criteria

In order to ensure that the patients were allocated to the two study groups in a systematic manner, the HOVIS team developed criteria for the home visit essential cohort. The criteria were developed in order to balance the clinical concerns of the therapists with research rigour.

In order to develop the criteria for the home visit essential cohort, preliminary work was undertaken with the clinical staff in the stroke rehabilitation unit to discuss the issues and concerns that they may have around including patients in a randomised controlled trial who then may not receive a home visit. Criteria were then established for the 'home visit essential' cohort that would cover the issues relating to those patients who needed

a home visit before discharge, according to the occupational therapists who were working with them. The intention was that the occupational therapist, in collaboration with the multidisciplinary team, would determine whether the patient should have a home visit according to the agreed criteria. All participants who did not meet the home visit essential criteria were eligible for entry into the randomised controlled trial and for randomisation to either receive a home visit or no home visit (hospital interview).

The home visit essential criteria were:

Patients which staff believe cannot be assessed without a visit, for example;

Not independent transferring e.g. from bed to chair, from wheelchair to another chair

Suitability of environment for safe use of new equipment such as walking aids, hoist and wheelchair access.

The criteria were an important part of the research design in order to try to standardise the reasons for entering patients into the cohort, and to implement a process that was both methodical and replicable in order to enhance the rigour of the research design. However, the research team also recognised that there needed to be some degree of flexibility within this to enable clinical judgement of the occupational therapists on the stroke rehabilitation unit. As part of a feasibility trial, the developmental aspect of the criteria was an important part of the research. It was accepted that individual patient circumstances may vary and that the home visit essential criteria would develop as the trial progressed and researchers gained a better understanding of occupational therapists' concerns about potentially not completing a home visit with certain patients.

4.1.5. Ethical and Research Governance Approvals

Favourable ethical approval for the HOVIS study was provided by Berkshire Research Ethics Committee (Ref: 10/H0505/41). Research governance approval was issued by Derby Hospitals NHS Foundation Trust.

4.2. The HOVIS Study Method and Recruitment Procedure

This section will describe the method used in the HOVIS study and describe how patients were allocated to the cohort or the RCT and the recruitment procedure. This section will begin with some background detail to the research site. It will then describe the inclusion and exclusion criteria and the procedure for allocation to the cohort study or the RCT. It will then describe the procedure for obtaining informed consent before describing the information collected from participants at baseline.

4.2.1. HOVIS Trial Site

The HOVIS feasibility study was conducted at the Stroke Rehabilitation Unit (SRU) at The Royal Derby Hospital, part of Derby Hospitals NHS Foundation Trust. The Royal Derby Hospital is the only acute hospital for the trust and serves a population of around 600,000 people. The hospital covers the Derby city area, the southern Derbyshire area (Derby Hospitals NHS Foundation Trust 2012), both urban and rural population centres. The Stroke Rehabilitation Unit is a 21-bedded unit providing in-patient stroke rehabilitation from a multidisciplinary team of nurses, therapists (occupational therapists, physiotherapists, and speech and language therapists), psychologists and rehabilitation consultants. The patients remain under the care of a stroke medicine or rehabilitation consultant whilst they are on the unit. The unit had an occupational

therapy staff of 3 full-time occupational therapists, 1 part-time occupational therapist and 2 part time occupational therapy assistants (although this varied throughout the period in which HOVIS was recruiting).

4.2.2. Inclusion and Exclusion Criteria

All patients who were admitted to the Stroke Rehabilitation Unit (SRU) at the trial site were screened for inclusion in the study. The inclusion criteria were:

- Patient has had a stroke
- Patient has been transferred to the stroke rehabilitation unit

Patients who were discharged directly from the Acute Stroke Unit (ASU) were not considered for inclusion into the study. Patients who were discharged directly from ASU would be considered to have returned to their previous level of functioning prior to discharge, or to have only very minimal residual functional impairments. These patients would be unlikely to be considered for a home visit by an occupational therapist prior to discharge.

For patients transferred to SRU additional exclusion criteria were:

- Patient on an end of life care pathway
- Patient being discharged outside Derbyshire
- Patient does not speak English
- Patient has had an access visit only (and is not deemed to need a subsequent home visit)

Patients on an end of life care pathway were excluded as they could be expected to experience a rapid deterioration in their functional abilities during the follow-up period, due to their medical condition, which could be a confounding factor in the analysis. Patients who were discharged outside of the Derbyshire area and patients who did not speak English were excluded for practical and financial reasons – it would not be possible to follow these participants up within the budget of the HOVIS study. As this was a feasibility study, it was acceptable to exclude these patients.

Patients who had an access visit were also excluded. Access visits are sometimes completed by occupational therapists prior to or instead of a pre-discharge home visit. An access visit is a visit by the therapist to the patient's planned address on discharge, *without* the patient. The purpose of an access visit is to assess the accessibility of the property for the patient to gain entry to the property or to assess the provision of internal space within the property (e.g. to accommodate equipment or turning space for a wheelchair). If an access visit has been completed then the therapist has already seen the patient's home environment and will have a detailed visual knowledge of it. This could also be a confounding factor in the analysis: as the therapist will have the detailed imagery of the patient's home environment this may impact upon therapy goals and discharge planning. Therefore, if the occupational therapist decided that an access visit would have been completed as part of a patient's routine care, then these patients were excluded from the study unless the therapist then decided that the patient met the criteria for the home visit essential cohort. If a home visit was also required, the patients were approached to be consented as part of the home visit essential cohort.

4.2.3. Allocation to ‘Home Visit Essential’ Cohort or Randomised Controlled Trial

All patients who met the inclusion criteria were then considered eligible for the study. During the patient’s first ten working days on the stroke rehabilitation unit a member of the HOVIS research team approached the patient’s named occupational therapist (sometimes in conjunction with members of the multidisciplinary team), to decide whether or not the patient met the criteria for the ‘home visit essential’ cohort. If not, and there was no clear indication as to whether a home visit should be provided (i.e. clinical equipoise) then the patient was deemed eligible for the RCT (randomisation). The HOVIS research team maintained a *Trial Screening and Recruitment Log* to monitor every patient who was admitted to the unit and to manage the timescales for the decisions by the clinicians. A blank example copy of the log can be found in Appendix B. The researchers recorded all new admissions and the ‘decision due’ date which was ten working days post-admission to SRU. The researchers then either approached the patient’s occupational therapist directly to obtain the decision, or the HOVIS research occupational therapist obtained this decision by attending the weekly multidisciplinary team meetings held on the ward. Researchers maintained a written log of the reasons which the clinicians gave for allocating individual patients to the home visit essential cohort.

4.2.4. Home Visit Essential Form

When the SRU occupational therapists deemed that a patient was eligible for the home visit essential cohort, the researchers recorded the reasons which they gave on the home visit essential form. This form was a free text form and the HOVIS researchers wrote down the exact explanation which the occupational therapists gave. The

occupational therapists could provide a number of reasons for their decision, if they felt that more than one factor had been important in the decision. These forms were retained by the research team for those patients in the home visit essential cohort who consented to take part in the study. A blank copy of the home visit essential form can be found in Appendix C.

4.2.5. Consent Procedure

Following the communication from the clinicians as to whether patients met the criteria for the home visit essential cohort or were eligible for the RCT, patients were approached by a member of the research team who introduced the research and provided an information pack according to their allocation to the cohort or RCT (see Appendix D and Appendix E). The patients were then given between 24 and 48 hours to consider whether they wished to take part in the study. They were then approached again to provide informed consent and sign the consent form (see Appendix F). Participants who were unable to sign the consent form, due to the stroke having affected their dominant hand, were asked to mark the consent form in the presence of an independent witness who was not involved in the trial.

4.2.6. Mental Capacity

Patients who lacked the mental capacity to consent to the study were considered eligible to participate. These patients are commonly excluded from rehabilitation research studies due to the difficulties in involving them in a rehabilitative intervention. However, it was considered to be important to include them in the HOVIS study as these patients may still be offered a pre-discharge home visit if the clinicians considered it an appropriate part of their stroke care pathway.

In the case of patients who lacked mental capacity to consent, the research team sought to identify a consultee. The procedure for identifying a consultee was in accordance with the Mental Capacity Act (2005) guidance (Department of Health 2008). The first option for seeking consultee was the patient's next of kin. If the patient did not have a next of kin, then the patient's hospital consultant would be asked to be the consultee. The consultees were given a consultee information pack, appropriate to either the 'home visit essential cohort' or 'RCT'. In line with the Mental Capacity Act (2005) the consultees were asked to offer their opinion as to whether the patient would have wanted to participate in the study if they were able to make the decision for themselves.

4.2.7. Inclusion of Care Home Participants

Prior to the commencement of recruitment to the HOVIS study, the occupational therapists at the site were completing some pre-discharge visits for patients who were being discharged to residential or nursing care homes. The purpose of completing these visits was to educate or train the care home staff; or to complete a handover of the patient's care plan and recommended moving and handling and transfer techniques, specifically if there were concerns about appropriate patient handling or positioning. As this was a routine practice for some patients, prior to the commencement of the trial, these patients were also included in the feasibility study. Therefore, the same procedure was applied regarding allocation to the home visit essential cohort and RCT: the occupational therapists were asked for a decision within ten working days of admission to SRU.

4.2.8. Demographic and Baseline Information

The demographic characteristics were collected from the participant's medical notes after consent had been obtained. Demographic information covered the participant's: age, sex, marital status, household composition and whether he or she had been receiving formal care services prior to admission to hospital. Medical information covered: type of stroke, whether the stroke was ischemic or haemorrhagic, Oxford Stroke Classification (Bamford et al 1991), past medical history including previous stroke, and whether the participant had aphasia. Researchers also recorded whether the participant had been provided consent or whether a consultee opinion had been sought.

Baseline assessment measures recorded levels of disability, dependency in personal activities of daily living (ADL), cognitive impairment, mood and quality of life. Disability was measured using the Modified Rankin Scale (van Swieten et al 1988). Dependency in ADL was measured using the Barthel Index (Collin et al 1988) to assess their pre-stroke and baseline abilities. Cognitive impairment was measured using the Addenbrookes Cognitive Examination (ACE-R) (Mioshi et al 2006). The ACE-R measures participants' level of cognitive function in five domains: attention and orientation, memory, fluency, language, and visuospatial ability, and provides a total score out of 100. Mood was measured using the General Health Questionnaire (12 question version) (Goldberg and Williams 1988).

4.3. Aim

The aim of the HOVIS study was to determine whether it was feasible to conduct a randomised controlled trial of pre-discharge occupational therapy home visits for

patients with a stroke. The addition of the home visit essential cohort was a component of the design which was intended to increase the overall acceptability of the feasibility study. The aim of this study was to analyse the characteristics of those patients in the home visit essential cohort and compare these to those in the RCT. It will also analyse the reasons given by the occupational therapists when allocating patients to the home visit essential cohort.

4.3.1. Proposed Analysis

The data used was collected from the occupational therapists and patients involved in the HOVIS study at the Stroke Rehabilitation Unit at Derby. These data were collected from the occupational therapists at the time they allocated the patients to the home visit essential cohort. It was collected from the patients at the baseline (recruitment) time point. The baseline time point was relevant because this is the stage at which the occupational therapists decided that the home visit was essential for this group of patients. Analysis of the characteristics of the patients at this point could reveal how their characteristics compared to those who were not deemed to be 'home visit essential'.

4.3.2. Analysis of the Home Visit Essential Form

The reasons given by the occupational therapists when allocating patients to the home visit essential cohort were recorded on the home visit essential form (Appendix C). The occupational therapists sometimes provided a detailed narrative explanation of the reasons which was recorded in writing by the researchers; other times the occupational therapists provided a list of reasons which was written in list form by the researchers.

These data were analysed by providing a code for each individual reason given. Reasons which were similar but described differently were grouped together into one category. The categories of reasons were then counted to quantify those which were the most frequently given by the occupational therapists, and reasons were ranked in order of most to least frequent. The numbers of reasons given by the occupational therapists for each individual patient were also counted. A mean was then computed.

4.3.3. Demographic, Medical and Baseline Data

Data were entered into a database on SPSS (version 16) by one researcher and double checked by a second researcher. The analysis of the patient data involved conducting a comparison of the data collected from the patients in the home visit essential cohort with those in the RCT. This analysis used descriptive statistical analysis to compare the two. For categorical variables (e.g. age, household composition, stroke classification) frequencies were reported alongside percentages of the patients in each part of the study. These percentages showed the relative proportion of patients in each group. In order to identify whether any differences were more than could reasonably be expected in the sample a chi-squared test was performed for these variables (Broughton-Pipkin 1984).

For the analysis of variables in which continuous data were collected (e.g. age, and scores of baseline assessments) the distribution of the data was checked to ascertain whether the distribution was normal (Castle and North 1995). Where these measures were normally distributed, then the mean and standard deviations were reported. Parametric tests were used with t tests conducted to compare the means of those in the home visit essential cohort and those in the RCT. An independent samples t test was used to compare the mean of the two groups. For baseline assessment measures

which were not normally distributed, the median and inter-quartile ranges were reported. Non-parametric tests were used to calculate and compare the mean ranks of the data (Broughton-Pipkin 1984). A Mann-Whitney U was used to compare the mean rank of the home visit essential cohort and RCT (unpaired data).

4.3.4. Care Home Participants

It was recognised that the inclusion of the participants being discharged to residential and nursing care homes could be a confounding factor in the analysis for this study. The findings from the interviews with the occupational therapists, presented in chapter three, indicated that the decision to complete a home visit is influenced by factors relating to the home environment. A care home may be considered to have extensive support available and be an environment which is modified and designed to accommodate for disability needs. Thus, the occupational therapists may be less concerned about patients being discharged to care homes and less likely to consider a home visit to be essential. Therefore the intention is to analyse the results including those being discharged to care homes in order to present the findings for the full HOVIS sample, but also to analyse the results without them in order to identify whether they present a confounding factor in the analysis.

4.3.5. Missing Data

Demographic and medical information which was missing is reported as missing in the results section. For baseline measures where less than 10% of the total individual items was missing, mean values were imputed for individual missing items. Where more than 10% of individual items were missing then the entire measure was coded as missing.

4.4. Results

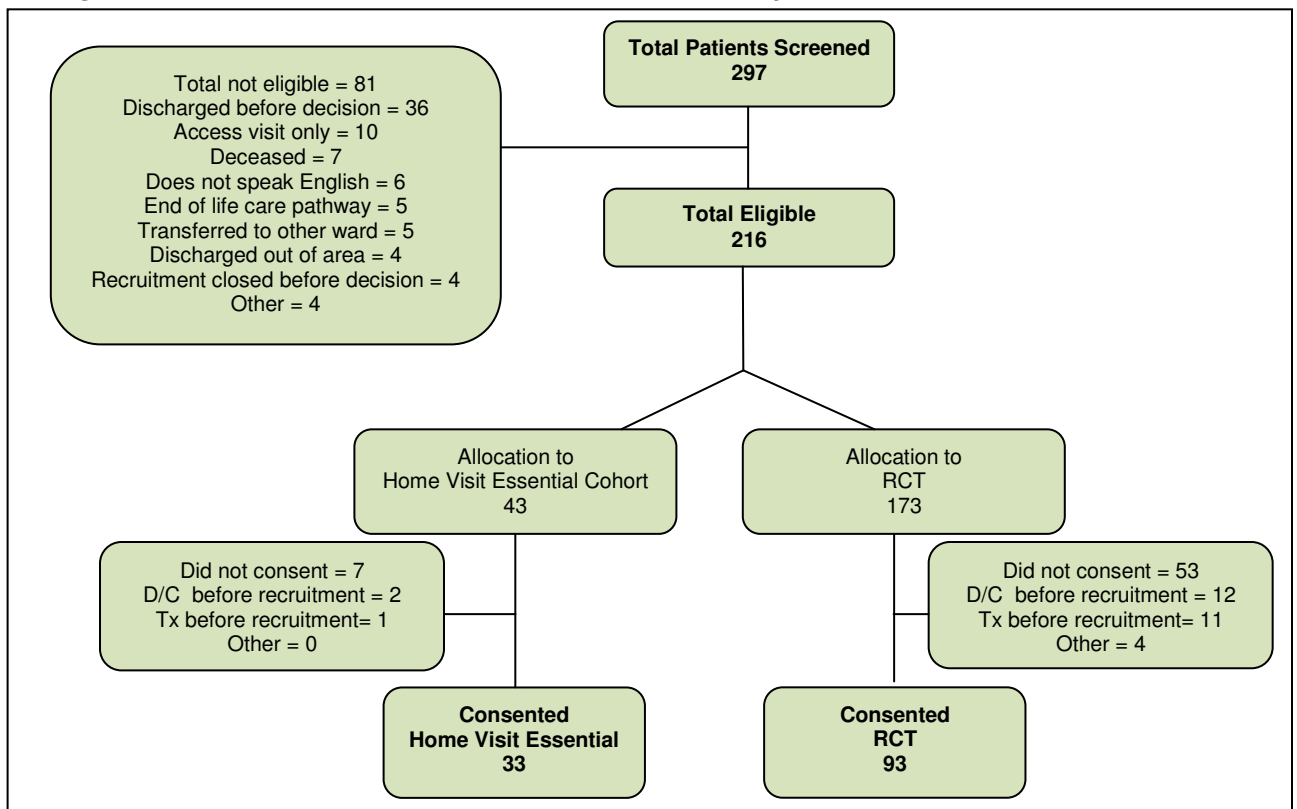
The results from the analysis of the data collected from the occupational therapists and patients at the HOVIS study site will now be presented. The first section of the results will provide a summary of the patients who were screened and recruited to the study. This will be followed by the findings of the analysis of the home visit essential allocation forms completed by the clinical occupational therapists. The final section will then present the results of the comparison between the characteristics of the patients in the home visit essential cohort and the RCT.

4.4.1. HOVIS Participants

The HOVIS feasibility study opened for recruitment on 12th July 2010 and closed to recruitment on 31st October 2011. During this time period, two hundred and ninety-seven patients were admitted to the stroke rehabilitation unit and were all screened for eligibility for the study. Eighty-one of these patients did not meet the eligibility criteria, and were thus excluded. The main reason which patients were excluded was that they were discharged or transferred to other wards or hospitals prior to a decision about their allocation to the home visit essential cohort or RCT (n= 41). Other reasons included the exclusion categories: requiring an access visit (n= 10), not speaking English (n= 6) and being on an end of life care pathway (n= 5). Four were excluded for other reasons: diagnosis of stroke was unconfirmed, second admission, planning not to return to own home, and one was missed. A total of 216 patients met the criteria for the study. Figure 5 shows the recruitment process, and the allocation by the ward based occupational therapists to the home visit essential cohort or the RCT. The ward based therapists allocated 173 patients (80%) to the RCT, and ninety-three were recruited. Forty-three patients (20%) were allocated to the home visit essential cohort, and 33 were recruited. Thus, a total of 126 patients were recruited to the study.

It was not always possible for the clinicians to decide within ten days of admission to the stroke rehabilitation unit, whether the patients would be eligible for the cohort or the RCT. Some patients required a period of further assessment before a decision regarding a home visit could be made. In other cases, it was not clear within ten days whether the patient would be returning home or into a care home and this had an impact on whether the clinicians viewed a home visit as 'essential' or not. In these cases, the researchers obtained the decision as soon as the clinicians were able to reach one, and recorded the number of days from admission to SRU to decision. The mean time between admission to SRU and the decision as to whether the patient was eligible for the home visit essential cohort or RCT was 15.00 days (SD 9.92), with a range of 0 to 54 days. This indicates that the occupational therapists generally took longer than the intended time, and in some cases took much longer.

Figure 5: Recruitment of Patients to the HOVIS Study



4.4.2. Occupational Therapists' Reasons for Allocating Patients to the Home Visit Essential Cohort

This section will present the analysis of the home visit essential forms which were completed with the occupational therapists working on the stroke rehabilitation unit at the time they made a decision to allocate a patient to the home visit essential cohort. The analysis of these forms was completed as described in the analysis section of this chapter.

Forms were completed for 24 (73%) of the home visit essential participants. It is not known why forms were not completed for the other nine participants in the cohort. It may have been that the researchers were unable to gain sufficient time with the occupational therapists at the point that the allocation decision was made to record this information. Table 3 shows the reason codes and their frequency of occurrence. Some reasons were similar but were not coded in the same category as they were considered to have different implications. For example, lack of insight could have been combined with 'cognitive impairment', however this was considered to have presented a more specific risk issue. Mobility has been separated into 'reduced mobility' and 'independent mobility' as both may present different risk factors when combined with other issues. Reduced mobility is also implied by several other reasons (e.g. wheelchair user, requiring ground floor existence, stairs issue, and hoist transfer) however these were all coded separately as they were deemed to have specific meanings and implications in respect of the home environment, rather than simply indicating the need for a home visit on the basis of the mobility impairment alone.

Table 4 shows a summary of the reasons given by the occupational therapist for each individual participant who was allocated to the cohort. There were a wide range of reasons reported and these have been combined and cross-referenced to the 35 different reason groups presented in Table 3. For each participant, each reason was counted once (i.e. if the occupational therapist referred to the same issue twice in their explanation, this was only counted as one reason). In Table 4 the summary of reasons is shown along with the total number of reasons per participant. The reason codes are shown in superscript font in the text and can be cross referenced to Table 3. These have been included to demonstrate the extent of the coding process which was undertaken.

In Table 3 the total number of reasons given was 100, with an average number of reasons per participant of 4, with a range of 1 to 8 reasons. The average and range of the number of reasons indicates that the factors which contributed to the occupational therapists' decisions to allocate patients to the home visit essential group were generally not straightforward and that there was more than one issue which contributed to this decision. However, there were some explanations that appeared fairly straightforward. For example, in Table 4 patient number HV003 was reported to have decreased memory post-stroke and lived alone. No other details were given, and it appeared that these two factors together indicated a clear need for a home visit. Similarly, patient number HV015 had decreased mobility and was using a powered indoor wheelchair post stroke, these two factors also appeared to make the reasoning clear cut for the occupational therapist.

Table 3 shows the frequency that each of the 35 different reasons was reported by the occupational therapists. The most frequently noted reasons were: living alone (n= 7),

environmental issue (n=7), cognitive impairment (n=6), lack of insight into condition/needs (n=6), a concern about the carer (n=6), and a risk or safety issue being identified (n=6). Although lack of insight and cognitive impairment were coded separately, it could be argued that in this context they could be considered to amount to the same thing. Similarly, environmental issues were coded generically, although more specific environmental issues were coded separately (e.g. stairs and access). Thus, totalling environmental issues and cognitive impairments together, the three most common reasons were: environmental issues, cognitive impairment and living alone.

Table 3 : Reasons Reported by Occupational Therapists for Home Visit Essential Decisions		
Code	Reason	Frequency
1.	Environmental Issue	7
2.	Lives Alone	7
3.	Cognitive Impairment	6
4.	Lack of Insight	6
5.	Concern about Carer	6
6.	Risk/Safety Issue	6
7.	Language/Communication Issue	5
8.	Reduced Mobility	4
9.	Previous Medical Issue	4
10.	Lives with Others	4
11.	Information about pre-admission situation	4
12.	Concern re Patient being Alone in Day	3
13.	Stairs Issue	3
14.	Not Compliant with Advice	3
15.	High Falls Risk	3
16.	Level of Impairment/Functional Needs	3
17.	Wheelchair User	2
18.	Dyspraxia	2
19.	Visit will be used to educate patient/carers at home	2
20.	Requires ground floor existence	2
21.	Positioning/Seating	2
22.	Independently Mobile	2
23.	Psychological/Anxiety	2
24.	Hoist Transfer	1
25.	ADL Support	1
26.	Family Influence	1
27.	Young	1
28.	Patient choice	1
29.	Concern re reliability of information from patient	1
30.	Reduced Confidence	1
31.	Visual Impairment	1
32.	Visit will be used to set up home environment	1
33.	Patient needs to see things happen in context	1
34.	Patient is Bariatric	1
35.	Specialist Equipment needed	1
Total Number of Reasons		100

Participant	Summary of Reasons for Decision	Number of reasons
HV001	Decreased function ¹⁶ . Using REA assist wheelchair ¹⁷ and hoist transfer ²⁴ . Requires support with ADLs ²⁵ and has dysphasia ⁷ . Environmental issue re property ¹ .	6
HV002	Son influenced decision. OT did not feel visit essential but son was not happy with this ²⁶ . Patient's mobility did deteriorate further after decision ⁸ and may have therefore been deemed to need a home visit.	2
HV003	Decreased memory post-stroke ³ . Lives alone ² .	2
HV004	Cognitive issues ³ , speech and language problems ⁷ . Main reason: to complete stair assessment ¹³ at home due to reported bend ¹ and patient having dyspraxia ¹⁸ .	5
HV005	Communication difficulties ⁷ . Lives alone ² .	2
HV006	Lives alone ² . Patient has cognitive problems ³ and poor insight ⁴ . Stairs – unclear if patient will get to this stage but will need physical aspect to be assessed at home ¹³ .	4
HV007	Limited insight into condition ⁴ . High level needs ¹⁶ due to bilateral strokes (residual weakness from previous) ⁹ . Husband is the main carer and has dementia ⁵ .	4
HV008	No reasons recorded	N/A
HV009	No reasons recorded.	N/A
HV010	Lack of insight ⁴ . Visit will be used to assess and educate patient re potential difficulties at home ¹⁹ . Environmental issues re property ¹ .	3
HV011	Refusing services ¹⁴ . Requires downstairs existence ²⁰ (refusing) ¹⁴ . High risk of falls ¹⁵ due to reduced gait ⁸ . Lack of insight ⁴ . Wife has dementia ⁵ .	6
HV012	Lives alone ² . Cognitive issues identified post-stroke ³ and patient had previous memory problems prior to admission ¹¹ . Assessment required due to risks ⁶ .	4
HV013	New property ¹ . Young ²⁷ . Re-emphasise correct position ²¹ . Safety concern as patient attempting to get up and is unsafe ⁶ . Cognitive issues ³ .	5

HV014	No reasons recorded.	N/A
HV015	Decreased mobility post-stroke ⁸ . Patient currently using an EPIC wheelchair ¹⁷ .	2
HV016	Patient chose to have a home visit ²⁸ . Patient requires stair assessment ¹³ .	2
HV017	Lives alone ² . High risk of falls ¹⁵ , previous fracture due to fall ⁹ . Mobile with assistance of 2 people and walking frame (change from previous) ⁸ . Previously had a care package ¹¹ . Environmental issue (unkempt) ¹ . Concern re reliability of information provided by patient ²⁹ . Concern re patient managing between care calls ¹² .	8
HV018	No reasons recorded.	N/A
HV019	No reasons recorded.	N/A
HV020	No reasons recorded.	N/A
HV021	No reasons recorded.	N/A
HV022	Access issue identified ¹ . Need for home visit with patient (in addition to access visit) changed over time.	1
HV023	Carer issue ⁵ . Complexity of needs/level of impairment ¹⁶ . Right-sided pushing ⁶ . Patient has problems with 'sitting out' ²¹ . Aphasia ⁷ .	5
HV024	Lives alone ² . Drop in blood pressure during tasks ⁶ . Reduced confidence ³⁰ . Issue regarding access ¹ . No previous input and struggled at home ¹¹ . Mobile with walking frame ²² . Anxiety problems ²³ . Visual impairment ³¹ .	8
HV025	New need for downstairs living ²⁰ – which patient and wife are resistant to ¹⁴ . Concern re transfer on/off stairlift ⁶ which family are installing against advice. Wife is stressed and low in mood ⁵ . Risk of transfers ⁶ . Psychological reasons ²³ .	5
HV026	Lack of insight into condition ⁴ . Lives with friend ¹⁰ and OT concerned that patient and friend do not have a realistic impression of needs on discharge ⁴ .	2
HV027	No reasons recorded.	N/A
HV028	Aphasia ⁷ . Patient is not demonstrating insight into problems ⁴ . Reduced cognition – sequencing and organisation ³ . Lives with son ¹⁰ -anxieties of son ⁵ . Patient will be on her own during the day ¹² .	6

HV029	Patient has dyspraxia ¹⁸ and is mobile independently ²² . Lives with son ¹⁰ who works during the day and patient will be alone for long periods ¹² . Some risks relating to be mobile and having dyspraxia ⁶ . OT would like to review set-up of home environment to reduce risks ³² .	6
HV030	High risk of falls identified in hospital ¹⁵ . Patient does not show that she would be compliant with advice ¹⁴ unless shown at home. Patient lives alone ² .	3
HV031	Learning disabilities ⁹ . Lives with parents ¹⁰ . Was previously dependent in many extended ADLs ¹¹ . Carer issues identified ⁵ . Home visit required for carer assessment and education (including use and positioning of equipment) ¹⁹ . Patient needs to see things happen in context due to learning disability ³³ .	6
HV032	Bilateral strokes (residual weakness from previous) ⁹ . Patient is bariatric ³⁴ . Equipment may be required for discharge and this equipment will be specialist and larger than standard due to weight of patient ³⁵ .	3
HV033	No reasons recorded	N/A
Total Number of Reasons		100

4.4.3. What were the Characteristics of the Patients in the Home Visit Essential Cohort?

In this section, the characteristics of the patients in the home visit essential cohort will be presented. A descriptive summary of the characteristics of all patients in the HOVIS study will be provided, followed by a comparative analysis of the characteristics of those patients into the home visit essential cohort comparing them to those in the RCT.

4.4.4. Description of HOVIS Participants

Of the 126 participants recruited to the HOVIS study, 115 (91%) provided informed consent, with a consultee acting for the remaining 11 (9%). Sixty-five (52%) participants were male. The ages of the participants ranged from 34 to 99 years, with a mean of 72.0 years (SD 14.14.). The majority were White British (91%) and 59 (47%) were married. Upon their admission to hospital 58 (46%) of the participants were living with their spouse, 46 (37%) lived alone, 20 (16%) lived with extended family (which may also have included their spouse), and two (2%) lived in shared accommodation. Eleven (9%) of the participants had a formal support package of care prior to their admission to hospital.

With regard to the type of stroke: one hundred and four participants (83%) had ischemic strokes, 17 (13%) had haemorrhagic strokes, four (3%) had both ischemic and haemorrhagic and one (1%) was unconfirmed. The Oxford classification (Bamford et al. 1991) was used to classify the type of stroke. Forty (32%) participants had a stroke which was classified as a PACS, 29 (23%) were classified as TACS, 19 (15%) as LACS and eight (6%) as POCS. However, for 30 participants this information was missing or not applicable (haemorrhagic stroke). This information was also categorised into cortical and non-cortical stroke, and 69 (72%) participants had a cortical stroke.

Twenty-five (20%) participants had aphasia at the time of recruitment to the study and twenty (16%) had had a previous stroke. The average length of stay from admission to hospital to discharge was 51 days (mean 50.61, SD 26.54), but there were wide ranges from ten to 168 days. The demographic characteristics and medical details of the patients in the study are shown in Table 5.

4.4.5. Baseline Assessment Measures for all HOVIS Patients

Table 6 shows the summary descriptive statistics for the baseline assessments for the HOVIS sample. Over half of the sample (54%) had a moderately severe disability as categorised on the Modified Rankin Scale, with just under a third (32%) having a severe disability. For the pre-stroke Barthel Index, the median score was 20 (IQR 19 to 20). This data demonstrates that most participants were independent in self-care before their stroke. However, the baseline Barthel Index shows a large amount of variability in the sample following their stroke, at the point that they were recruited to the study. The interquartile range for the baseline Barthel Index scores was six to 13, with a median of nine. This indicates that most participants had major deficits in their ability to manage self care independently, at the time they were recruited to the study.

The median general health questionnaire score was nine with a range of three to 34 indicating some variability in the mood of the participants in the sample. A lower score on this measure indicates a better outcome. A score of nine indicates some low mood and worse health state than usual, but overall the mood of the participants at baseline can be considered to be within the normal range.

Table 5: Demographic and Medical Characteristics of HOVIS Participants	N=126
Gender	
Male	65 (52%)
Female	61 (48%)
Age	Mean: 72 (SD 14.14) Range: 34 to 99
Length of Stay	Mean 50.61 days (SD 26.54) Range: 10 to 168 days
Ethnicity	
White British	114 (90%)
Black - Caribbean	5 (4%)
Asian – Indian	4 (3%)
White – European	2 (2%)
White – Other	1 (1%)
Marital Status	
Single	10 (8%)
Married	59 (47%)
Divorced/Separated	8 (6%)
Widow/Widower	35 (28%)
Living with Partner	9 (7%)
Information missing	5 (4%)
Household Composition	
Living Alone	46 (37%)
Living with Spouse	58 (46%)
Living with Family	20 (16%)
Living in Shared Accommodation	2 (2%)
Care Package Prior to Admission	
Care Package	11 (9%)
No Care Package	115 (91%)
Consent/Consultee	
Participant Consented	115 (91%)
Consultee Opinion	11 (9%)
Type of Stroke (Oxford Classification)	
TACS	29 (23%)
PACS	40 (32%)
LACS	19 (15%)
POCS	8 (6%)
Missing or Not Applicable	30 (24%)
Cortical/Non-Cortical Stroke	
Cortical	69 (55%)
Non-Cortical	27 (21%)
Missing or Not Applicable	30 (24%)
Ischemic or Haemorrhagic Stroke	
Ischemic	104 (83%)
Haemorrhagic	17 (14%)
Ischemic and Haemorrhagic	4 (3%)
Unconfirmed	1 (1%)
Patient has Aphasia	
Aphasia	25 (20%)
No	97 (77%)
Missing	4 (3%)
Previous Stroke	
Yes	30 (24%)
No	92 (73%)
Missing	4 (3%)

Table 6: Baseline Scores of all Patients	
Modified Rankin	
Moderate Disability	17 (13%)
Moderately Severe Disability	68 (54%)
Severe Disability	40 (32%)
Missing	1 (1%)
Barthel Index (Pre-stroke)*	Median:20 IQR:19-20
Barthel Index (Baseline)*	Median: 9 IQR: 6-13
General Health Questionnaire (Baseline)**	Median:14 IQR: 10-21
ACER (Baseline)***	Median:70 IQR: 53-81
Legend	
* n=125	
** n=118	
*** n=123	

A large degree of variability in cognitive function was demonstrated by the results from the ACE-R. A median score of 70 indicates some cognitive impairment in the sample and the interquartile range from 53 to 81 demonstrates that some participants had a very high level of impaired cognition whilst others were not at all cognitively impaired.

4.4.6. Comparison of Participants' Characteristics in the Home Visit Essential cohort and RCT

The previous two sections described the demographic characteristics, medical details and baseline assessment outcomes for all of the participants in the HOVIS study. This section will now present the comparison between the participants in the home visit essential cohort and the RCT. This section will begin with a presentation of descriptive information for the two groups of patients. For categorical variables frequencies and percentages will be reported. For continuous variables the mean and standard deviation will be reported. For baseline assessment measures with numerical scores the distribution of the data has been visually checked. None of these measures were normally distributed, and therefore the median and interquartile ranges will be reported

for these variables. Exploratory analysis was conducted as described in the proposed analysis section of this chapter. The results of the comparison between the participants in the home visit essential cohort and RCT are shown in Table 7.

Table 7: Comparison of the Characteristics of Patients in the Home Visit Essential Cohort and the RCT			
Characteristic	Home Visit Essential Cohort n=33	RCT n=93	P Value~
Gender			
Male	15 (45%)	50 (54%)	0.41
Female	18 (55%)	43 (46%)	
Age	Mean: 71.73 SD:12.72	Mean: 72.13 SD: 14.67	0.89 [#]
Length of Stay (Days)*	n=32 Mean: 55.00 SD: 28.89	n=91 Mean: 49.07 SD: 27.66	0.28 [#]
Ethnicity			
White British	30 (91%)	84 (90%)	0.92
Other	3 (9%)	9 (10%)	
Household Composition			
Alone	16 (48%)	30 (32%)	0.10
With others	17 (52%)	63 (68%)	
Pre-admission Support Service (excl family)			
Yes	6 (18%)	5 (5%)	0.03
No	27(82%)	88 (95%)	
Consent/Consultee			
Consultee	5 (15%)	6 (6%)	0.13
Consented	28 (85%)	87 (94%)	
Ischaemic/Haemorrhage			
Ischaemic	28 (85%)	76 (82%)	0.96
Haemorrhage	4 (12%)	13 (14%)	
Ischaemic and Haemorrhage	1 (3%)	3 (3%)	
Missing	0	1 (1%)	
Classification of Stroke**	n=25	n=71	
Cortical	22 (88%)	47 (66%)	0.04
Non-cortical	3 (12%)	24 (34%)	
Previous Stroke			
Yes	9 (27%)	21 (23%)	0.76
No	24 (73%)	68 (73%)	
Missing	0 (0%)	4 (4%)	
Aphasia			
Yes	10 (30%)	15 (16%)	0.10
No	23 (70%)	74 (80%)	
Missing	0 (0%)	4 (4%)	
Legend			
~ chi-squared test unless stated; # t test			
*Two participants died before discharge and 1 withdrew			
**Information not applicable for haemorrhagic strokes and missing for 8 participants			

The demographic characteristics the participants in the two groups were similar in terms of their ages and ethnic origins. There was a slight preponderance of females in the home visit essential cohort (55%), although this was not statistically significant. With regard to the household composition, there was a higher proportion of patients who lived alone in the home visit essential cohort (49%) compared to the RCT (32%), and this difference was not statistically significant. There was also a higher proportion of patients who had pre-existing support services (formal care services at home, excluding family support) prior to their stroke in the home visit essential cohort (18%) compared to the RCT (5%). This difference was statistically significant $\chi^2(1, n=126)=5.01, p=0.03$.

The comparison of the medical details of patients in the two groups is also shown Table 7. The proportion of patients who had had a previous stroke was similar in the two groups of patients. Also the percentages of ischemic strokes were similar in the two groups. However, when this was compared by classification into cortical and non-cortical strokes there was a higher proportion of cortical strokes in the home visit essential cohort (88%) compared to the RCT (66%). This difference was statistically significant $\chi^2(1, n=96)=4.35, p=0.04$. The proportion of patients with aphasia was higher in the home visit essential cohort (30%) when compared with the RCT (16%), although this difference was not statistically significant. There were also a higher proportion of patients for whom a consultee opinion was obtained in the home visit essential cohort and this may be linked with a higher percentage of aphasic patients in this study group.

4.4.7. Participants being Discharged to Care Homes

Ten patients were recruited to the HOVIS study that, at the time the allocation decision (home visit essential cohort or RCT) was made, were planned to be discharged to a

care home. All ten of these patients were allocated to the RCT, and this was statistically significant $\chi^2(1, n=126)=3.85, p=0.05$. This is a clear indication that the occupational therapists allocated these patients to the RCT because they believed that a home visit was not 'essential' for these patients. These patients were not returning home, and therefore the issues which the occupational therapists considered relevant appeared to be less applicable to the care home participants. In the interviews with the occupational therapists in the previous chapter, it was reported that the therapists based their reasoning to complete a home visit on balancing aspects of the patient's ability to function with the characteristics of the home environment. Thus the environment can be considered to be a vitally important factor and patients being discharged to a care home may be considered to be going to a safe environment which does not need to be assessed.

Thus, in light of the above findings, the comparative analysis of the demographic and medical details of the participants was completed again *excluding* the ten care home participants. Table 8 shows the comparison of the characteristics in the two groups, excluding care home patients. When the care home participants had been excluded, participants in the home visit essential cohort were significantly more likely to live alone and to have spent longer in hospital (in addition to those variables which previously achieved significance), see Table 8.

Excluding the patients who were planned to be discharged to a care home, at the time the allocation decision was made, altered the significance for the result for participants who lived alone. This indicates that a plan to return home (rather than to a care home) may have been a factor in the occupational therapists' reasoning of the need for a home visit. Furthermore, this demonstrates that the care home patients could present a

Table 8: Comparison of the Characteristics of Patients in the Home Visit Essential Cohort and the RCT (excluding patients being discharged to care homes)			
Characteristic	Home Visit Essential Cohort n=33	RCT n=83	P Value~
Gender			
Male	15 (45%)	46 (55%)	0.33
Female	18 (55%)	37 (45%)	
Age	Mean: 71.73 SD:12.72	Mean: 70.99 SD: 14.92	0.80 [#]
Length of Stay (Days)*	n=32 Mean: 55.00 SD: 28.89	n=82 Mean: 45.39 SD: 23.70	0.05[#]
Ethnicity			
White British	30 (90%)	74 (89%)	0.78
Other	3 (10%)	9 (11%)	
Household Composition			
Alone	16 (48%)	23 (28%)	0.03
With others	17 (52%)	60 (72%)	
Pre-admission Support Service (excl family)			
Yes	6 (18%)	79 (95%)	0.02
No	27(82%)	4 (5%)	
Consent/Consultee			
Consultee	5 (15%)	5 (6%)	0.11
Consented	28 (85%)	78 (94%)	
Ischaemic/Haemorrhage			
Ischaemic	28 (85%)	68 (82%)	0.80
Haemorrhage	5 (15%)	14 (17%)	
Missing	0	1 (1%)	
Classification of Stroke **			
Cortical	n=25 22 (88%)	n=63 41 (65%)	0.03
Non-cortical	3 (12%)	22 (35%)	
Previous Stroke			
Yes	9 (27%)	17 (21%)	0.47
No	24 (73%)	64 (77%)	
Missing	0 (0%)	2 (2%)	
Aphasia			
Yes	10 (30%)	14 (17%)	0.11
No	23 (70%)	68 (82%)	
Missing	0 (0%)	1 (1%)	
Legend			
~ chi-squared test unless stated			
# t test			
*Two participants died before discharge			
**Information not applicable for haemorrhagic strokes and missing for 8 participants			

confounding factor in the analysis for this study and that their inclusion may affect some of the other variables in the study. Therefore, these patients have been excluded for the

rest of the analysis for this chapter. Further results will be presented based *only* on those patients who were planning (at the time the allocation decision was made) to return home to a community dwelling situation and not a care home on discharge (n=116).

The mean length of stay for those participants who were returning home was 55 days for those in the home visit essential cohort compared with 45 days for those in the RCT. Thus, those in the home visit essential cohort spent longer in hospital than those in the RCT. In order to ascertain whether this was an artefact based upon the home visit increasing the length of stay (due to the increased time spent organising and the visit and arranging any follow up actions) the mean length of stay was compared for patients in the home visit essential cohort compared with those in the RCT who were randomised to the home visit group. This finding was still significant $t(71) = 2.17, p = 0.05$.

4.4.8. Comparison of Participants in the Home Visit Essential Cohort and RCT Excluding Care Home Participants

Figure 6 illustrates patients' level of disability as categorised on the Modified Rankin Scale (van Swieten et al 1988). This figure shows the percentages of patients in each group that were classified in each of the categories on the Modified Rankin Scale. There were no patients in the 'no symptoms', 'no significant disability' or 'slight disability' categories. This was not surprising as any patients in these categories would be unlikely to have rehabilitation needs and would not have been transferred to the Stroke Rehabilitation Unit. The proportion of patients in the 'moderate disability' category was almost equal in the home visit essential cohort and the RCT. These patients require some degree of assistance with activities of daily living, but are able to

walk independently. However, a higher proportion of the home visit essential cohort were in the ‘moderately severe’ category (67%) compared to the RCT (53%), these patients are unable to attend to their own personal care needs and are unable to walk without assistance. In the RCT 31% were in the ‘severe’ category compared to 21% of the home visit essential cohort. Patients in the severe category have very high levels of disability and require constant nursing care and are confined to bed.

A chi-squared test was conducted on the groups for the three categories of disability, and these differences were not statistically significant $\chi^2(2, n=115)=1.70, p=0.43$. However, it does show that two thirds of the home visit essential cohort participants were in this category, compared with just over half of those in the RCT.

Figure 6: Level of Disability (Modified Rankin Scale)

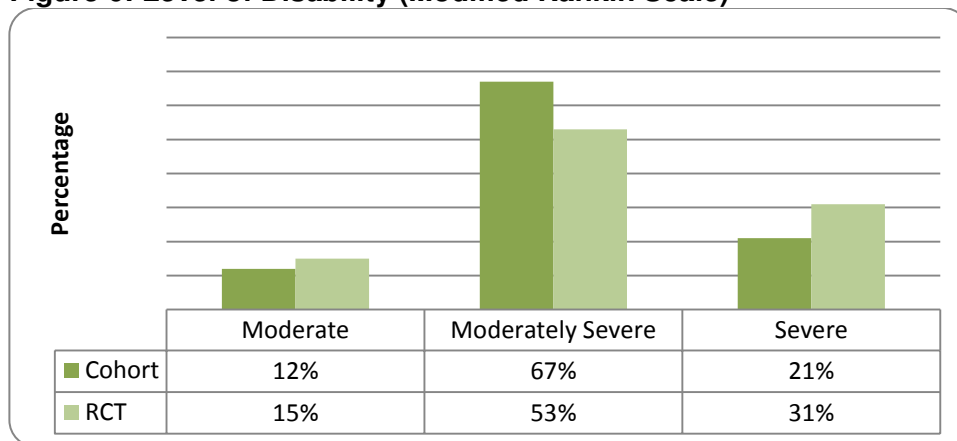


Table 9 shows the comparison of the other baseline measures between the participants in the cohort and the RCT. The groups were comparable in terms of independence in activities of daily living, at both the pre-stroke and the baseline time points, as measured using the Barthel Index. This was also the case for the mood of the participants, as measured using the General Health Questionnaire (12 question

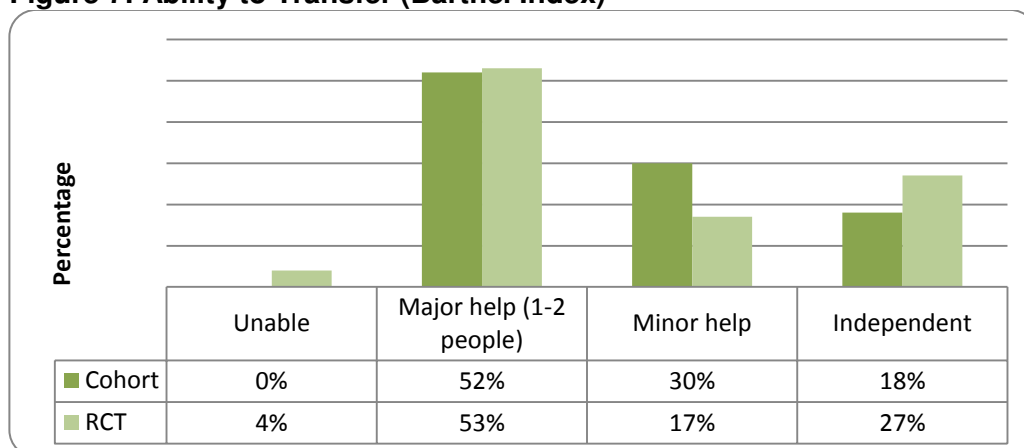
version). A Mann-Whitney U test was completed and there were no significant differences between the groups in any of these variables (see Table 9).

The Addenbrooke's Cognitive Examination (Revised Version) (ACE-R) was used as a measure of cognitive function. However, some participants were unable to complete sections of the ACER. For example, if they had language problems (e.g. expressive aphasia) they may have been unable to complete the reading tasks. Participants who had a hemiparesis which affected their dominant side may have been unable to complete the writing and drawing tasks with precision or accuracy. Forty-three participants were unable to complete the whole of the ACER, and their data were excluded from the analysis of this measure. Therefore 73 participants were able to complete the whole ACER and were included. The median ACE-R score for the home visit essential cohort was 73 compared to 78 for those in the RCT, which shows that there was a greater degree of cognitive impairment in the participants in the cohort. Although this difference was not statistically significant the median and interquartile ranges were higher in the RCT group indicating less cognitive impairment. The p value on the Mann Whitney U test was 0.08 and this may suggest that larger numbers of patients may achieve a significant result.

Assessment Measure	Home Visit Essential Cohort n=33 Median (IQR)	RCT n=83 Median (IQR)	P Value (Mann Whitney U Test)
Pre-morbid Barthel Index	20 (20-20)	20 (19-20)	0.49
Baseline Barthel Index	10 (6.5-13)	9 (6-14)	0.88
General Health Questionnaire	13.5 (9.75-21)	14 (10-20)	0.92
ACER	n=22 73(56.5-81.25)	n= 51 78(70-87)	0.08

Figure 7 shows the participants' ability to transfer as classified on the transfer section of the Barthel Index. Only three participants were unable to transfer at all and they were all in the RCT, representing 4% of participants in the RCT. The groups of participants were equally matched in terms of the proportions of patients requiring major help to transfer. The biggest difference between the two groups was those patients who required minor help and those who were independent. There were more patients in the RCT who were able to transfer independently (n= 22) and they made up 27% of the RCT group. This compared to six in the home visit essential cohort, representing 18% of the cohort group. Thirty percent of the home visit essential cohort required minor assistance to transfer compared with 17% of those in the RCT.

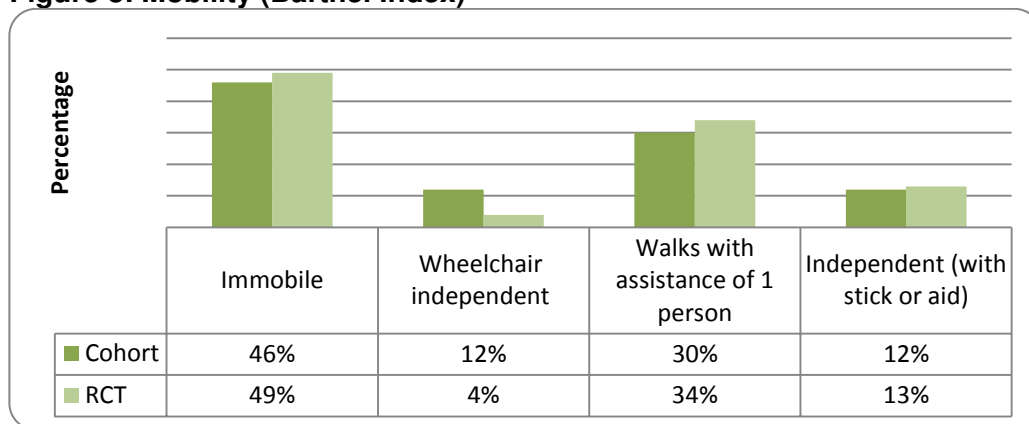
Figure 7: Ability to Transfer (Barthel Index)



Being unable to transfer independently was one of the criteria for inclusion in the home visit essential cohort of the HOVIS study. However, these results indicate that the majority of participants in both groups were not independent (requiring minor or major help) in their ability to transfer at the time the allocation decision was made. Although there were a higher proportion of participants in the RCT who were able to transfer independently, this difference was not statistically significant.

Figure 8 shows the mobility levels of the participants in each group. This figure demonstrates that the proportions of patients in each group were similar for all categories of mobility, with the exception of those who were wheelchair independent. There were a higher proportion of patients who were using wheelchairs independently in the home visit essential cohort (12%) compared to the RCT (4%), although this difference was not statistically significant.

Figure 8: Mobility (Barthel Index)



4.5. Discussion

4.5.1. Occupational Therapists' Reasons

An average of four reasons was given by the occupational therapists when they allocated their patients to the home visit essential cohort, with a range from one to eight reasons. This suggests that the reason for completing a home visit with each patient is generally not straightforward or based on only one or two factors. It suggests that the occupational therapists take a range of reasons into consideration and combine these in their clinical reasoning process. Thirty-five different categories of reasons were reported for 24 patients, which also suggests that there is a great deal of variability in

the types of reasons and the factors which occupational therapists considered. Some of these factors had dual meanings such as 'mobility' which could either be listed as 'reduced or impaired mobility' or 'independent mobility'. The risks associated with being independently mobile or having impaired mobility were also, in some cases, inextricably linked to other factors such as cognitive impairment, apraxia or living alone. Thus, for some patients being independently mobile could be a reason for a home visit not being indicated, whilst for others it presented a risk factor when combined with other risk issues. These findings indicate that in many cases the decision to complete a home visit was complex and not clear cut.

4.5.2. Home Visit Essential Cohort

There were a higher proportion of participants in the home visit essential cohort that had cortical strokes, compared with participants in the RCT. Although when allocating their patients to the home visit essential cohort the occupational therapists did not use the terms 'cortical', 'sub-cortical' or 'non-cortical', they commonly gave reasons which included cortical features such as 'aphasia'. However, the number of participants who had aphasia in the home visit essential cohort was not significant. This could suggest that occupational therapists are attuned to the features of a cortical stroke or that the complexity and diversity of the symptoms associated with a cortical stroke, when combined, may attenuate a need for a pre-discharge home visit.

Participants in the home visit essential cohort were more likely to have had formal care support services prior to their stroke. This would appear to indicate that they were more dependent in activities of daily living prior to their stroke, as they required formal support from carers. However, this indication was not supported by the comparison of their pre-stroke Barthel Index scores. In terms of the pre-stroke Barthel Index, the

participants in the two groups of the study were well matched and there appeared to be a high level of independence in self-care activities in both groups. This could possibly indicate that the Barthel Index was not a sensitive enough measure to use for this, or that the differences between the groups were very subtle. It may also indicate that the home visit essential patients had carers for reasons other than to provide assistance with self-care activities. One such reason could be that they were more cognitively impaired and that they had a care package to assist with daily living activities on this basis, which may not have been picked up by the pre-stroke Barthel Index measure. The HOVIS study did not include a measure of pre-stroke cognition and therefore it is not possible to determine whether this was the case.

Of the participants who were returning home to a community dwelling, those in the home visit essential cohort were significantly more likely to live alone. Living at home alone with new levels of disability due to increased physical or cognitive impairments is likely to present additional risks for patients following discharge. It is therefore not surprising that occupational therapists may be more cautious about discharging these patients without a pre-discharge home visit, and that more patients in the home visit essential cohort lived alone. However, the living circumstances of patients is a complex issue and is a potential confounding factor in the analysis of home visit decisions. Participants with more severe levels of disability may only have been able to return home *because* they lived with another person. The availability of care support within the home environment may have facilitated a discharge home because there would be a carer present during the day to provide support. Thus, participants in either the home visit essential cohort or the RCT may have been more likely to be able to return home *because* they lived with someone else. Participants who lived alone may be more likely

to be discharged to a care home because there was insufficient support within the home environment to facilitate their return home.

Level of disability was measured using the Modified Rankin Scale (van Swieten et al 1988) which has been found to be a valid and reliable measure of disability for patients with a stroke (Banks and Marotta 2007). As classified by the Modified Rankin Scale (MRS), 21% of the home visit essential cohort had a 'severe disability' compared with 31% of those in the RCT. 67% of the home visit essential cohort had a 'moderately severe disability' compared with 53% of those in the RCT. Although these differences were not statistically significant, they indicate a trend that it is not necessarily the most disabled patients who were most likely to be deemed to need a home visit and that it may be those with more 'moderately severe' levels of disability as categorised on the MRS. These are patients who need assistance with mobility and with managing activities of daily living.

Examination of individual items of the Barthel Index revealed that there were no significant differences between participants in either group for any of the areas of self care. However, ability to transfer and mobility were analysed in more detail as these were highlighted by the senior occupational therapists who were interviewed in chapter two. This revealed that there was a trend toward increased ability to transfer independently in those in the RCT, and those who needed minor help to transfer in the home visit essential cohort. The groups were well matched in terms of those who needed major assistance to transfer. This could suggest that those patients who need minor assistance are considered to be more at risk, or that treatment or equipment for minor transfer needs can be better assessed or provided in the home environment than for major assistance.

There were also a higher proportion of participants in the home visit essential cohort who were using wheelchairs independently. Although this difference was not statistically significant, there were very few participants using wheelchairs independently at the time of recruitment to the HOVIS study (n= 7) and so there are insufficient numbers in the sample to ascertain this. Some of the occupational therapists who were interviewed in chapter two highlighted that home visits would usually or always be completed with new wheelchair users. Being a wheelchair user was also stated as a reason by the occupational therapists on two of the home visit essential forms.

The presence of a cognitive impairment was the most frequently cited reason (jointly with living alone and environmental issue) by the occupational therapists when allocating patients to the home visit essential cohort. The participants in the home visit essential cohort did have a higher degree of cognitive impairment as measured by ACE-R and this was the case across all areas of the ACE-R (attention and orientation; memory; fluency; language; and visuospatial ability). Although the differences in overall scores were not statistically significant, there was a definite trend towards impaired cognition in the home visit essential cohort. There were a number of problems with the ACE-R measure, as only 73 participants were able to complete the whole ACE-R. This was due to difficulties with reading, language or being unable to draw or write because of a hemiparesis. Thus, these results exclude some of the participants and may not necessarily be representative of the cognitive abilities of all patients with a stroke, particularly if patients with aphasia were routinely unable to complete this measure.

Patients in the home visit essential cohort spent significantly longer in hospital than those in the RCT. Whilst this cannot be considered to be a characteristic of the patients in the cohort, it is likely to be a reflection of the complexity of the characteristics which

lead the occupational therapists to deem a home visit to be essential. However, this level of complexity is not necessarily reflective of the most severe disabilities as there were more patients with severe disabilities in the RCT. The definition of 'complex' may be based on more moderately severe disabilities (i.e. needing some level of assistance with mobility and daily living activities) and the presence of other risk factors relating to the home environment or patient's symptoms.

4.5.3. Limitations

There are some limitations of the research reported in this chapter. The principal limitation is that the data for this analysis was gathered within the context of the HOVIS study. Thus, the data were collected in a somewhat artificial environment, in that the occupational therapists were being asked to make decisions about whether a home visit was needed for each patient within ten working days of admission to the Stroke Rehabilitation Unit. This was not routine practice or procedure. However, as part of the HOVIS study this provided the opportunity to gather information on the reasons behind home visit decisions and systematically analyse the characteristics of patients who were specifically deemed to need home visits which would be difficult to capture in a 'real world' setting.

Another limitation is the small number of participants in the home visit essential cohort in comparison to the RCT, with a total of 33 participants. Thirty-three is a small cohort and this means that the statistical power of the analysis is limited. For example, the trend towards a higher degree of cognitive impairment in the home visit essential cohort was not significant, but may have become so if more participants had been recruited. It is therefore possible that some of these findings may be an artefact based on the small number of participants in the cohort which may attenuate certain patient characteristics.

4.6. Conclusion

Although a wide number of reasons were given by the occupational therapists when allocating patients to the home visit essential cohort of the HOVIS study, the most frequently cited were: environmental issues, cognitive impairment (including lack of insight) and living alone. Comparison of the participants in the two study groups revealed that participants in the home visit essential cohort were significantly more likely to live alone, more likely to have a cognitive impairment, have cortical strokes and pre-existing support services. It appeared that several reasons were factored together into the decision and that there may be interplay between levels of impairment and other issues. It also appeared that there was a trend towards those with moderately severe disabilities being allocated to the home visit essential cohort, compared to more severe disabilities in the RCT.

Chapter Five
Overall Discussion and Conclusions

5.1. Introduction

This chapter will draw together the strands of the research presented in the three preceding chapters. It will discuss the findings from the literature review, interviews with occupational therapists and the analysis of the characteristics of the patients in the home visit essential cohort. Four characteristics which were identified as key factors in the need for a home visit will be discussed. A model for the decision making process for home visits is postulated based upon the findings from this research. The strengths and limitations, wider implications, and recommendations for further research are also discussed.

5.2. Discussion: Four Key Characteristics

Four key characteristics relating to patients and their home environment were identified across the three strands of research conducted. These were: moderately severe levels of physical disability; mild to moderate cognitive impairments; cortical strokes; and living alone. These will now be discussed.

5.2.1. Moderately Severe Levels of Physical Disability

The characteristics that were most commonly identified were linked to patient's levels of disability and how this impacted upon their ability to function in activities of daily living. This is perhaps unsurprising as the principal component of occupational therapy practice in stroke rehabilitation is to provide assessments and treatments targeted at increasing independence in activities of daily living (Ivey and Mew 2010). The evidence base for the interventions provided in this area is strong and based on robust research consisting of systematic reviews and individual patient meta-analysis (Legg et al 2006; Walker et al 2004). Therefore, it is not surprising that occupational therapists discuss

their reasoning for the need for assessments and interventions based on the link to and the likely impact upon performance in activities of daily living.

The interviews conducted with the occupational therapists in this study indicated that ability to carry out activities of daily living independently was a strong component of whether a home visit was needed or not. Whilst a visit was generally thought to be necessary for people who had some difficulties in managing tasks independently, those with the highest levels of dependency were not the most likely to have a home visit and the occupational therapists were more uncertain about the beneficial impacts of home visits with those who were the most heavily dependent.

This finding was supported by the quantitative analysis conducted for this study: although the differences between the groups in levels of disability (as categorised by the Modified Rankin Scale) were not significant, there appeared to be a trend towards those with moderately severe levels of disability being more likely to be allocated to the home visit essential cohort and those with severe disabilities being more likely to be allocated to the RCT. This is consistent with the findings from the interviews which suggested that occupational therapists complete home visits for those with some level of impairment, but those with the most severe impairments are not necessarily those who are believed to be most in need of a visit. However, there were exceptions and this was not the case for all patients as each case was based upon individual reasoning.

A separate component of work which was undertaken as part of the HOVIS study (Fellows et al, in preparation) examined the perceptions of six experts on home visiting practice. The experts also reported that home visits would be most appropriate for those patients with moderate levels of impairment rather than those with milder or more

severe physical impairments. However, in relation to the literature, the study conducted by Clarke and Gladman in 1995 reported that pre-discharge home visits were more likely to be completed with those with lower Barthel Index Scores (i.e. the patients who were most dependent in self care activities). This was a statistically significant finding and based upon a relatively large group of people with a stroke (n=297). However in contrast, Luker and Grimmer-Somers (2009) reported that home visits were not more likely to be completed with the most dependent patients as assessed using the Functional Independence Measure, although they only included a small sample of 18 patients who had a home visit. Thus, the findings from the literature seem to be contradictory.

In this study, there appeared to be no relationship between the Barthel Index scores and the allocation to the cohort or RCT. However, there did appear to be a trend towards those with moderately severe disabilities (as categorised on the Modified Rankin Scale) being allocated to the cohort.

5.2.2. Mild to Moderate Cognitive Impairment

A cognitive impairment was identified as being a fundamentally important characteristic of patients who were believed to need a home visit by occupational therapists. Cognition featured as a strong theme in the interviews with the occupational therapists and in the home visit essential cohort of the HOVIS study.

In the interviews with the senior occupational therapists, the presence of a cognitive impairment appeared to be the factor that was the most difficult to incorporate into the reasoning process as to whether a home visit was necessary or not. When asked to provide an example of a patient about whom they would be unsure whether to complete

a home visit, a cognitive impairment was most commonly cited. Some occupational therapists reported that the home visit provided the opportunity to assess the patient in the familiar environment of their own home which presented a more realistic and 'real world' environment. However, this opportunity had to be balanced alongside whether the patient would be able to understand the nature and purpose of the visit, the likelihood that the patient would be willing to return from the visit, and the risks associated with potentially unpredictable behaviour.

In the reasons given by the occupational therapists in HOVIS study when allocating the patients to the home visit essential cohort, a cognitive impairment was cited in six of the 24 examples and a lack of insight in another six examples. Thus, 50% of the participants for whom reasons were obtained had either impaired cognition or a lack of insight into their condition. When comparing the scores on the Addenbrookes Cognitive Examination (Revised Version) (ACE-R) the participants in the home visit essential cohort had a lower median score than those in the RCT. This indicates that, as a group, the home visit essential cohort had a greater degree of cognitive impairment than those in the RCT. Although the difference between the two groups was not statistically significant this could be due to the small number, or to the presence of other variables (such as the home environment and the availability of support from other people) also having influence on these results.

Whilst it appears that home visits would be more likely to be considered essential for those with a cognitive impairment, this is not ultimately the case. Other factors and concerns relating to a high level of cognitive impairment may suggest that occupational therapists would be cautious about completing a home visit. This may be due to the

potential to cause distress, unpredictable behaviour of the patient on the visit, or being unwilling to return to the hospital after the visit.

Whilst the qualitative and quantitative research conducted for this study highlights the importance of cognition as an important characteristic, this is largely overlooked in the literature. The two previous randomised controlled trials which were identified in the literature search in chapter two (Pardessus et al 2002; Lannin et al 2007) both excluded participants who had cognitive impairments. This is a significant omission. These trials were completed with groups of older people and were not stroke specific. However, a stroke specific study by Luker and Grimmer-Somers (2009) also excluded patients who did not have “adequate cognition”. Perhaps this was due to the potential difficulties in recruiting and including patients with cognitive impairments in research studies. Nevertheless, the findings from this study suggest that patients with a stroke who have a mild-to-moderate degree of cognitive impairment would be highly likely to be deemed to need a home visit by occupational therapists.

5.2.3. Cortical Strokes

An interesting finding from the analysis of the characteristics of the patients in the home visit essential cohort was that they were significantly more likely to have cortical strokes. It may be that this is an artefact based on the small numbers in the home visit essential cohort, but it is an interesting observation and one that requires further investigation.

Common features of a cortical stroke are: reduced sensation, aphasia, neglect and dyspraxia, which are present in addition to other symptoms of stroke (Bamford et al 1991). Although the occupational therapists who were interviewed and those who

participated in the HOVIS study did not use the word 'cortical' they often listed cortical features when providing their examples or reasons which warranted a home visit. Individually these features (e.g. aphasia) were not significantly more prevalent in the home visit essential cohort, but this may indicate that the range and complexity of the features of cortical strokes in combination are an important factor in the decision to complete a home visit. These may be identified by occupational therapists in relation to their impact on functional ability rather than directly relating to a cortical diagnosis. Thus, this may mirror the range of some of the reasons reported by the occupational therapists when allocating patients to the home visit essential cohort: language/communication problems, dyspraxia, visual impairment which were combined with other factors such as reduced mobility and physical impairment. It may also be linked to the fact that those in the home visit essential cohort spent longer in hospital than those in the RCT. The complexity of the issues related to cortical strokes may mean that there are more issues related to the discharge of these patients, which take longer to resolve and increase the total length of hospital stay.

5.2.4. Living Alone

The studies identified in the literature review that examined the living circumstances of patients who had home visits reported that they were not significantly more likely to live alone (Clarke and Gladman 1995; Johnston et al 2010). Although intuitively, it may seem that occupational therapists would be more concerned about patients being discharged home to live alone than those who live with other family members. In the interviews with the occupational therapists, living alone did not feature extensively in the examples that were given regarding the reasons for which they would complete a home visit with a particular patient. However, it was referenced by some as being a consideration alongside other issues.

However, the findings from the analysis of the participants in the HOVIS study are in stark contrast to the findings from the literature review and interviews and indicate that patients who live alone may be more likely to have a home visit. Living alone was one of the top three reasons given by the occupational therapists when allocating patients to the home visit essential cohort and was given as a reason in seven of the 24 examples (29%). However, living alone was never given as a standalone reason and was always considered alongside other factors such as communication, cognitive, physical or visual impairments, or environmental problems such as access to property. Furthermore, comparison of the patients in the home visit essential cohort with those in the RCT (excluding those being discharged to care homes) revealed that those allocated to the cohort were significantly more likely to live alone. This indicates that, on the whole, the occupational therapists in the HOVIS study were more likely to deem a home visit to be 'essential' for patients who lived alone, than for a patient who lived with other people.

Combining the findings from these three stands suggests that living alone is not, in itself, a reason that would lead an occupational therapist to deem that a particular patient with a stroke would need a home visit. However, when combined with other characteristics of the patient and the patient's environment, living alone may attenuate the need for occupational therapists to consider that a visit is indicated. Alternatively, it was identified in the interviews with the occupational therapists that the presence of other family members may reduce occupational therapists' concerns and therefore it may be that home visits were considered to be less necessary for those who lived with other people rather than being more necessary for those who live alone.

5.3. Synthesising the findings: Interaction of characteristics - Person and environment

This research identified a number of characteristics of individual patients which were incorporated into the decisions of occupational therapists regarding the need for a pre-discharge home visit. It appeared that the decision was commonly based on more than one reason in each individual case. The mean number of reasons given by the occupational therapists when allocating patients to the home visit essential cohort of the HOVIS study was 4 with a range of one to eight. In total 100 reasons were provided across 35 categories spanning characteristics that related to the person and to their home environment. Combining this myriad of reasons with the interview findings, identified four patient characteristics as being particularly important to occupational therapists in the decision making process.

However, the analysis of the interviews with the occupational therapists also illustrated *how* the occupational therapists balanced information about the patient and his or her ability to manage activities independently with information about the home environment. It appeared that they considered characteristics about the person and the environment in tandem. These factors, when considered together, suggest that the need for a pre-discharge home visit is reasoned on the combination of a number of different characteristics relating to the person and to the characteristics of the home environment (including the availability of support from other people within the home environment).

5.3.1. Person-Environment-Occupation Model

The findings linking characteristics of the person with the environment are consistent with a model of occupational therapy performance *The Person-Environment-*

Occupation Model (Law et al. 1996). This model postulates a transactive approach between the person, the environment they inhabit, and their occupational performance. In this approach all three components: the person, the environment and occupation are dynamic and continually interact with each other. Law et al. (1996) state that:

“The closer their overlap or fit, the more harmoniously they are assumed to be interacting. The outcome of greater compatibility is therefore represented as more optimal occupational performance” (pg. 17).

In essence, Law et al (1996) propose that the greater the degree of compatibility between the person and their environment, the greater the person’s ability to function independently within the environment (better occupational performance). Law et al (1996) also suggest that occupational therapy interventions should seek to promote the maximum amount of ‘fit’ between the person, the environment and their occupations. They state that occupational therapy interventions can maximise the level of person-environment-occupation ‘fit’ in two ways: by improving the enabling aspects of the environment, or by increasing the abilities of the person.

There are some clear similarities between the principles of the person-environment-occupation model and the findings from the interviews. When the occupational therapists identified a concern about a patient’s level of independence that resulted from a physical or cognitive impairment, they commonly balanced this information with the information they had about the home environment. In some cases this information was able to attenuate their concerns (i.e. a particularly competent carer, or provision of information about the fabric of the home environment), and in other cases this information intensified their concerns (i.e. a concern about the carers’ ability to cope,

numerous steps and thresholds within the home). Thus, information about the person and their environment had to be balanced by the occupational therapists.

A potential imbalance between the two areas may occur when the occupational therapist was concerned about a patient's ability to manage tasks independently and their level of ability did not appear to 'fit' with the information they had about the home environment (or this information was unknown or unclear). Examples of this were given by occupational therapists of dependent patients whose environment had potential hazards or barriers (such as rugs, steps, or stairs). In cases where an imbalance between the two areas was identified, then a home visit may be indicated as a tool to gather further information and seek a way to restore or promote the balance between the two areas (such as through equipment or increased carer support). When there are no concerns about a patient's level of independence, then a home visit is not indicated as there is no imbalance.

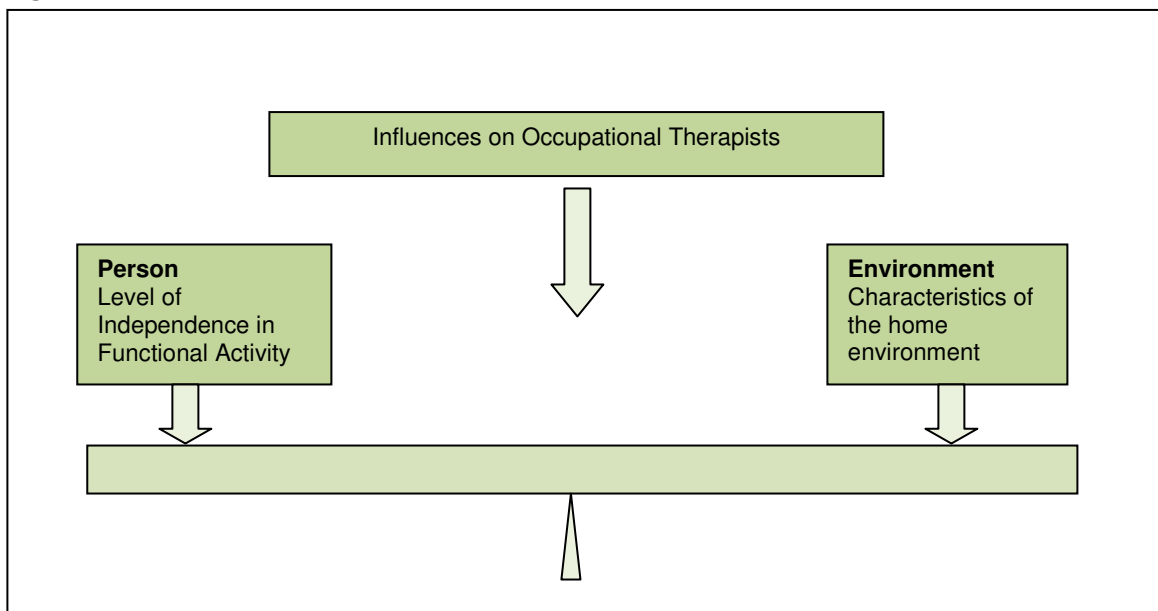
However, there were additional factors which were identified which impacted upon this process. The influences on occupational therapists which were identified in theme three comprised external and internal factors which may, in some circumstances, override the reasoning process. These influences may prevail over the occupational therapists' judgement on the relationship between level of independence in functional activity and characteristics of the home environment in some circumstances.

The relationship between the three themes identified in this research is illustrated in Figure 9. The seesaw depicts the balance which the occupational therapists appear to strive to maintain between the person's functional ability and whether they think the home environment is suitable to sustain this level of ability. If these two are balanced,

then there is no need to complete a home visit. Where there is an imbalance, a home visit may be indicated. However, other influences on occupational therapists may factor in the decision making process and override the balancing of the decision. This model indicates how the *process* of considering the need for a home visit is undertaken by occupational therapists, when incorporating a number of factors into their decision making.

The importance of the compatibility between the person and the home environment was also highlighted by the experts who were interviewed as part of the HOVIS study (Fellows et al in preparation).

Figure 9: Person-Environment Seesaw



5.4. Analysis of the Strengths and Limitations of the Study

This is the first study that has explicitly examined the characteristics of patients who are believed to need a home visit by occupational therapists. Although it is already well established that home visits are a commonplace occupational therapy practice it is not

clear which particular patients are believed to need home visits. This is an important issue as differences in practices between occupational therapists may potentially lead to inequitable services for patients in different regions across the country. As there is no clear evidence to guide practice in this area, home visits may be completed unnecessarily with certain patients, or certain patients may not receive access to them. This study has laid the foundations for a more in-depth analysis into the characteristics or types of patients whom occupational therapists believe most need a visit. This will assist in informing future national clinical guidelines in order to increase consistency in practices between different occupational therapists and different stroke units.

A particular strength of the literature review conducted for this study is that it contains the first analysis of the information on characteristics of patients who have home visits. In the review a systematic search was conducted and information was extrapolated on patient characteristics as related to the research question. However, the review is limited due to the paucity of research on home visits generally, the lack of information about patient characteristics specifically, and the heterogeneity of the studies that have been conducted on home visits. Furthermore, the literature review contains a publication bias as the grey literature was not extensively searched. Due to limited time and limited resources available to complete this research, it was not possible to conduct an extensive search of the grey literature. The grey literature is more likely to have negative results due to the publication preference for trials with a positive result (Dwan et al 2008). Therefore, this literature review may also contain some bias. However, as there is a general paucity of published information on this topic it is unlikely that they grey literature will be extensive.

This study utilised both qualitative and quantitative methods in the investigation and this is a particular strength. As both approaches were combined, the strengths of each were utilised and able to complement each other. As highlighted in chapter three, qualitative research is used when the overall aim of the research is exploratory and to generate new ideas or insights into a situation or phenomenon (Patton 1990). Pope and Mays (2006a) recommended that quantitative research methods are used to follow up findings which have been generated using a qualitative enquiry. This two-phase approach was applied in this study. The analysis of the interview component of this research identified a number of key characteristics. These characteristics were then substantiated by the findings from the quantitative component, increasing the overall reliability of the findings of this study.

A limitation of all qualitative research is that it may not necessarily be generalised to other people, participants or settings beyond the sample of participants who were included in the research (Barbour 2008). Thus, it cannot be assumed to be representative of the wider population. This is a limitation of this study: although twenty occupational therapists were interviewed and data saturation was achieved, the views of the occupational therapists may not necessarily be representative of national home visiting practice. The occupational therapists were selected from a sample of volunteers and were all members of the College of Occupational Therapists Specialist Section for Neurological Practice. They are therefore likely to represent a group of highly motivated and enthused therapists who self selected to take part in the interviews. They may have had particularly strong views about home visits, or they may have been especially motivated to participate in research. However, 20 occupational therapists were selected from 75 who volunteered and thus a purposive sample was achieved based on a geographical spread of the UK encompassing both urban and rural localities. Thus,

although the sample consisted of volunteers it was possible to select them based on the predetermined criteria.

A limitation of the analysis of the cohort of the HOVIS study is that the information about the participants was not captured in a 'real world' situation. The data on the home visit decisions was collected within the context of the HOVIS feasibility study and this does not necessarily represent how these decisions would be made in actual everyday practice. When allocating patients to the RCT the occupational therapists were aware that there was a 50% chance that they would receive a home visit anyway. However, this data does provide the opportunity to access data on home visit decisions that were made in a systematic and consistent manner and yielded data that would not be readily accessible in an everyday clinical setting. A further limitation of this component of the study is that it was conducted at one NHS site only. Prior to the start of the HOVIS study at the Royal Derby Hospital site, the occupational therapists on the stroke rehabilitation unit completed home visits with the majority of patients. Therefore, this is not necessarily generalisable to home visiting practice at sites within other NHS trusts where fewer home visits may be completed.

However, by triangulating the qualitative and quantitative methods, the limitations of each approach were, to some extent, mitigated by the inclusion of the other approach. The findings from the quantitative component were consistent with the interviews. Whilst neither of these can be considered to be representative of national practice there is a definite trend within the data from each component. The key characteristics which were identified in this study were all substantiated, to some extent, by both the qualitative and quantitative parts of this research. In particular, the importance of the patient's cognitive ability was identified as being a key factor in both the qualitative and

quantitative components of this study. Difficulties in cognition have not been extensively highlighted in the literature on home visits for patients with a stroke. The prevalence of cognition across both the qualitative and quantitative sections gives greater reliability and credibility to the findings from this research and emphasises the importance of cognition. This is an important finding as 11-56% of patients may have a cognitive impairment following a stroke (Patel et al 2002), and these issues will therefore affect a large proportion of the stroke patient population.

It could be argued that another limitation of this study is that it did not provide a definitive answer to the research question “what are the characteristics of patients with a stroke who are believed to need a pre-discharge home visit by occupational therapists?” However, a definitive answer would not be possible based on this data. This study has illustrated some key characteristics which could be explored further using both qualitative and quantitative approaches. Furthermore, this study has highlighted the multifaceted nature of the home visit and identified a wide range and diversity of factors which are incorporated into occupational therapists’ decisions as to whether home visits are needed with particular patients. It has further revealed a complex process which is reasoned for each individual patient by each individual occupational therapist. This finding is an important one. The qualitative component of this work has facilitated an understanding of the *process* of how these factors interact together and this has provided additional depth to the interpretation of this research.

5.5. Implications for Policy and Practice

5.5.1. National Clinical Guideline for Stroke

As highlighted in the introduction, the current *National Clinical Guideline for Stroke* clearly links the rationale for the completion of a home visit with dependence in activities of daily living:

“Before discharge of a patient who remains dependent in some activities, the patient’s home environment should be assessed and optimised, usually by a home visit by an occupational therapist” (Intercollegiate Working Party 2012: 27).

Although none of the occupational therapists included in this study referred to any specific formal national guideline or policy to guide their reasoning, there were some strong similarities between components of the theme ‘Level of Independence in Functional Activity’ and the above guideline. However, this guideline would appear to be indicative of the need for a linear relationship between level of dependence and the need for a home visit and that those who are more dependent would be more likely to need a home visit. Whilst some of the findings from the literature review appeared to support this notion, the findings from the qualitative and quantitative research suggest that it is those with more moderately severe levels of disability whom occupational therapists believe are the *most* likely to need a home visit.

The national clinical guideline overlooks two other important aspects which were identified in this research: cognition and environmental factors. The guideline does not

refer to cognition or make any explicit reference to the role of the home visit in assessing or mitigating for concerns about cognitive function. Also, the national guideline does not incorporate any acknowledgement of environmental factors having an influence on the need for a home visit or not. The findings from this research strongly suggest that environmental factors were considered alongside physical dependency and cognitive impairment. The person-environment model provides a framework within which to analyse the interaction between these two components. This model has the potential to be applied more widely in occupational therapy practice of pre-discharge home visits with other patient groups in addition to those with stroke, and provides a starting point for further research into the relationship between person-environment characteristics.

5.5.2. Differing Purposes for Home Visits

Earlier in this study, the difficulties in collecting audit information on pre-discharge home visits, and the difficulties in conducting home visit research, were highlighted. This study has highlighted the multifaceted nature of the home visit and the myriad of factors which contribute to occupational therapists' decisions about whether a home visit is needed. In the analysis of expert opinion conducted by Fellows et al (in preparation) the experts believed that home visits may be completed by occupational therapists for differing purposes (e.g. to manage risks associated with the discharge or to increase independence in activities of daily living). This has implications for research which attempts to evaluate outcomes of home visits; it is essential that the appropriate outcomes are measured. If visits have been conducted for different *purposes* then it is likely that different outcomes will be affected. For example, if a home visit has been completed because of a concern about how a family member will cope with a caring role, then carer strain may be the most pertinent outcome to measure. Similarly, visits

completed with patients with impaired cognition or impaired physical abilities are likely to have different purposes and therefore affect different outcomes. Thus, the characteristics of patients who have home visits are also inextricably linked to the purpose of the home visit and future research may need to explicitly incorporate these links.

Completing home visits for different purposes may also lead to difficulties in standardising procedures around home visits. This is problematic in terms of making recommendations for practice or policy, in that it is difficult to standardise the nature, content and purpose of the home visit. In the HOVIS study (Drummond et al 2012b) there were some issues with protocol adherence in terms of providing the home visit as per a standardised research protocol. Six patients in the home visit (intervention) group did not receive the intervention; eight patients were discharged on the home visit (i.e. they did not return to the hospital after the visit); and three patients had the home visit *after* they were discharged from hospital. A number of factors impacted on these protocol deviations including: patient choice, staff availability and changes in discharge plans. This is indicative of the factors which may impact upon the timing, implementation and content of the home visit. This range and diversity of factors indicates that there may be a practical component to whether a home visit can be completed. Thus, occupational therapists' decisions about those patients who need a visit may be increasingly influenced by the practicalities of everyday clinical practice.

5.5.3. Number of Home Visits and Impact of ESD Services

Also highlighted in the introduction was the recommendation that all patients who have a stroke should be admitted to hospital. Thus, significant numbers of patients are likely to be discharged from hospital with new levels of functional impairment. However, the

number of home visits appears to be decreasing. The 2006 National Sentinel Stroke Audit reported that 73% of patients who were admitted to a stroke unit had a home visit (Royal College of Physicians 2006). The survey undertaken as part of the HOVIS study (Drummond et al 2012a) reported that stroke units in England completed an average of just under one pre-discharge home visit per week. Comparing the figures from the HOVIS survey with earlier figures may suggest that the number of pre-discharge home visits is decreasing over time. Lannin et al (2011) also suggested that the number of pre-discharge home visits is decreasing in Australia. A decrease in the overall number of patients with a stroke who have a home visit is also likely to affect the types or characteristics of patients who have these visits. Recently, there have been a number of changes and transformations in stroke service delivery and more widely within the National Health Service. These changes may affect the overall number of visits completed and therefore the types of patients who most commonly have them.

The introduction of early supported discharge services (ESD) for stroke has formed a major national initiative to accelerate patient discharge, improve the transfer of care from the hospital to the community, and continue rehabilitation in the home environment (Langhorne 2003). The evidence indicates that patients with mild to moderate impairments are the most likely to benefit from ESD services, and that the services reduce long term dependency and length of hospital stay (Langhorne 2005). A consensus of the early supported discharge trialists placed the eligibility benchmark for ESD at a Barthel Index score of between 10 and 17 out of 20 (Fisher et al 2011).

The impact of the evidence base for ESD services has led to the implementation of many such services (Fisher et al 2011) meaning that patients with mild to moderate levels of physical impairment are likely to be discharged from hospital more quickly with

their rehabilitation care handed over to an ESD team. This has significant implications for discharge planning within acute stroke care services, and thus has implications with regard to home visiting practice. This has the potential to hugely alter the role of the home visit in the discharge process, with the possibility of fewer visits being completed. Home visits may be completed with the purpose of facilitating a handover of care to the ESD team rather than to discharge the patient to the home environment. It appears that there is an overlap between the patients who are believed to need home visits by occupational therapists, and those for whom ESD services are indicated: those with more moderate to moderately severe levels of physical disabilities. This may mean that fewer home visits will be needed as those patients whom occupational therapists believe are most in need of a visit are discharged with ESD services instead. Further research on home visits after stroke should explore the relationship between the pre-discharge home visit and the early supported discharge care pathway.

5.5.4. Economic Influences

Changes which are occurring at a national level within the UK central government are also likely to have an impact on home visiting practice. The UK economy is experiencing unprecedented austerity and economic difficulties following a 'double dip' recession (Moulds 2012). Consequently, a widespread and extensive cost cutting programme has been implemented affecting all government departments including the National Health Service (NHS). The NHS has been tasked with delivering £20bn of cost savings by 2015 (QIPP 2012). To deliver this extensive cost saving, it is clear that all NHS services and departments will be intensively scrutinised in terms of their resources and cost effectiveness. This has a twofold effect on home visiting practice.

Firstly, home visits are perceived to be a resource intensive and thus expensive intervention. Whilst a number of papers included in the literature review reported that home visits are costly (Barras 2005; Harries et al 2008; Lannin et al 2007; Mountain and Pighills 2003), they did so without referencing any information on the costs or cost effectiveness. Only Hibberd (2008) actually calculated the cost of a home visit and reported this at £135 per visit, but this calculation was based on only three visits from intermediate care and included limited details as to how the costs were calculated. None of the papers identified in the literature search reported on cost effectiveness, despite the claims regarding the resource intensity of the home visit. Information on cost effectiveness is vital in order to demonstrate that occupational therapy interventions represent value for money for service providers, and is a priority for research area for the profession (College of Occupational Therapists 2011). However, there is currently limited information to indicate whether home visits are cost effective in terms of delivering positive outcomes for patients and thus represent a judicious use of occupational therapists' time. Therefore information on the types of patients who are believed to need pre-discharge home visits is vital in order to evaluate whether occupational therapists are targeting home visits appropriately. Therefore it is essential to evaluate whether these patients have successful outcomes, and whether the intervention is cost effective for these patient groups.

Secondly, as part of the quality improvement programme being implemented to deliver efficiency savings in the NHS (QIPP 2012) it is recognised that costs savings can be delivered by reducing length of stay for patients in acute hospital beds (NHS Institute for Innovation and Improvement 2012). Planning for discharge is a vital component of this process and home visits are a core component of discharge planning (Drummond et al 2012a; Lannin et al 2011). It is currently unclear whether home visits actually reduce

length of stay. They may do this by facilitating a more rapid discharge through the identification of issues which may speed up the discharge process. Alternatively, home visits may delay discharge by adding to the total time taken to organise, complete and implement the actions following the visit. In the main HOVIS study the mean length of stay was 50.98 days (SD 28.27) for those in the home visit (intervention) group compared to 47.02 (SD 27.17) days for those in the control group. Further research is required to examine whether this is generalisable nationally and whether those patients who have home visits actually spend longer in hospital.

This is an important area where further research is required and is likely to have a significant impact on the willingness of commissioners to fund occupational therapy home visits. If home visits were shown to be successful in reducing the length of stay for certain patient groups, then this would be an additional factor which may impact upon the characteristics of those patients who are believed to need home visits. This would indicate an important role for the pre-discharge home visits within the overall strategic vision of the NHS. Alternatively, given the national push to deliver cost saving and discharge patients from hospital sooner, patients may be *less* likely to have home visits due to time constraints and practical factors, particularly if home visits were shown to *add* to the total length of stay.

5.5.5. Evidence Based Practice

What is the overall impact of this research on occupational therapy practice? Welch and Lowes (2005) argued that the rationale for completing a home visit is intuitively embedded within occupational therapy practice. Clinical reasoning of patients' need and selection of appropriate, relevant assessments and interventions are core skills of the occupational therapist. It could be argued that home visits are always based on

individual situations meaning they are not something that can be standardised, and should always be based on individual clinical reasoning. However, the fact that home visits are a customary practice with an intuitive element to them, should not allow them to be exempt from the scrutiny of evidence based practice. If the merits of home visits are to be recognised and substantiated, then this 'intuitiveness' needs to be converted into evidence which demonstrates that they are indeed an effective tool. A core element of this process is identifying those patients for whom they are most appropriate.

In the absence of clear evidence-based guidelines for when a home visit may be indicated, the decision as to whether to complete one with a particular patient must be based on the clinical reasoning and experience of each individual occupational therapist. This has implications for both occupational therapists and their patients, as it is likely that practice will vary depending on the particular department or therapist. This may lead to inequity in service provision regionally and nationally. This research has identified four characteristics of patients with a stroke which are particularly key factors in occupational therapists' decision to complete a pre-discharge home visit. These characteristics have the potential to develop greater consensus within the occupational therapy profession as a whole. A greater understanding of these characteristics will also enable further research on home visits to be focussed on and directed towards those patients whom occupational therapists believe most need a visit.

5.6. Suggestions for Future Research

It is suggested that further research on pre-discharge home visits for patients with a stroke should focus on the four key characteristics which were identified in this study: moderately severe physical disabilities, mild to moderate cognitive impairments, cortical

strokes, and living alone. In particular, it is suggested that research should focus on patients' level of dependence or disability. As this research has highlighted it is not necessarily those with the most severe impairments who may be deemed most likely to need a home visit and this may overlap with the criteria for early supported discharge services. The purpose, role and function of the home visit in the early supported discharge pathway should also be examined.

There is a need for further research that focuses on the outcomes of home visits for patients who have impaired cognition. These outcomes may principally revolve around safety within the home and independence in activities of daily living. Some of the occupational therapists who were interviewed reported that home visits may be useful for patients who lack insight in terms of facilitating a greater degree of insight into their conditions; however, it is not clear whether the visits do achieve this. It is therefore important that research also focuses on the views of patients (and their carers) with impaired cognition, and what they perceive the value of the home visit to be. Further research could explore the ways in which participation of cognitively impaired patients could be facilitated in randomised controlled trials. Research also needs to focus on the perceptions and opinions of occupational therapists as to what they feel the value of the home visit is for patients who are cognitively impaired. This will ensure that appropriate outcome measures are included in further RCTs.

However, given that a diverse range of characteristics was identified which interacted with each other, further research should also focus on the reasoning process which occupational therapists undertake when deciding whether a home visit is needed for a particular patient and *how* they balance and process this information to reach a

decision. The person-environment-occupational model (Law et al 1996) may provide a fruitful framework within which to conduct this analysis.

5.7. Conclusions

In conclusion, what are the key characteristics of patients with a stroke who are believed to need a pre-discharge home visit by occupational therapists? This research suggests that a patient who has suffered a cortical stroke, with a moderately severe physical impairment, mild to moderate cognitive impairment, and who lives alone would be highly likely to be deemed to need a visit.

Synthesising the findings from the three strands suggests that the pre-discharge home visit is multifaceted and that occupational therapists consider numerous factors when deciding whether a visit may be indicated for a particular patient. It therefore may not be possible to extrapolate individual 'characteristics' in order to make a standardised recommendation as to those patients who require a home visit: it is likely to be based on a combination of factors in each individual case. However, in addition to highlighting those characteristics that are particularly important, this dissertation has also indicated how occupational therapists may seek to balance characteristics of the person with the characteristics of the home environment. This research has postulated a novel model that also incorporates external or internal influences on the occupational therapist into this process.

Intuitively it may seem that occupational therapists believe that those patients with the most severe physical and cognitive impairments would need a home visit. However, this was not the case. There were concerns about whether the most physically and

cognitively impaired patients would be able to cope with the demands of the visit. Those with moderately severe disabilities were the most likely. This research also highlighted the importance of cognition within the decision making process. This is a significant addition to the literature, which has so far overlooked the role of the patient's cognition in this process.

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Appendix A: Interview Topic Guide

HOVIS Study – Topic guide for telephone interviews with senior Occupational Therapists

Introduction

We are undertaking these interviews because our study is very interested in Occupational Therapists' decision making processes about which people who have had a stroke are offered a pre-discharge home visit, and which are not. We are also interested in OTs descriptions of what pre-discharge home visits involve in practice. The intention of this interview is not to judge or check your decision making or the quality of care you provide, rather we are interested in how and why it is decided that certain patients require a pre-discharge home visit, and others do not.

Consent

I would like to audio record the interview – is that ok? [Turn on recorder] Could you please give your name and consent to be interviewed for the recorder?

Topic areas

- 1) Could you start by briefly introducing yourself and telling me a bit about the service you work in?
 - How many patients are on the ward/in the unit? What is the average length of stay?
 - How many OTs are in the team? What range of grades?
- 2) How many stroke patients do you currently have on your caseload?
- 3) Could you tell me about the purpose of doing pre-discharge home visits for people who have had a stroke?
 - Why are they done? Why is it important that they are done? Should they be done at all?
 - What are the effects/benefits of undertaking home visits for people who have had a stroke? What is their value?
 - Are there any disadvantages to undertaking pre-discharge home visits for people who have had a stroke
 - Could you broadly tell me about what they involve/the content of the visit?
 - How long do they take?
 - Who goes on these visits and why?
 - Do you use checklists? Which ones?
 - How commonly do you undertake either discharge and/or access visits? Why are/would these types of visits completed?
- 4) Could you tell me what happens with the information that is collected on the pre discharge home visit?
 - How is the report/information used?
 - How are issues followed up or passed on to the relevant people?

- 5) Could you tell me about a stroke patient on your caseload that you would do a pre-discharge home visit for, one you wouldn't and one you are not sure about?
 - Could you talk me through how and why you came to that particular decision for each of those patients, and what their home visit will involve?
 - When in their patient journey did it become clear whether they required a home visit or not?
 - Do you complete pre-discharge home visits for patients going into a nursing home? Could you tell me what that would involve?

- 6) Who makes the decision to undertake a pre-discharge home visit for a patient who has had a stroke?
 - The Occupational Therapist? Physiotherapist? Consultant? Patient & family?

- 7) Is there a memorable pre-discharge home visit for a person who has had a stroke that you were involved in that you could tell me about?

- 8) Have you ever done a home visit for a stroke patient where you got there and it was not essential?

- 9) Do you think there are ways in which pre-discharge home visits for people who have had a stroke could be improved?
 - are there ways in which things could be done differently?

- 10) Are there ways in which information about the patient's home environment could be collected differently?

- 11) Have there been any new ways of doing things/changes to the way in which pre-discharge home visits for people who have had a stroke are done?
 - Changes put in place by you or your team? How successful have they been?
 - Changes imposed on the team? Why?
 - Have changes been attempted that were not successful? What happened?

- 12) Is there anything else you would like to say about pre-discharge home visits for stroke patients?

- 13) Is there anything you would like to ask me?

Thanks and end

Appendix B: Trial Recruitment and Screening Log (Blank)

THIS DOCUMENT IS STRICTLY CONFIDENTIAL

Record Form – Participant Screening and Enrolment Log – The HOVIS Study
 Royal Derby Hospital – Stroke Rehabilitation Unit

No.	Name of Participant, DOB and Hospital Number	Date of Admission to SRU	Eligible?*	Decision to be made by (date)	Essential (E)/Trial (T) and date decision made	Investigator Signature and Date
1.						
	Date of Consultation	Entered into the study? Y/N	If N give reason**	Date Consent Obtained	Trial Number	
No.	Name of Participant, DOB and Hospital Number	Date of Admission to SRU	Eligible?*	Date Decision to be made	Essential/Trial	Investigator Signature and Date
2.						
	Date of Consultation	Entered into the study? Y/N	If N give reason**	Date Consent Obtained	Trial Number	
No.	Name of Participant, DOB and Hospital Number	Date of Admission to SRU	Eligible?*	Date Decision to be made	Essential/Trial	Investigator Signature and Date
3.						
	Date of Consultation	Entered into the study? Y/N	If N give reason**	Date Consent Obtained	Trial Number	

Appendix C: Home Visit Essential Decision Form (Blank)

Appendix D: Home Visit Essential Participant Information Sheet

Home Visits after Stroke

'Home Visit' Participant Information Pack

A research study for patients who have had a Stroke is taking place in Derby. We would like to invite you to take part in this study. To help you decide whether to take part, this sheet explains why the research is being done and what it would involve for you. Please take time to read the following information carefully. Talk to others about the study if you wish.

What is the purpose of the study?

Some stroke patients receive a home visit by an occupational therapist, prior to returning home from hospital. This is usually to assess how the patient will manage at home and to identify any equipment and support they may need. Other patients do not receive a visit and instead these issues are discussed with staff in the hospital. There is limited research on the need for home visits and we do not know which of these options is best. For this reason, we are carrying out a study to compare one group of patients who have a home visit with another group of patients who have a hospital based interview.

Why have I been invited to take part?

You have been invited because you have had a stroke and are being treated on the Stroke Rehabilitation Unit at the Royal Derby Hospital, which is the centre for this study. We are inviting everyone who is in a similar situation to you to take part in the study. The ward staff have recommended that you have a home visit with an occupational therapist before you go home.

What will happen to me if I take part?

If you choose to take part all your normal rehabilitation and care will continue and you will receive the home visit as above. In addition, we would like to collect some more information from you. We will carry out some assessments whilst you are still on the Stroke Rehabilitation Unit, which will look at your general health and how the stroke may have affected you. When you have your home visit, information on the visit will also be recorded.

You will then receive two follow-up visits after being discharged from hospital, the first after one week and the second after one month. These visits will be conducted by a member of the research team. They will discuss how you have

been managing since you have returned home/been discharged to a new home. They will also complete some further assessments looking at your general health, emotional and physical abilities. If you would like another person to be present, this can be arranged.

Do I have to take part?

It is up to you to decide whether to take part in the study. You have some time to think about it. The study researchers Phillip Whitehead or Karen Fellows will contact you within two days of receiving this information sheet, to ask if you would like to participate in the study. They will also be able to answer any further questions that you may have. If you do decide to take part, you will be given this sheet to keep, and asked to sign a consent form. Even if you give your consent, you can withdraw from the study at any time, without giving a reason. This will not affect the care you receive.

You will still receive the care normally available even if you decide not to take part in the study.

What will I have to do if I want to take part?

If you decide to take part in the study you do not have to do anything – a member of the research team will contact you on the ward to ask whether you want to take part.

What are the potential benefits of taking part?

There may be no direct benefit to you. However the information we get from the study should help us to determine how to allocate home visits in future. The study also aims to help NHS staff best use the resources available to them when treating stroke patients.

Are there any problems with the study?

At present it is not possible to include non-English speakers, as this is a pilot study. However this research will help us design a larger study, which will include non-English speakers.

Will it cost me anything to take part?

It will not cost you anything to take part. All costs of additional visits will be paid for by the research.

Will my taking part in the study be kept confidential?

Yes. We will follow established ethical and legal practices and all information about you will be handled confidentially. All information which is collected about you during the course of the study will be kept strictly confidential and any information about you will have your name and address removed so you cannot be identified.

Will the research team have access to my medical details?

Yes with your consent. The research team will need to collect basic information about you from the medical notes, such as your date of birth. This information will only be collected once you have consented and will be held in line with the Trust's confidentiality policy.

What will happen if I don't want to carry on with the study?

Your participation is voluntary and you are free to withdraw at any time, without giving any reason, and without your legal rights being affected. If you withdraw then the information collected so far cannot be erased and that this information may still be used in the project analysis. You will continue to receive treatment as normal from the Stroke Rehab Unit.

What if there is a problem?

If you have any concerns about the study you are encouraged to speak to a member of the research team and they will do their best to answer your questions. You can also contact the principal investigator, Dr Avril Drummond. If you remain unhappy and wish to complain formally you can do this through the NHS complaints procedure. The contact details are given at the end of this document.

What will happen to the results of the research?

It is intended that the results of the research will be published formally in scientific journals and published in patient newsletters. You will not be identified in any report or publication.

Who is organising and funding the research?

The research is being organised by The University of Nottingham and CLAHRC NDL (Collaboration for Leadership in Applied Health Research and Care Nottinghamshire, Derbyshire and Lincolnshire), with support of Derby Hospitals NHS Foundation Trust. CLAHRC NDL is funded by *The National Institute for Health Research*.

There is a steering group that meets regularly to advise the research team. The group includes experienced research therapists, a stroke patient representative and a member of the Stroke Rehabilitation Unit multi-disciplinary team.

Who has given permission for the study to be carried out?

All research in the NHS is looked at by an independent group of people, called the Research Ethics Committee to protect your safety, rights wellbeing and dignity. This study has been reviewed and given favorable opinion by Berkshire Research Ethics Committee.

Further information and contact details for the study:

Phillip Whitehead, Research Associate & **Karen Fellows**, Research Occupational Therapist. University of Nottingham, CLAHRC NDL, 9 Triumph Road, NG7 2GT

Tel: (0115) 8231432

Email: phillip.j.whitehead@nottingham.ac.uk or karen.fellows@nottingham.ac.uk

Karen and Phillip will also be present on the ward during the week if you wish to talk to them.

Dr Avril Drummond, Chief Investigator.

Division of Rehabilitation and Ageing, B Floor, Medical School, Queens Medical Centre, Nottingham, NG7 2UH. Tel: (0115) 8230226

Email: avril.drummond@nottingham.ac.uk

NHS complaints procedure

Patient Advice and Liaison Service (PALS) –Royal Derby Hospital

Uttoxeter Road

Mobile: 08007837691

DE1 2QY Derby

Phone: 01332 785156

Out of hours 24 hour phone service text facility 07799337717

NHS direct: 0845 4647

Thank you for taking the time to read this information pack

Appendix E: Trial Participant Information Sheet

Home Visits after Stroke

'Trial' Participant Information Pack

A research study for patients who have had a Stroke is taking place in Derby. We would like to invite you to take part in this study. To help you decide whether to take part, this sheet explains why the research is being done and what it would involve for you. Please take time to read the following information carefully. Talk to others about the study if you wish.

What is the purpose of the study?

Some stroke patients receive a home visit by an occupational therapist, prior to returning home from hospital. This is usually to assess how the patient will manage at home and to identify any equipment and support they may need. Other patients do not receive a visit and instead these issues are discussed with staff in the hospital. There is limited research on the need for home visits and we do not know which of these options is best. For this reason, we are carrying out a study to compare one group of patients who have a home visit with another group of patients who have a hospital based interview.

Why have I been invited?

You have been invited because you have had a stroke and are being treated on the Stroke Rehabilitation Unit at the Royal Derby Hospital, which is the centre for this study. We are inviting everyone who is in a similar situation to you to take part in the study. The staff on the Stroke Rehabilitation Unit have identified you as being suitable for this trial.

What will happen to me if I take part?

If you choose to take part all your normal rehabilitation and care will continue. In addition, we would like to collect some more information from you. We will carry out some assessments whilst you are still on the Stroke Rehabilitation Unit which will look at your general health and how the stroke may have affected you. You will be put into one of two groups by chance (Randomly). We randomise to

make sure that there is a 50% chance of being in either group. The two groups are:

Hospital Interview- An interview before leaving hospital will be completed. Patients will be assessed on the ward and will discuss their home environment in detail with the occupational therapist. They will have the opportunity to discuss any concerns and potential problems. A carer or family member can be involved if the patient would like. Patients will be offered advice on equipment (for example bath seats or rails) as required. They will be referred onto any other services they need (for example, community occupational therapy).

Home visit- A home visit will be completed, before patients are discharged from hospital. Patients will have the opportunity to discuss any concerns and potential problems with an occupational therapist on the visit. A carer or family member can be involved if the patient would like. Patients will be assessed in their home environment and may be offered advice, given practice in transfers and offered equipment (for example bath seats or rails) as required. They will be referred onto any other services they need (for example, community occupational therapy).

All participants

As part of the research all the patients in both groups will receive two follow-up visits after being discharged from hospital, the first after one week and the second after one month. These visits will be conducted by a member of the research team. They will discuss how you have been managing since you have returned home/been discharged to a new home. They will also complete some further assessments looking at your general health, emotional and physical abilities. If you would like another person to be present, this can be arranged.

Do I have to take part?

It is up to you to decide whether to take part in the study. You have some time to think about it. The study researchers Phillip Whitehead or Karen Fellows will contact you within two days of receiving this information sheet, to ask if you would like to participate in the study. They will also be able to answer any further questions that you have. If you decide to take part, you will be given this information sheet to keep, and will be asked to sign a consent form. Even if you give your consent, you can withdraw from the study at any time, without giving a reason. This will not affect the care you receive.

What will I have to do if I want to take part?

If you decide to take part in the study you do not have to do anything- a member of the research team will contact you on the ward to ask whether you want to take part.

What are the potential benefits of taking part?

There may be no direct benefit to you. However the information we get from the study should help us determine how to allocate home visits in the future. The study also aims to help NHS staff best use the resources available to them when treating stroke patients.

Are there any problems with the study?

At present it is not possible to include non-English speakers, as this is a pilot study. However this research will help us design a larger study, which will include non-English speakers.

Will it cost me anything to take part?

It will not cost you anything to take part in the study. All costs of additional visits will be paid for by the research.

Will my taking part in the study be kept confidential?

Yes. We will follow established ethical and legal practices and all information about you will be handled confidentially. All information which is collected about you during the course of the study will be kept strictly confidential and any information about you will have your name and address removed so you cannot be identified.

Will the research team have access to my medical details?

Yes with your consent. The research team will need to collect basic information about you from the medical notes, such as your date of birth. This information will only be collected once you have consented and will be held in line with the Trust's confidentiality policy.

What will happen if I don't want to carry on with the study?

Your participation is voluntary and you are free to withdraw at any time, without giving any reason, and without your legal rights being affected. If you withdraw then the information collected so far cannot be erased and that this information may still be used in the project analysis. You will continue to receive treatment as normal from the Stroke Rehab Unit.

What if there is a problem?

If you have any concerns about the study you are encouraged to speak to a member of the research team and they will do their best to answer your questions. You can also contact the chief investigator, Dr Avril Drummond. If you remain unhappy and wish to complain formally you can do this through the NHS complaints procedure. The contact details are given at the end of this document.

What will happen to the results of the research?

It is intended that the results of the research will be published formally in scientific journals and patient newsletters. You will not be identified in any report or publication.

Who is organising and funding the research?

The research is being organised by The University of Nottingham and CLAHRC NDL (Collaboration for Leadership in Applied Health Research and Care Nottinghamshire, Derbyshire and Lincolnshire), with support of Derby Hospitals NHS Foundation Trust. CLAHRC NDL is funded by *The National Institute for Health Research*.

There is a steering group who meets regularly to advise the research team. The group includes experienced research therapists, a stroke patient representative and a member of the Stroke Rehabilitation Unit multi-disciplinary team.

Who has given permission for the study to be carried out?

All research in the NHS is looked at by an independent group of people, called the Research Ethics Committee to protect your safety, rights wellbeing and dignity. This study has been reviewed and given favourable opinion by Berkshire Research Ethics Committee.

Further information and contact details for the study:

Phillip Whitehead, Research Associate & **Karen Fellows**, Research Occupational Therapist .
University of Nottingham, CLAHRC NDL, 9 Triumph Road, NG7 2GT

Tel: (0115) 8231432

E-mail: Phillip.J.Whitehead@nottingham.ac.uk Karen.Fellows@nottingham.ac.uk

Karen and Phillip will also be present on the ward during the week if you wish to talk to them.

Dr Avril Drummond, Chief Investigator

Division of Rehabilitation and Ageing,

B floor, Medical School

Queens Medical Centre

Nottingham

NG7 2UH

Tel: 0115 8230226

E-mail: Avril.Drummond@nottingham.ac.uk

NHS complaints procedure

Patient Advice and Liaison Service (PALS) –Royal Derby Hospital

Uttoxeter Road

DE1 2QY Derby

Phone: 01332 785156

Mobile: 08007837691

Out of hours 24 hour phone service text facility 07799337717

NHS direct: 0845 4647

Thank you for taking the time to read this information pack

Appendix F: HOVIS Participant Consent Form



The University of Nottingham



National Institute for Health Research



CONSENT FORM

Home Visits after Stroke

REC ref: 10/H0505/41

Name of Researcher:

Name of Participant:

Please initial box

1. I confirm that I have read and understand the..... participant information pack final version two dated 04/5/10 for the above study and have had the opportunity to ask questions.
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, and without my medical care or legal rights being affected. I understand that should I withdraw then the information collected so far cannot be erased and that this information may still be used in the project analysis.
3. I understand that relevant sections of my medical notes and data collected in the study may be looked at by authorised individuals from the University of Nottingham, the research group and regulatory authorities where it is relevant to my taking part in this study. I give permission for these individuals to have access to these records and to collect, store, analyse and publish information obtained from my participation in this study. I understand that my personal details will be kept confidential.
4. I agree to take part in the above study.

Name of Participant

Date

Signature

Name of Person taking consent

Date

Signature

3 copies: 1 for participant, 1 for the project notes and 1 for the medical notes