The LoTS (Longer-Term Stroke) care system of care:

An evaluation of its local implementation at two community stroke services

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The candidate confirms that the work submitted is her own and that appropriate credit has been given where reference has been made to the work of others.

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Abstract

The longer-term problems of stroke are well documented but are often poorly addressed by community services. The Longer-Term Stroke (LoTS) care system of care aimed to address this gap through enhancing the practice of health care professionals termed 'Stroke Care Coordinators'. The system was evaluated in a Randomised Controlled Trial (RCT) that measured patient and carer outcomes in comparison to usual care. These outcomes do not reveal how, why or to what extent the system enhanced the practice of the Stroke Care Coordinators. This study was designed to complement the RCT using a theory-driven approach to explore the implementation and the impact of the system at two community stroke services (both multidisciplinary teams). The theory of change (how and why the system was expected to work) was elicited for comparison against service practice. The study drew on the principles of realist evaluation, which hypothesise that successful outcomes (O) will be realised if appropriate ideas and opportunities (mechanisms (M)) are introduced into appropriate contexts (C). CMO propositions were drawn out from the wider theory for testing at the two research sites. Qualitative methods were employed for data collection including observations of service practice, interviews with stakeholder groups and a review of service documentation. The findings revealed that local facilitators and barriers shaped how the system was implemented, resulting in two distinct applications of the intervention that deviated from the theory of change. The extent to which the system enhanced the Stroke Care Coordinators' practice was dependent on context e.g. their background and experience. Further to this, the system's impact was mediated by the information and support available from within the multidisciplinary teams. For this reason, the extent to which the service enhancements realised in practice impacted on the patient and carer outcomes measured was hard to discern.

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List of Abbreviations

ADL: Activities of Daily Living

IADL: Instrumental Activities of Daily Living

BI: Barthel Index

CMOC: Context Mechanism Outcome Configuration

FAI: Frenchay Activities Index

GHQ-12: General Health Questionnaire

GP: General Practitioner

GW: Generic Worker

HADS: Hospital Anxiety and Depression Scale

ICF: International Classification of Functioning and Disease

LN: Liaison Nurse

LoTS: Longer-Term Stroke

LUNS: Longer-term Unmet Needs after Stroke

MDT: Multidisciplinary Team

mRS: modified Rankin Scale

NHS: National Health Service

OT: Occupational Therapist

PCT: Primary Care Trust

PT: Physiotherapist

PSY: Psychologist

SLT: Speech and Language Therapist

SN: Specialist Nurse

UK: United Kingdom

US: United States

WHO: World Health Organisation

Introduction

There are approximately 111,000 new strokes in the United Kingdom each year (Mohan et al, 2011, Scarborough et al, 2009). Fortunately improvements in inpatient care, underpinned by a strong evidence base, have been shown to reduce death and disability post-stroke (Stroke Unit Trialists' Collaboration, 2007). These improvements mean that more individuals will return to the community setting and it is here that the longer-term problems of stroke, which encompass physical, functional, psychological, emotional, and social domains are fully realised. Developing effective and efficient community stroke services is, therefore, necessary to support stroke survivors over the longer-term. This point is further emphasised as there are political drivers at work to reduce the length of inpatient stay, shifting the provision of ongoing care into the community setting (Thane, 2009).

The recommended care pathway for all stroke survivors in the inpatient setting is the stroke unit, however less progress has been made in developing a comprehensive community stroke service (Ellis, 2010). The Longer-Term Stroke (LoTS) care system of care intended to address this gap in service provision, with the ambitious aim of meeting the diverse needs of community dwelling stroke survivors. The system of care included an assessment booklet (including a post-stroke assessment tool and care plan) and treatment algorithms in the form of a manual (the LoTS care manual). Health care professionals, termed 'Stroke Care Coordinators', were provided with two days training in order to implement the system of care appropriately. To ascertain its superiority over usual practice, the system of care was evaluated in a Randomised Controlled Trial (RCT) that measured patient and carer outcomes. This thesis documents a theory-driven evaluation designed to complement the RCT by examining the system's implementation and impact at two community stroke services (both multidisciplinary teams).

Chapter one provides an introduction to the thesis, defining stroke and its causes and describing the longer-term problems associated with the condition. The disabling effects of stroke are categorised according to the International

Classification of Functioning, Disability and Health (ICF). This classification system demonstrates that post-stroke problems are heterogeneous and manifest in different ways. Rehabilitative interventions can target different areas, they are provided by different professional groups and are delivered in different settings. This thesis focuses on rehabilitation provided in the community setting and interventions provided in this context are reviewed to establish their effectiveness. This review highlights that there are many questions still to answer regarding an optimum post-stroke service. The LoTS care system of care is then described in comparison to the interventions reviewed and presented as a possible solution in longer-term stroke care. The system of care was considered novel; however, it shared characteristics with policy initiatives dating back to the late eighties. These policy initiatives were significant to the LoTS care trial, as they shaped the context in which the system of care was evaluated.

Chapter two reviews the policy initiatives that have attempted to improve the provision of community services. This review demonstrates that using an assessment of need and care management principles (similar to those advocated by the LoTS care system of care) to allocate services appropriately have been a central theme in UK policy for many years. The chapter discusses how weaknesses in early initiatives have been addressed over time by new strategies, and their relevance to the community dwelling stroke population. Stroke was eventually prioritised on the policy agenda with the publication of the National Stroke Strategy in 2007. These national drivers of change shaped the context in which the system of care was evaluated as part of the LoTS care trial. The second half of the chapter argues that the use of the RCT, traditionally viewed as the gold standard in health services research, has limitations when used for the evaluation of complex interventions (such as the LoTS care system of care) inserted into complex social systems (such as community health services). The term 'complex' is defined and the limitations of the RCT discussed. This discussion provides a rationale for the theory-driven approach applied in this study.

Chapter three clarifies the study objectives and the research questions addressed in the thesis. The LoTS care trial asked 'does the intervention work to improve the patient and carer outcomes measured'. The overarching question asked in this

study was 'how does the system of care work to address post-stroke problems'. This question was broken down to focus the study on the implementation of the system of care and how it enhanced service practice i.e. process rather than patient and carer outcomes. The role of theory in the evaluation process and the realist concepts of mechanism, context and outcome are clarified for the reader. The choice to use two intervention sites as case studies is explained as an appropriate strategy to examine the inner workings of the system of care in context. The sampling strategy is clarified, which resulted in the use of two multidisciplinary stroke teams. The methods utilised (observations of service practice, qualitative interviews, document review and respondent validation) are explained in detail. The data collected was organised using the framework approach advocated by Ritchie and Spencer (1994). The analysis process compared the theories of change prioritised for investigation (defined in chapter four) against day-to-day practice. The realist formula, Context + Mechanism = Outcome was influential in this process and was used as an explanatory tool to describe what had worked to enhance service practice, for whom, how and in what circumstances.

Chapter four describes the theory elicitation process and the theories of change prioritised for investigation. The sources used to surface the theory of change are initially clarified. The chapter proceeds by describing the problem perceived by the intervention architects i.e. the problem that prompted the system's development, the system's component parts and the changes in service delivery expected. The changes in service delivery are described as the 'outputs' that were of interest in this study, in contrast to the patient and carer outcomes measured as part of the LoTS care trial. The chapter explains how and why the system of care was expected to generate the outputs anticipated and also discusses some of the negative theories surfaced in the elicitation process i.e. why the system might fail to achieve its aims. The chapter concludes by summarising the theory of change in a logic model from which sub-theories are prioritised for investigation. The sub-theories focus on implementation principles i.e. problem solving, goal planning and the iterative process of assessment, care planning, monitoring and review, and educational and structural mechanisms intended to promote a) the use of evidence based or recommended service responses and b) a comprehensive post-stroke assessment.

Chapter five describes the context of each research site e.g. the composition of each team, their location and the characteristics of their local population. The chapter explains how the physical components of the system of care (the client checklist, the LoTS care manual and the assessment booklet) became embedded in practice and also describes how the components were adapted to meet the specific needs of each service. Chapter six examines the implementation of the system's components, focusing on the principles prioritised for investigation. Examination of these principles highlighted that the Coordinators implemented the intervention components according to established processes, which did not reflect the iterative process of assessment, care planning, monitoring and review envisaged by the intervention architects. Instigating change in the delivery process, therefore, proved a more exacting challenge than embedding the system's physical components. The conclusion drawn from these findings was that the system of care did not enhance service practice in regards to the amount or type of contact provided by the Stroke Care Coordinators.

Chapter seven and chapter eight examine the realist propositions prioritised for investigation in chapter four. The first proposition followed that the educational materials provided to each service, in the LoTS care manual, would be used to address gaps in the Stroke Care Coordinators' knowledge. The output (service enhancement) anticipated was the use of evidence based or recommended service responses to the problems identified. The proposition explored in chapter eight considered whether a stroke specific assessment structure would extend the scope of the Stroke Care Coordinator's assessment, resulting in a comprehensive post-stroke assessment for each service user. Exploration of these propositions revealed that the system of care worked to varying extents, depending on the context, and not always with the outputs anticipated. Further to this, service enhancements were mediated by the support accessed through the multidisciplinary team and the fact that both services had provided a holistic assessment, using tools adapted from the Single Assessment Process, prior to the system of care. The findings are used to refine the starting propositions and their significance to the outcomes measured as part of the LoTS care trial is reflected upon.

In chapter nine the preceding chapters are summarised and the main findings recapitulated. The study findings and methods are reflected upon i.e. their strengths and weaknesses are discussed and alternate explanations considered. The chapter concludes by discussing the implications of the study findings for policy and practice and makes recommendations for future research

Chapter 1: Stroke and the longer-term consequences

1.1   Introduction

Stroke was recognised as a condition by Hippocrates, 'the father of medicine', as early as 300 years BC (Demarin. et al., 2011). Known as apoplexy its reference indicated that someone had been struck done by sudden paralysis, although the specific cause was unknown. For hundreds of years the only established treatment was to feed and care for the patient until the attack had run its course. It was not until the late twentieth century that new technologies, surgical procedures, and pharmaceutical drugs dramatically improved the ability to diagnosis and treat the condition. This chapter provides a brief overview of stroke and its consequences, as an introduction to the thesis. It will describe the causes of stroke and report the mortality, incidence and prevalence rate in the United Kingdom. The economic burden of stroke will also be discussed and a more efficient use of existing resources is suggested to reduce the cost and improve the quality of care.

Improvements in inpatient stroke care have been supported by a firm evidence base, established (largely) through the use of the Randomised Controlled Trial (RCT). However, the disabling effects of stroke, categorised in this chapter according to the International Classification of Functioning, Disability and Health (ICF), are multifaceted and manifest as problems that can endure over the months and years following the incident. For this reason, community services are required to facilitate the rehabilitation process post-discharge from hospital. Some interventions provided in this context are reviewed and demonstrate that the evidence base supporting longer-term stroke care remains an evolving area of research. The Longer-Term Stroke (LoTS) care system of care was a recent attempt to add to the evidence base in this area. The aim of the LoTS care system of care was to address the 'longer-term needs' of stroke survivors; this term will be clarified and the system of care briefly described in comparison to other types of community stroke services.

1.2   Definition of stroke

The World Health Organisation defines stroke as '*a clinical syndrome characterised by rapidly developing clinical signs of focal (or global) disturbance or cerebral function, with symptoms lasting 24 hours or longer, or leading to death, with no apparent origin other than of vascular origin*' (Aho et al., 1980). Stroke results from a haemorrhage (a bleed, which accounts for 15 % of all strokes) or ischaemia (a clot, which accounts for 85% of all strokes) in the brain (National Audit Office, 2010). The damage is usually manifest externally as a unilateral weakness or paralysis most notable in the limbs and face. These symptoms were the subject of a public awareness campaign to treat the condition as a medical emergency (Leatherman et al., 2008). A Transient Ischaemic Attack (TIA) is sometimes known as a 'mini stroke'; by definition symptoms of TIA resolve within twenty-four hours. However, a more severe stroke event can lead to death or permanent disability (Leatherman et al., 2008).

The Oxford Community Stroke Project (OCSP) categorised completed stroke into four subtypes based on presenting signs and symptoms (Bamford et al., 1991). These are, Total Anterior Circulation Stroke (TACS), Partial Anterior Circulation (PACS), Lacunar Stroke (LACS), and Posterior Circulation Stroke (POCS). The classifications indicate the clinical localisation of the stroke (Bamford et al., 1991). They are also predictive of the risk of deterioration with TACS having the greatest risk and LACS the least; deterioration is associated with a worse prognosis (Sprigg et al., 2007). Stroke is, therefore, a heterogeneous condition affecting individuals in different ways depending on the part of the brain affected and the extent of the damage.

1.3   Mortality, incidence and prevalence rates

The World Health Organisation has estimated that 15.3 million people worldwide suffered a stroke in 2002, of which one third (5.5 million) resulted in death (Mohan et al., 2011). In the UK the incidence (new events) of stroke is an estimated 111, 000 each year and accounts for 53,000 deaths (around 9% of all deaths) (Mohan et al.,

2011, Scarborough et al., 2009). It is the third biggest killer after coronary heart disease and cancer and it is a major cause of premature mortality (Cox et al., 2008). The incidence of stroke increases with age, but a significant proportion (approximately 20%) occur in those aged under 65 (Rothwell et al., 2004). Data from the National Audit Office suggested that there were 900, 000 people living with stroke in England (National Audit Office, 2005b). Up to one third of stroke survivors are left with long-term residual disabilities and can remain functionally dependent on carers (often family members) for activities of daily living (Care Quality Commission, 2011, Rothwell et al., 2004). Stroke is also associated with psychosocial problems, which can impact on functional recovery but can also manifest independent of physical disability (Gurr and Muelenz, 2011, Ellis, 2008).

1.4   Economic implications

The economic impact of stroke is considerable and results from a period of hospitalisation (the average length of an inpatient stay in the UK is 28 days) (Cox et al., 2008) and the ongoing health, social and voluntary support that might be required post-discharge from hospital (Cox et al., 2008). Production losses from death and ill health in those of working age, and from the informal care provided to stroke survivors also contribute to the economic burden (National Audit Office, 2005a). In 2006/2007 the economic cost of stroke to the UK was estimated at £4.5 billion, with 56 per cent being attributed to health and social care costs (Scarborough et al., 2009). An alternate estimation, which used a 'bottom-up' approach to calculate costs, has suggested that the total might be much higher at 9 billion per year (Scarborough et al., 2009). The UK is reported to spend as much if not more on stroke services in comparison to other European countries, but achieves poorer outcomes (Bayer et al., 2010). A more efficient use of existing resources has been advocated, involving service reconfiguration along the entire stroke care pathway (Cox et al., 2008), see figure 1 below.

Figure 1: Stroke Care Pathway, adapted from (Leatherman, 2009)
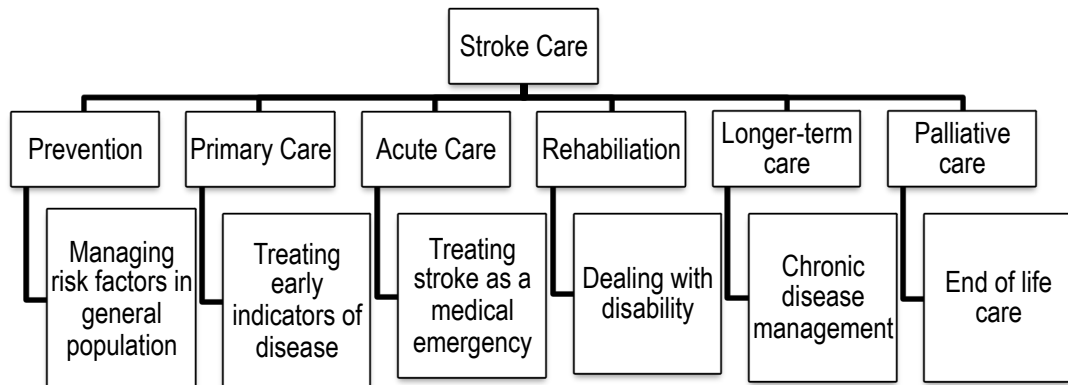
Service reconfiguration could lead to annual savings of up to £20 million, and to fewer deaths and case fatalities (National Audit Office, 2005b). This thesis focuses on the patient pathway following a stroke incident, in particular rehabilitation and longer-term care in the community.

Endeavours to improve health services increasingly focus on the implementation of 'evidence based' practice (Sackett et all, 1997). In health services research the Randomised Controlled Trial (RCT) has generally been regarded as the 'gold standard' for establishing new evidence, since it was first used in 1948 to test the drug streptomycin as a treatment for tuberculosis (Harrison et al., 2010, Hearn et al., 2003, Mol, 2006). The RCT is a form of experimentation, but has a comparative element where a sample is randomly allocated to either receive an intervention or not (Cartwright, 2010). This method provides a powerful tool for establishing cause and effect through isolating the relevant variables, randomising choice, controlling confounding factors and using objective measures (Wade, 2005, Bowers et al., 2006). Explanation by this mode has been referred to as 'successionist', where one thing (the intervention) is thought to lead to another (the outcome) (Pawson, 2008, Dyson and Brown, 2006).

1.5 An evidence-based pathway: inpatient care

The RCT has established a firm evidence base for many aspects of stroke care, particularly in the inpatient setting. For example, Thromboylsis is used to treat certain subgroups of patients with ischaemic stroke by dissolving the obstructing clot and restoring blood flow to the affected area (Sandercock et al., 2008). This treatment has been shown to reduce mortality and residual disability (Sandercock et al., 2008). The Chinese Acute Stroke Trial (CAST) demonstrated that Aspirin reduced the risk of recurrent stroke for individuals with ischaemic stroke (Chen, 1997). The evidence base supporting the use of organised inpatient care (stroke units) has also been established over the last twenty-five years in clinical trials (Stroke Unit Trialists' Collaboration, 2007). A stroke unit is defined as a multidisciplinary team, including specialist-nursing staff that are based on a discrete ward and care exclusively for stroke patients (Wellwood and Langhorne, 2011). Stroke units have been shown to reduce death and disability for all stroke survivors regardless of stroke severity, and the positive effects are sustained over many years (Indredavik et al., 1999, Jorgensen et al., 1999).

The growing evidence base informs the development of guidelines, such as the Royal College of Physicians (RCP) Clinical Guidelines for Stroke (Royal College of Physicians, 2008), and the development of policy at a national level, such as the National Stroke Strategy (Department of Health, 2007). These guidelines provide markers against which services can be monitored through audit and help drive forward service improvement. Data from the most recent audit performed reported that all hospitals treating acute stroke patients in England, Wales and Northern Island have a stroke Unit, and that 95% of individuals with stroke were being treated on such units on the day of audit (Intercollegiate Stroke Working Party, 2012b). However, for many stroke survivors the hospital experience is only the beginning of their rehabilitative journey. Stroke is a disabling condition and the longer-term implications are fully realised when the individual has returned home.

1.6   The disabling effects of stroke

Stroke damages the brain, which impacts on body functions. Hemiplegia refers to the paralysis of the affected side (Marque., 2012). Dysarthria refers to a lack of control over the muscles of speech (Mahler and Ramig, 2012). Two thirds of people experience cognitive impairments, affecting concentration, processing speed and memory (Hoffmann et al., 2010). Hemianopia refers to loss of vision in half the visual field, and diplopia to double vision (Royal College of Physicians, 2008). Dyspraxia describes an inability to perform purposeful movement even though the individual understands the task and has the physical ability to perform it (Vogel et al., 2010). This list is not exhaustive, but demonstrates that stroke can result in multifaceted problems. Not long ago a prevailing attitude was that stroke survivors could not contribute productively to society, for example:

> *The old wives tale was that you had one stroke and then you sat around waiting for a second, or a third or however many it took to kill you. If you had any kind of brain injury affecting your locomotive functions, everyone assumed your life was over* (Lanksa, 2009: p 12)

The physical effects of stroke, particularly those affecting locomotive functions, were considered to prevent participation in the social world. However, attitudes towards disability have changed dramatically in the latter half of the twentieth century. The biomedical and the social model of disability were greatly influential in this process. The biomedical model calls for medical or other treatment or intervention to 'correct' the problem with the individual (Bickenbach et al., 1999). The social model countered that disability was the result of the social environment that did not address the needs of those with physical or mental limitations (Bickenbach et al., 1999). This model requires a political response since attitudes and other features of the social environment are thought to create the problem (Bricher, 2000). An Independent Living Movement has campaigned to change perceptions, attitudes and consequently the law using arguments based on the social model (Power, 2013, Community Care Act (Direct Payments), 1996, The Equality Act, 2010, Pfeiffer., 1993).

Both the medical and social models are useful to understand the effects of disability, but they are also limited by their focus on either the social environment or the individual's physical function. Synthesising elements from both has led to the development of a 'biopsychosocial' model of disability (Jette, 2006). The biopsychosocial model acknowledges that performing a socially accepted activity depends not only on the characteristics of the individual, but also on the social and physical environment in which they live (World Health Organisation, 2013b).This model has informed the International Classification for Functioning, Disability and Health (ICF) developed by the WHO, which aims to provide a unified and standard language for defining health and health related outcomes (World Health Organisation, 2002).

1.6.1   The International Classification of Functioning Disability and Health

The ICF framework is structured around two broad components, 1) body functions and body structure, and 2) activities and participation (World Health Organisation, 2002). Body function and structures describes the anatomy and the physiology/psychology of the human body. Health conditions (diseases, disorders and injuries) can impact on body functions and structures (as discussed in section 1.5), which can lead to activity limitations and/or participation restriction. According to the ICF the impact of disease is also mediated by environmental and personal factors (World Health Organisation, 2002). Environmental factors include social attitudes, architectural characteristics and legal structures, and personal factors include characteristics of the individual, such as gender, age, education levels and coping styles (Wade, 2003). Figure 2 below categorises the impact of stroke using the ICF model.

Figure 2: ICF sets for stroke - adapted from Langhorne et al (2011)

Most relevant body functions affected	**Most relevant activities affected**	**Most relevant restrictions in participation**
• Consciousness orientation and intellectual • Temperament and personality• Energy and drive• Sleep, attention, and memory • Psychomotor and perceptual • Cognitive and seeing• Proprioception and touch• Voice and articulation • Ingestion, defecation, urinary, and sexual • Mobility and stability of joints• Muscle power, tone, and reflexes • Muscle endurance • Control of (in) voluntary movement • Gait pattern functions	• Communicating with and speaking • Reading, writing, and calculating• Solving problems• Undertake single and multiple tasks • Transferring oneself • Maintaining body position • Walking• Mobility• Toileting• Dressing• Moving around, driving, and transportation • Washing and self-care• Hand and arm use• Eating and drinking• Preparation of meals• Use of transportation• Recreation and leisure• Doing housework	• Acquisition of goods and services • Doing housework• Preparation of meals• Basic interpersonal• Recreation and leisure activities• Remunerative employment
Most relevant structures affected • Brain• Cardiovascular system • Leg and arm• Shoulder region		

Most common affected contextual factors (environmental and personal)

• Technology and products for personal use
• Health professionals
• Health services, system, and policies
• Products or substances for personal communication
• House services, systems, and policies
• Support and relationships

The domains in the ICF help set the rehabilitation agenda, currently defined by the WHO as '*a process aimed at enabling people to reach and maintain their optimal physical, sensory, intellectual, psychological and social functional levels*' (World Health Organisation, 2013a). A 'working' definition of rehabilitation has also been provided by Wade (2005) as follows: '*Rehabilitation is an educational, problem solving process that focuses on activity limitations and aims to optimise patient social participation and well-being, and so reduce stress on carer/ family.*' These definitions are broad and numerous interventions can be categorised within the

process described. Interventions can target different domains, they can vary in duration, content, intensity, timing and can be provided in different settings e.g. as an inpatient, or in the community (Wade, 2005).

This study focuses on rehabilitation provided in the community setting; three factors are identified in shifting the provision of rehabilitation to this context, 1) increasing awareness of disability, 2) evidence that rehabilitation has a beneficial effect in reducing dependency, care costs and improving quality of life, and 3) increasing pressure to shorten the time spent as an inpatient (Wade, 2003). The necessity to develop effective and efficient community stroke services is recognised (Ellis, 2008). However, in comparison to inpatient care the evidence base informing this part of the stroke care pathway is less conclusive than that of inpatient care. The literature in stroke rehabilitation is vast. The following section discusses some systematic reviews, in particular those performed as part of the Cochrane collaboration, of rehabilitative interventions provided post-stroke.

1.7 An evidence based pathway: rehabilitation and community stroke care

The longer-term problems of stroke can encompass physical, functional, psychological, emotional and social domains. Specific interventions to address these types of problems include physiotherapy, occupational therapy, information provision and psychological therapies. These interventions are often provided with the aim of increasing levels of activities and participation (Sumanthipala, 2012). Repetitive Task Training (RTT) is an intervention that combines intensity of practice with a functional approach to rehabilitation (French et al., 2007). A Cochrane review aimed to establish whether RTT improved upper or/and lower limb function compared to usual practice or a placebo. The review identified 14 randomised and quasi-randomised trials and included 659 patients recruited between 14 days of the incident and the chronic phase of the condition (French et al., 2007). The pooled data demonstrated that there was an improvement in walking abilities and the execution of activities of daily living (a secondary outcome measure) (French et al., 2007). However, no difference was found in hand or arm function, or sitting balance or reach between the intervention and control groups (French et al., 2007).

RTT was found to improve some of the outcomes of interest; however, the studies included in the review were heterogeneous e.g. they differed in content, timing and duration. For example, one intervention was provided in the patients' home in 30-minute sessions, everyday, over a period of two weeks, whilst another was provided in a rehabilitation centre in 60-minute sessions, 3 times a weeks, over 4 weeks (Dean, 2000, Dean, 1997). It is difficult to specify what type of intervention should be replicated to produce the benefits identified. The authors suggested that further research should investigate the type and amount of training provided and how to maintain functional gains, as there was no evidence that improvements were sustained post-treatment (French et al., 2007).

Occupational therapy aims to promote recovery through participation in occupation i.e. purposeful activities (Legg et al., 2006). These purposeful activities can form the specific goal and the basis of the intervention (Legg et al, 2006). A Cochrane review of occupational therapy interventions, defined as any treatment provided by or under the supervision of an occupational therapist, included 9 trials and 1258 participants (Legg et al., 2006). Participants were recruited at different time points post-stroke, and follow-up was performed between 3 months and one year. The findings demonstrated that those who received the interventions were less likely to deteriorate and more likely to perform personal activities of daily living, these were the primary outcomes of interest (Legg et al., 2006). However, similarly to RTT, the occupational therapy interventions were heterogeneous e.g. one intervention was described as a client centred occupational therapy programme, delivered by a qualified occupational therapist, who also provided liaison with other services, whilst another study evaluated a home based intervention in the use of bathing devices (Gilbertson et al., 2000, Chiu and Man, 2004). The authors of the Cochrane review suggested that the exact nature of the intervention e.g. the intervention components and the organisation and delivery methods, needed to be defined in order to establish what worked to produce the optimum benefit for stroke survivors (Legg et al., 2006).

A review of therapy-based services, delivered specifically in an outpatient setting, considered RCT's of occupational therapy, physiotherapy and multidisciplinary teams provided to individuals living at home up to one year post-stroke. Combining

the data of these different services was justified as they shared a broad aim - to improve task-orientated behaviour e.g. walking, dressing, and some leisure activities. The results from 14 studies (1617 patient) indicated that these interventions improved personal activities of daily living and reduced the odds of a poor outcome (the primary outcomes of interest). However, it was again suggested that more research was needed to define the most effective service, the economic benefits and the most appropriate level of service delivery (Outpatient Service Trialists, 2003). Further to this, there was a paucity of evidence supporting the use of such services after one year post-stroke (Aziz et al., 2008).

Post-stroke problems also include dissatisfaction with information and depression and anxiety (Forster et al., 2012, Hackett et al., 2008). A systematic review of information provision assessed whether this intervention improved knowledge of stroke or stroke services and mood scores. The interventions were categorised as either passive (e.g. dissemination of written materials) or active strategies (e.g. lectures with some follow-up objectives). The findings highlighted an improvement in patient and carer knowledge, some aspects of patient satisfaction and reduced depression scores (Forster et al., 2012). However, the reduction in depression scores was small and thought to be clinically insignificant (Forster et al., 2012). Further to this, there was not much evidence that information provision impacted on other areas of recovery, such as independence or social activities, which are two outcomes prioritised in the rehabilitation process (Forster et al., 2008, Wade et al., 2009). A Cochrane review of pharmaceutical treatment and psychotherapies to treat post-stroke depression included 17 studies (13 pharmaceutical and 4 psychotherapy interventions). There was some evidence that pharmaceutical treatments reduced depression scores, but there was also an associated increase in adverse events. There was no benefit in receiving psychotherapy, which included studies of problem solving and motivational interviewing (Hackett et al., 2008). The conclusions were that more research was needed before recommendations could be made regarding the use of these treatments.

The interventions reviewed targeted specific problems e.g. functional problems, information provision and depression. Although many questions remain regarding an optimum service, clinical and national guidelines recommend that stroke survivors

should have access to ongoing rehabilitation and support post-discharge where necessary (Intercollegiate Stroke Working Party, 2012, Department of Health, 2007). However, stroke survivors have reported feeling abandoned and isolated on returning home (Ellis et al., 2010, Murray et al, 2003a). The Stroke Liaison Worker is one service that has attempted to address this problem; it is a multifaceted intervention, which offers two or more of the following, 1) emotional and social support, 2) information provision, and 3) liaison with other services. The role was thought to facilitate access to community resources that were associated with good outcomes in a number of domains, see figure 3 below.

Figure 3: Resources and Threats (Ellis, 2008)
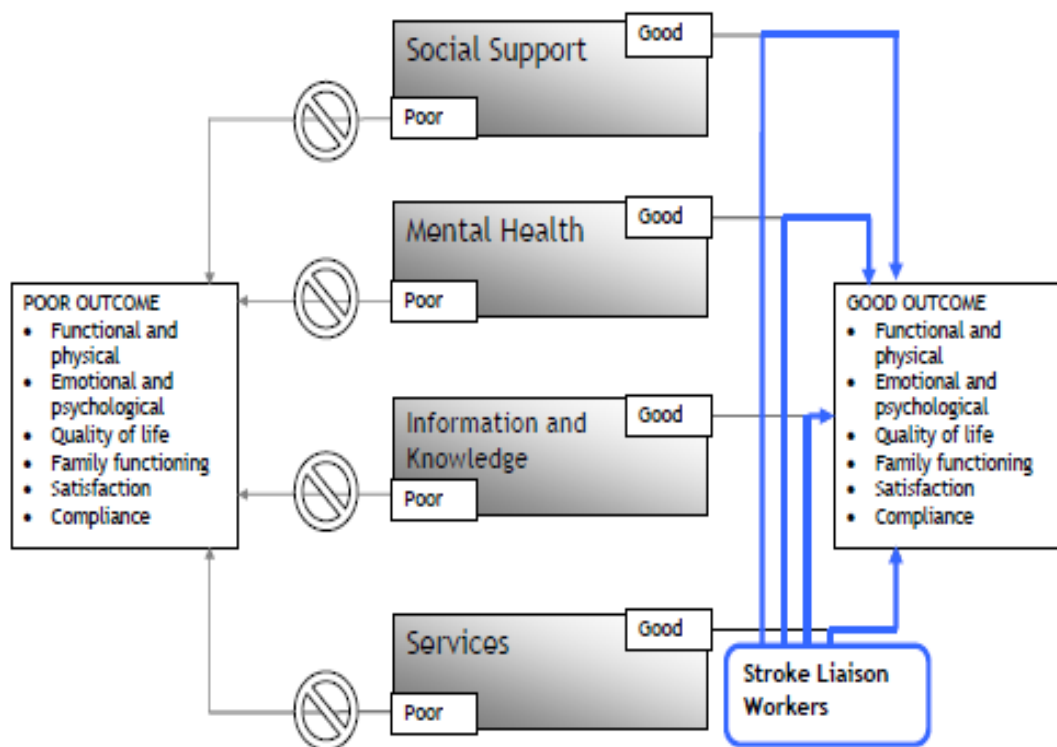
A meta-analysis of 16 RCTs of the Stroke Liaison Worker service included interventions delivered by a health or social care professional or a voluntary worker and considered whether the intervention improved participation and quality of life (Ellis, 2008). The authors identified 3 subgroups of the intervention 1) proactive and

structure, 2) reactive and flexible and 3) proactive and focused (Ellis et al., 2010). The pooled data demonstrated that there was no patient benefit from accessing a Stroke Liaison Worker service compared to usual care for the primary outcomes of subjective health status or extended activities of daily living. However, some improvement was observed in those with mild to moderate disability, and patients and carers were said to report improved satisfaction with some aspects of service provision.

One of the main difficulties in synthesising this data, as discussed by the study authors, was identifying a primary outcome. The interventions consisted of a broad range of activities and there was no clear underlying 'mechanism of action' from which an appropriate outcome could be isolated (Ellis et al., 2010). The RTT interventions were based on assumptions about how the intervention might work to restore function i.e. repetition of movement is hypothesised to reduce muscle weakness and spasticity and forms the physiological basis of motor learning (French et al,. 2007). Therefore the RTT intervention aims to restore strength and coordination, which would enable functional tasks to be performed and measured as outcomes. In comparison, the Stroke Liaison Worker service was described as developed on an intuitive and pragmatic basis (Ellis et al., 2010). For this reason, the links between their activities and the numerous outcomes measured in the included studies were unclear (Ellis., 2010). For example, information provision was one function of the intervention; this might result in increased knowledge, however it is unclear how or to what extent knowledge is linked with subjective health status or extended activities of daily living (Ellis et al,.2010). Therefore the outcome selected might not be the area impacted most by the multifaceted intervention.

This discussion incorporates evidence from systematic reviews of clinical trials i.e. evidence considered 'the gold standard' of health services research. However, many questions remain regarding an optimum community stroke service. Some of the main questions presented regard the implementation of the intervention e.g. timing, duration and frequency; an area not thoroughly examined using the trial design, which prioritises outcomes. Most rehabilitative interventions are considered complex, defined as '*interventions that are not drugs or surgical procedures, but have many potential 'active ingredients'. A complex intervention combines different*

components in a whole that is more than the sum of its parts' (Oakley et al., 2006). Accurately describing rehabilitation interventions has been discussed as a methodological issue in their evaluation (Wade et al., 2009, Wade, 2005). The limitations of the trial design when evaluating complex interventions are discussed further in chapter two, section 2.9. The studies reviewed here demonstrate that describing an effective comprehensive community stroke service that benefits all stroke survivors remains an evolving area of research. The LoTS care system of care (the focus of the current study) aimed to address this gap in service provision through evaluation in a Randomised Controlled Trial (referred to hereafter as the LoTS care trial). The main features of the system are discussed below in comparison to the interventions described.

1.8   The LoTS care system of care

The aim of the LoTS care system of care (referred to hereafter as the system of care) was to address the needs of community dwelling stroke survivors. To achieve this aim the system of care offered health care professionals, termed Stroke Care Coordinators, a 16-domain assessment tool to facilitate problem identification. The assessment domains linked, where possible, to evidence based or recommended treatment algorithms presented in a manual (the LoTS care Manual). The intervention architects envisaged that the Stroke Care Coordinators would use an iterative process of assessment, problem solving, care planning, monitoring and review to implement the system of care. These principles were advocated at two training days provided to the intervention group. The intention was to improve the identification of post-stroke problems, which would then be linked in a care plan to appropriate service responses, provided by the Stroke Care Coordinator or external agencies. Unlike the therapy-based services discussed, the system of care shared characteristics with the Stroke Liaison Worker service i.e. it targeted numerous problems rather than focusing on mood or task orientated behaviour. However, it also differed from these interventions as it aimed to provide a comprehensive, structured and evidence based approach, informed by systematic reviews of the literature that reported patient and carers post-stroke problems. These problems are described in more detail following the section below, which clarifies the term 'longer-term needs' and how this was measured as part of the LoTS care trial.

1.9   Defining 'longer-term needs'

There is no standard definition for the term 'longer-term' in stroke care. The RCP Clinical Guidelines for Stroke (2012a) suggests that stroke survivors have their needs reviewed at six-months, whereas the National Stroke Strategy (2007) suggests that a stroke review be performed at six weeks, six months and annually thereafter i.e. there is no clear beginning or end for the provision of longer-term stroke care (Sumathipala et al., 2012). Some studies have considered the period between one and five years post-stroke as the remit of long-term stroke care (McKevitt et al., 2011, Sumathipala et al., 2012). In regards to the LoTS care system of care service users recruited to the LoTS care trial completed the selected outcome measures at baseline (recruitment to the trial), 6 months and at one year, this marked the end of their involvement in the LoTS care trial. Therefore, the expectation was that the system of care would have some impact within this time frame.

Similarly to 'longer-term' there is no standard definition for the term 'needs'. Bradshaw (1972) provides a taxonomy of social need which distinguishes between normative, felt, expressed, and comparative need. Normative need describes the professional viewpoint, for example, a need for immunisation. Felt need is an individual's experiences e.g. a shoulder pain or a headache. Expressed need is the articulation of the felt need i.e. a request for help or support. Comparative need is established by reference to a user receiving a service that might be required by others with similar characteristics (Bradshaw, 1972). Using this taxonomy 'need' is dependent on the perspective used e.g. a risk factor, such as smoking, might reflect a 'normative need' for cessation; however, smoking cessation might not reflect a felt or expressed need of a service user.

In the remit of health services a distinction is also made between the need for health care and the need for health. The need for health care commonly refers to the capacity to benefit from the provision of a health service (Wright et al., 1998). A need for health care is met when it has received an intervention that is at least partially successful, however defining needs in this way is thought to promote the

medical model of care (Asadi-Lari et al., 2003). The need for 'health' is broader, it is defined by the WHO as, '*a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity*' (Awofeso., 2013). This definition was coined in 1948 and was said to overcome the more negative view of health, which was considered as the absence of disease (Huber et al., 2011). However, it is also criticised as being idealistic, categorising the majority of people as lacking health (Huber et al., 2011). These varied definitions serve to highlight that 'need' is a complex concept and not easily defined, and consequently not easily addressed or measured.

In regards to the system of care the term 'need' was used interchangeably with 'problems' and 'experiences' in the system of care's development papers (Murray et al., 2003b, Murray et al., 2003a). However, the system appeared to target stroke related problems that were reported by stroke survivors and their carers after discharge from hospital. Problems might manifest as a need for health, social or voluntary services, others might require the provision of information or advice. The components of the system were designed to improve the identification of stroke related problems and link these to appropriate service responses i.e. to enhance the role of the Stroke Care Coordinator. To establish the superiority of the system of care over usual practice several outcomes were measured. The primary outcome was the General Health Questionnaire (GHQ)-12, secondary outcomes included the Frenchay Activities Index (FAI), the Barthel Index (BI), and the Longer-term Unmet NeedS (LUNS), which was a checklist of unmet needs developed in the same programme of research as the system of care. Therefore, although the articulated aim was to address post-stroke needs, success was primarily measured using a psychological outcome and activities of daily living (personal and extended). The links between addressing post-stroke need and the outcomes selected were not made clear.

One way in which the system of care differed from previous interventions was that its component parts were mapped against the longer-term problems reported by stroke survivors and their carers. Qualitative and quantitative reviews of the relevant literature were performed with this purpose (Murray et al., 2003a, Murray et al., 2003b); the findings of which are discussed in more detail in the following section.

1.10 The longer-term problems reported by stroke survivors

Researchers based at the Academic Unit of Elderly Care and Rehabilitation (AUECR), University of Leeds developed the system of care. These researchers performed the literature reviews that informed the development of the system of care. The qualitative literature review identified problems that were said to represent patient and carer experiences of the later stages of their stroke recovery, as opposed to a professional viewpoint (Murray, 2003). Five domains and fourteen sub-domains were used to categorise the problems identified, see table 1 below for overview. These domains informed the subsequent quantitative review that identified prevalence rates and added an additional domain 'other'. The new domain accounted for health related complications, including continence, shoulder pain and falls (Murray et al., 2003b). Prevalence estimates were identified for ten of the original fourteen sub-domains; the exceptions were 'hospital experience of therapy', 'hospital experience of critical events', 'post-discharge abandonment' and 'verbal communication'. Prevalence estimates are also shown in table one.

Table 1: Longer-term problems associated with stroke

Domain	Sub Domain	Prevalence Estimates (%)
Hospital experience	Therapy	None identified
	Critical events	
Transfer of care	Process	33-100
	Preparation for living at home	
	Abandonment	
Communication	Written	32-81
	Verbal	
Services	Social services	13-77
	Health	
	Cross cutting service issues	
Social and emotional	Mood	Social and relationships: 17-46
	Social changes	
	Attitudes to recovery	Emotional and psychological: 11-62
	Self perception and relationships	
Other	Incontinence, shoulder pain and Falls	10-73

Social and emotional problems were the largest domain accounting for 39% of all problems identified in the qualitative review. Examples of the problems categorised in this domain included isolation from family and friends, abandonment after termination of services, depression, reduction in leisure activities, unemployment, and loss of identity (Murray et al., 2003a). Service provision was the second largest domain and represented 29% of all problems identified in the qualitative review. Issues with both primary care and therapy services were raised e.g. individuals were unhappy with the lack of contact with their General Practitioner (GP) and with social workers. Delays in the provision of aids and adaptations were also a recurring problem, as were the absence of longer-term reviews (Murray et al., 2003a). Patients and carers also reflected upon negative hospital and discharge experiences e.g. being unprepared physically and psychologically for their discharge home. Deficiencies in relevant written information including information about their condition, services, social provision and benefits were also a common theme. The complementary needs of carers were also identified. Carers experienced difficulties coping with their new role, and experienced depression, tiredness, and ill health (Murray et al., 2003a).

The authors recognised that many of the problems identified were not new e.g. depression and anxiety following a stroke are well documented (Hackett et al., 2005, House, 1987). However, the reviews provided insight into patient and carer experiences and established a framework on which to develop a comprehensive community stroke service including the 16 domain assessment. This framework distinguished the system of care from previous interventions and it was thought to be the first of its kind in the UK (Murray, 2007). However, meeting the needs of service user through the process of assessment, care planning and review has been a central theme of government policy for many years. The significance of this to the system of care will be explored further in the following chapter.

1.11 Summary

The last twenty years have witnessed many changes in the provision of stroke care, particularly in the hospital setting. These changes have improved outcomes for stroke survivors by reducing death and disability. However, for many individuals the

hospital experience is one stage of a much longer journey. The full impact of stroke is realised when the individual has returned home. The problems experienced in the community setting are multifaceted and can cross physical, functional, psychological, emotional and social domains. Community services are required to support stroke survivors and facilitate the ongoing rehabilitation process where necessary. However, the evidence informing an optimum outpatient service remains an evolving area of stroke research. The LoTS care system of care was developed to address this gap in service provision. However, it was implemented in a context where similar initiatives were at work. Chapter two will examine some of these initiatives and their significance to the community dwelling stroke population and consequently the LoTS care trial.

Chapter 2: Coordinating community stroke services

2.1 Introduction

This chapter reviews policy initiatives that have shaped the provision of community care over the last 25 years and discusses their strengths and weaknesses in regards to the community dwelling stroke population. The chapter begins by describing individuals' who might require community care, including stroke survivors. The dilemma facing various governments has been how to address the needs of this diverse group in a resource and cost effective manner. The initiatives reviewed will highlight that an assessment of need and care management principles i.e. strategies similar in nature to the LoTS care system of care, have been a recurring theme in government policy for many years. These themes were echoed in the National Stroke Strategy published in 2007, which made recommendations to improve the entire stroke care pathway. The discussion emphasises that the context in which the system of care was evaluated, like the intervention itself, was complex and shaped over many years by national drivers of change.

The second half of this chapter considers the strengths and weaknesses of the trial design. Traditionally the RCT has been viewed as the 'gold standard' in health services research. However, this experimental design has been unable to provide a conclusive evidence base for longer-term stroke care, this was emphasised by the interventions reviewed in chapter one, section 1.7. There are a number of limitations of using the RCT to evaluate complex interventions inserted into complex social systems; some of these are forwarded as a possible explanation for the inconclusive findings to date, using examples from the stroke rehabilitation literature. The limitations of the RCT provide a rationale for the current study, which used a theory-driven approach to examine the implementation and impact of the system of care at two stroke services participating in the LoTS care trial.

2.2   Individuals in need of community care

In the context of this thesis 'community care' can be defined as: *'providing the right level of support to enable people to achieve maximum independence and control over their own lives*' (Department of Health, 1989). This sentence refers to individuals who reside outside the hospital environment in their own homes, or who are in residential or nursing homes (the community). The definition of community care is equally broad as the term rehabilitation (defined in chapter one), and the '*right level of support*' might require the services of health, social, voluntary and/or housing organisations. Individuals who are in need of such support form a heterogeneous group, for example:

'*Many people need some extra help and support at some stage in their lives, as a result of illness or temporary disability. Some people as a result of the effects of old age, of mental illness, including dementia, of mental handicap or physical disability or sensory impairment, have a continuing need for care on a longer-term basis. People with drug or alcohol related disorders, people with multiple handicaps and people with progressive illness such as AIDS or multiple sclerosis may also need community care at some time*' (Department of Health, 1989 p.10)

Stroke survivors can cross the boundaries of traditional user groups e.g. stroke is more prevalent with age and individuals might be categorised as the frail elderly, or they might have a pre-existing health condition such as diabetes. However, the disabling affects of stroke (described in chapter one) can impact on individuals regardless of their age or pre-stroke health. Problems that persist in the longer-term are multifaceted, encompassing emotional, social, functional, physical, and psychological domains, and will vary depending on the severity of the stroke incident. Administering the '*right level of support*', therefore, presents a challenging problem and is likely to cross organisational boundaries.

Chapter one described a number of factors driving rehabilitation into the community

setting (Wade, 2003). One of these factors was the desire to reduce the prolonged use of hospital beds, and this has been a focus of government policy for many years. The latter half of the twentieth century saw the gradual run down of many long-stay institutions (Means et al., 2008, Sharkey, 2000). The shift from institutionalised to community care had many triggers e.g. a belief that community care would improve the quality of life of older and disabled people, and improved medical knowledge and treatments (Thane, 2009). The most influential driver (arguably) was the belief that community care was cheaper to provide when demand for and the cost of care was growing (Thane, 2009). The retraction of long-term hospital care meant that community services, in particular health and social care, were responsible for meeting the needs of an increasing number of people. At this time the two services worked as separate organisations with split funding streams (Means et al., 2008, House of Lords, 2013). This separation was recognised as a barrier to the provision of coordinated community services and led to a number of reforms to the health and social care system (Weiner et al., 2003).

2.3   Health and social care reforms

Many stroke survivors (as well as other service users) will require the services of both health and social care to remain independent in the community. Various strategies have been employed to promote collaboration between these two organisations. In 1995 a government circular responded to concern that health services were withdrawing too far from community care arrangements; this stated that health services should define their responsibilities in collaboration with the local authority (LAC(95)5, 1995). In 1997 the Government sought to modernise the health and social care system and break down traditional boundaries - the so called 'Berlin Wall' (Glasby, 2003). The modernisation agenda introduced 'partnerships' with pooled budgets and encouraged joint commissioning arrangements (Walter, 1999, Department of Health, 1999b) The National Service Frameworks, introduced over the same period, included standards that promoted collaborative working and set milestones against which progress could be monitored (Department of Health, 2005a, Department of Health, 2001b, Department of Health, 1999a).

The extent to which collaboration has been achieved is debateable and new

strategies continue to form part of government policy (Hudson, 2002, Health and Social Care Act, 2012). However, coordinating service delivery at the level of the service user has also been a policy aim. To coordinate has been defined as '*to bring into order as parts of a whole*' (Ovretveit, 1998). The concept of case management was introduced to the UK with this purpose in the NHS and Community Care Act (1990) and the NHS Improvement Plan (2004) (Thornicroft, 1994, Huxley, 1993). There is no standard definition for the term 'case management', however there is general agreement that its primary components include the identification of a population group, assessment of their needs, care planning, linking and coordinating, monitoring, evaluation and advocacy (Norris et al., 2002, Bryant and Bickman, 1996). Another central theme is that an individual or team take responsibility for meeting the needs of their service users (Oeseburg et al., 2009, Franklin et al., 1987).

Evidence suggests that case management can improve outcomes for a range of long-term conditions including diabetes, mental health, and the frail elderly (Norris et al., 2002, Lim et al., 2003, Zigarus and Stuart, 2000). However, models of case management vary in form and function, and do so according to the system within which they are applied (Franklin et al., 1987). Examples include the 'brokerage model', which aims to coordinate services whilst containing costs through preventing inappropriate use of services (Zwarenstein et al., 2009). The self managed care model, in which the case manager empowers the service user with the knowledge and confidence required to manage their own care (Zwarenstein et al., 2009), and Assertive Community Treatment (ACT), which has been distinguished from other models in several dimensions including lower case loads, delivery through a team who can address numerous problems (rather than through onward referral), and an emphasis on outreach (Zigarus and Stuart, 2000). This list is not exhaustive, it demonstrates that models of case management share characteristics but can have very different aims.

Evaluations of case management interventions demonstrate their heterogeneous nature. For example, Norris (2002) found that both case and disease management improved glycemic control and provider monitoring of gylcemic control for people with diabetes. Lim (2003) used case management to facilitate the transition between

the hospital and community for older people (those aged over 65 and older). The findings from this study demonstrated that case management improved quality of life scores in the intervention group at one month and reduced the length of inpatient stay, if hospital readmission occurred (Lim et al., 2003). These results apply to specific user groups and to different models of care with different aims. Further to this, the health care system in which case management is applied varies between countries. For these reasons, research findings must be interpreted with caution when seeking to apply similar models in the UK.

2.4   Care management and assessment in the UK

Case management was initially advocated in the late eighties in the 'Griffiths Report' and the White paper 'Caring for people' (Griffiths, 1988, Department of Health, 1989). The term 'care' was used in the NHS and Community care Act (1990) as 'case' was considered offensive and it was the care (not the case) that was being managed (Thornicroft, 1994). Care management and assessment were considered the 'cornerstone' of good quality care (Lewis et al., 1997, Thornicroft, 1994). The aim was to allocate resources according to the needs of the service user, in contrast to the fragmented service led approach previously employed (Weiner et al., 2003, Department of Health, 1990, Department of Health, 1991). Care managers were budget holders (usually from social services) and were expected to perform an assessment that crossed health and social care boundaries, organise a package of care based on the findings and perform follow-up objectives, see table 2 below (Thornicroft, 1994).

Table 2: Care management processes, adapted from Thornicroft (1994)

Determining level of assessment	Making an initial identification of need and matching the appropriate level of assessment to that need.
Assessing need	Understanding individual needs relating them to agency policies and priorities, and agreeing the objectives for intervention.
Care Planning	Negotiating the most appropriate ways of achieving the objectives identified by the assessment of need and incorporating them into an individual care plan
Implementing the care plan	Securing the necessary resources or services
Monitoring	Supporting and controlling the delivery of the care plan on a continuing basis
Reviewing	Reassessing needs and the service outcomes with a view to revising the care plan at specified intervals

As budget holders the care manager would also act as a 'rationing agent' (Lewis et al., 1997), i.e. helping to achieve the policy aim of controlling and, where possible, reducing public expenditure (Sharkey, 2000). Pilot projects conducted in the UK had demonstrated that care management reduced health and social care costs by up to one third (Challis et al., 1987). However, recommendations from this research were made with reference to the elderly and targeted a specific group within this population i.e. those who were at highest risk from readmission to hospital or residential care (Means et al., 2008, Challis et al., 1987). The authors of the pilot projects emphasised that extending care management to the wider population would not necessarily result in the same reduction in costs (Means et al., 2008, Lewis et al., 1997). Nevertheless policy documents suggested that care management should be provided to all clients and its implementation was rolled out nationwide (Lewis et al., 1997).

The NHS and community Care Act (1990) marked a turning point in community care policy. The act introduced the concept of a 'needs led' assessment i.e. identifying the individuals multifaceted needs and allocating services appropriately in response (Sharkey, 2000). In theory care management would provide a seamless service,

crossing organisational boundaries to meet service user needs (Sharkey, 2000); however, the extent to which individuals, including stroke survivors benefitted from this new approach is hard to discern. Practitioners at 'street level' had to interpret contradictions in the policy e.g. they were expected to provide a needs led package of care but had limited funds with which to achieve this (Sharkey, 2000, Parry-Jones and Soulsby, 2001). One way of coping with limited funding was to narrow eligibility for the service. Table 3, below, provides and example of an eligibility criteria; when care management was first introduced a local authority might be able to respond to the first three categories, whilst in later years this might be retracted to categories one and two (Sharkey, 2004).

Table 3: An example of care management eligibility criteria (Sharkey, 2004)

Category one	High priority: an emergency or crisis point has been reached
Category two	Medium priority: a high level of need is assessed
Category three	Low priority: A need appears to exist and a response from the social authority is appropriate
Category four	Non-priority: help may be desirable, but it is not essential that it comes from the social service authority

The change in the assessment from 'service' to 'needs' led was also problematic. There was little guidance that clarified the concept of 'need' to the care managers or how this should be reflected in their assessment process (Parry-Jones and Soulsby, 2001, Abendstern et al., 2008). Therefore, the 'needs led' rhetoric in policy documents was not necessarily translated into practice. Stroke survivors can have multiple ongoing needs, but these might not require intervention from health or social care services. For this reason, stroke survivors were potentially overlooked by the care management approach, which, due to financial restraints, prioritised those at highest risk of institutional care and did not clarify how needs should be identified. Concern grew that care management was not reducing the cost of care or meeting the needs of specific user groups (Stewart et al., 2003, Thane, 2009).

These problems were addressed, to a certain extent, as part of the governments 'modernisation agenda' in the form of the National Service Frameworks (Means et al., 2008). The National Service Frameworks targeted specific user groups e.g. Older People, people with Diabetes, people with Coronary Heart Disease and Long-Term Conditions (Department of Health, 2001a, Department of Health, 2001b, Department of Health, 2000a, Department of Health, 2005a). High priority was placed on the targets and milestones documented within these frameworks as a way of driving forward health and social care improvement (Department of Health, 2000b). Stroke did not have a dedicated framework, however, the National Service Framework for Older People contained one standard that addressed the condition, and this is discussed further below.

2.5   The National Service Framework for Older People

The aim of standard five (stroke) in the National Service Framework (NSF) for Older People was to '*reduce the incidence of stroke and ensure that those who have had stroke have prompt access to integrated services*' (Department of Health, 2001b). A large proportion of the recommendations focus on the acute period of care, for which there was a growing evidence base. However, the role of Stroke Coordinator was advocated to provide advice to patients, arrange reassessment when their needs or circumstances changed, coordinate their long-term support and arrange specialist care (Department of Health, 2001b). The details of who should provide this role and their competencies were not made clear in the document (Murray et al., 2003a). In a recent survey 219 clinicians were contacted to establish whether the role existed within their locality. There were 126 responses, but only 39 Coordinators were used in the survey (46 clinicians reported that there was no such role available in their area). The responses indicated that the role had not been widely implemented; therefore access to this service was limited across localities. Further to this, the survey revealed much variation in role including timing, frequency of contact with service users and in the content of the assessment process (Murray et al, 2008). Therefore, the evidence suggested that the Stroke Coordinator role was not a panacea for longer-term stroke problems. However, recommendations for longer-term stroke care also referred back to standard two of the NSF for Older People.

The aim of standard two was to ensure that '*older people are treated as individuals and they receive appropriate and timely packages of care which meets their needs as individuals, regardless of health or social care boundaries*' (Department of Health, 2001bp.23). This aim would be achieved (partly) through the implementation of the 'Single Assessment Process' (Clarkson et al., 2009). The Single Assessment Process was based around four levels of assessment 1) a Contact assessment which recorded basic patient data, 2) an Overview assessment, which provided a holistic overview of the individuals need, 3) a specialist assessment, performed by experts in specific areas, and 4) a Comprehensive assessment, which was also holistic but designed for those with complex needs that compromised their independence (Wilson et al., 2005). The Single Assessment Process intended to address the weaknesses in care management through, 1) reducing duplication through encouraging the use of a joint care plan, 2) promoting a greater degree of standardisation, and 3) providing a more holistic approach to the assessment (Abendstern et al., 2008).

The NSF for Older People addressed some gaps in care management, stipulating what areas should be addressed as part of a holistic assessment (see appendix i) and stating that everyone aged 65 and over should receive an assessment when in contact with health or social care services. Some positive impacts were reported e.g. there was a definite shift towards the coverage of the domains advocated (see appendix i, Department of Health, 2001b), which meant that areas previously neglected were being considered e.g. problems with cognitive ability (Abendstern et al., 2005, Challis et al., 2006). However, the extent to which the assessment process was standardised was hard to discern, as many areas used locally developed tools instead of those accredited by the Department of Health (Challis et al., 2007). This variation raised questions about transferability and comparability between areas (Challis et al., 2010a, Challis et al., 2007). Further to this, implementation of the Single Assessment Process began at a time of considerable change in community care. For this reason, isolating the effect of this policy change from other initiatives, such as Fair Access to Care Services (FACS), was hard to discern (Challis et al., 2007).

The inclusion of stroke in the NSF for Older People associates the condition with this demographic (those aged 65 and older) and means that stroke survivors (aged 65 and over) were assessed using tools designed specifically for this population. Stroke is more prevalent with age, however, a significant amount of people under 65 are also affected by the condition (Department of Health, 2007). For this reason, a holistic post-stroke assessment needs to consider individuals of all ages and their associated needs, such as returning to work, an area not included in the Single Assessment Process. The Stroke Coordinator might have addressed these issues, but access to this service was variable, as was the content of the role. However, another initiative, introduced shortly after the NSF for Older People, targeted all long-term conditions regardless of the individual's age and is discussed further below.

2.6   A model of service delivery for Long-Term Conditions

A long-term condition has been defined as '*any condition that requires ongoing medical care, limits what one can do and is likely to last longer than one year*' (Hudson, 2005). Unplanned hospital admission by those with long-term conditions and the associated cost has continued to be the subject of UK health and social care policy (Hudson, 2005). In 2004 a public service agreement set a target for a 5% reduction in emergency bed usage (HM Treasury, 2004). The publication of the NHS Improvement Plan introduced the role of Community Matron with which to achieve this aim (Department of Health, 2005b). However, the role of Community Matron formed one part of a model of care (influenced by US systems) for long-term conditions that stratified individuals according to their level of need, see figure 4 below.

Figure 4: The Kaiser Permanente triangle

Level 3:
Case
Management
High complexity

level 2: Disease
Managment

High risk

Level 1: Self management
70-80% of LTC population
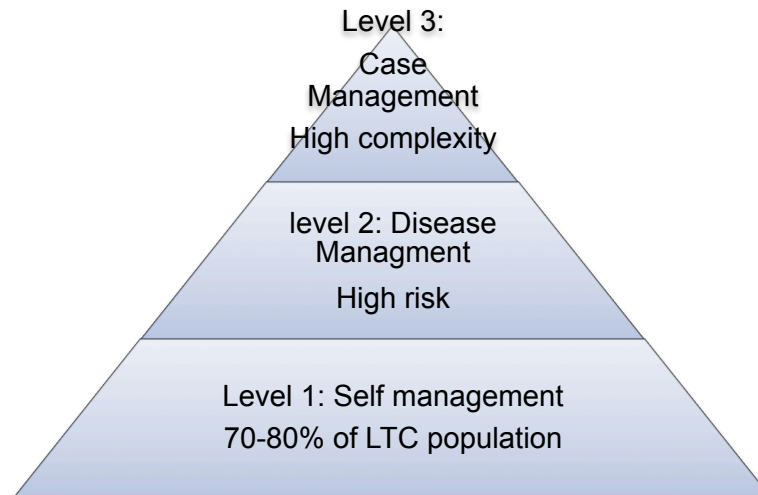
According to this model high intensity users of unplanned secondary care would receive case management provided by Community Matrons. Community Matrons were expected to have specific competencies in order to clinically manage complex needs (Drennan et al., 2011, Hudson, 2005). The implicit assumption was that medical management in the community was poor and that this was the cause of unplanned hospital admission (Drennan et al., 2011). The case load of the Community Matron was to be kept small (around 50-80 patients) i.e. targeting the most vulnerable service users (Hudson, 2005). The target set by the government was to have 3000 community matrons employed by 2007, however this was never achieved (Hudson, 2005, Drennan et al., 2011). Implementation of the role varied and was hindered by confusion over funding arrangements, the identification of appropriately qualified nurses and duplication with existing roles at a local level (Challis et al., 2010b, Drennan et al., 2011). Pilot projects evaluating this type of case management also indicated that there was no reduction in the cost of care, which may also provide explanation as to why more Community Matrons were not employed (Gravelle et al., 2007).

Disease management would be delivered by community multidisciplinary teams and targeted people with one or multiple conditions (Department of Health, 2005b). The teams would use disease specific protocols and pathways, such as the National

Service Frameworks to manage the individual's condition(s). A named contact would be allocated to act as an initial point of contact for the service user, to help them navigate services and to support their access to members of the multidisciplinary team where appropriate (Department of Health, 2005b). The use of teams in the provision of community care has a long history (Ovretveit, 1998) and in the area of rehabilitation they are generally regarded as superior to a single practitioner working alone (Wade, 2003). Community stroke teams have been in existence for many years, for example, Geddes and Chamberlain (2001) described 4 types of coordinated, multidisciplinary, community stroke services (Early Supported Discharge rehabilitation, Post-Discharge rehabilitation, G.P. orientated post-stroke rehabilitation and late community rehabilitation) (Geddes and Chamberlain, 2001). The services were introduced in response to the Community Care Act (1990) and national initiatives such as the Health of the Nation and were developed according to local needs (Geddes and Chamberlain, 2001). However, these teams were not comparable as they varied in their target population, timing and duration (Geddes and Chamberlain, 2001). Further to this, in 2007 only 32% of NHS trusts reported having community based stroke teams, which suggests that access to this type of service is limited across localities (Murray et al., 2008).

According to the stratification system, the majority of individuals would receive services to develop their knowledge, skills and confidence in order to self-manage their condition (Department of Health, 2005b). These principles reflect the self managed care model of case management (Zwarenstein et al., 2009). Strategies in this tier of the triangle include initiatives such as the 'expert patient programme' that intend to make individuals 'experts' at navigating the health and social care systems (Hudson, 2005).

There are obvious parallels between stroke and other long-term conditions. Stroke survivors could be stratified to all three levels of the triangle, depending on the severity of their incident and other factors. However, stroke has gradually been prioritised on the policy agenda as a separate condition. The necessity to improve stroke services was highlighted in 1988 by the Kings Fund Consensus, in a report that was extremely critical of the organisation and delivery of stroke services in the UK (Kings Fund, 1988). The years that followed saw an increase in stroke research,

the introduction of the RCP Clinical Guidelines for Stroke (the first edition was published in 2000 with new editions in 2004, 2008 and 2012 (Wise, 2000, Intercollegiate Stroke Working Party, 2012a)), and the establishment of the National Sentinel Stroke Audit (Langhorne and Rudd, 2009, Intercollegiate Stroke Working Party, 2012a, Rudd et al., 2001). The audit process highlighted deficiencies in the provision of services in key areas of the stroke care pathway and in 2005 recommended that stroke form a greater part of national priority (National Audit Office, 2005b). Concerns about the provision of stroke care, and the slow implementation of evidence based recommendations culminated in the publication of the National Stroke Strategy (2007).

2.7 The National Stroke Strategy

The National Stroke Strategy stated that only half of stroke survivors received the rehabilitation they required to meet their needs in the first six months after discharge from hospital, and that a third of people developed depression or communication difficulties (Department of Health, 2007). Therefore, a service response was required to address these deficiencies. Twenty quality markers were provided in the National Stroke Strategy that were derived from the RCP Clinical Guidelines for Stroke, the relevant National Service Frameworks, the emerging evidence base and consultation with stake holder groups (Department of Health, 2007). The quality markers were developed to drive forward improvement in the entire stroke care pathway. Unlike previous guidance documents an entire chapter including nine quality markers was dedicated to life after stroke. Quality marker 14 referred to the processes of assessment and review and stated that a good assessment process would involve a '*multidisciplinary, person-centred assessment of needs and signposting to other services, such as housing and transport*' (Department of Health, 2007) The Single Assessment Process was provided as an example of how this might be achieved i.e. drawing on the recommendations in the National Service Framework for Older People and consequently care management principles. The strategy also stated that stroke survivors should receive a review of their health and social care status within six weeks of discharge from hospital, again before six months and annually: '*to facilitate a clear pathway back to further specialist review, advice, information, support and rehabilitation where required*' (Department of

Health, 2007). These reviews were not evidence based, but informed by expert opinion and therefore stipulated markers of a quality stroke service.

In 2010 the National Audit Office re-examined the provision of stroke care in follow up to the critical report published in 2005 (National Audit Office, 2010, National Audit Office, 2005b). Whilst improvements in the acute stages of care were identified, deficiencies in the longer-term care remained (National Audit Office 2010). Consequently, the Department of Health committed the NHS to a year of accelerated improvement in stroke care, which launched in April 2010 (NHS Improvement Programme, 2008). Nine aspects of the National Stroke Strategy were targeted including quality marker 14 'assessment and review' and quality marker 10 'delivering high quality specialist rehabilitation' (NHS Improvement Programme, 2008). However, recent surveys have indicated that stroke survivors needs are not adequately addressed by existing services and that novel methods are required to address this problem (McKevitt et al., 2011).

The LoTS care system of care had the potential to provide a solution; its articulated aim was to address the longer-term needs of stroke survivors. The system of care was implemented within established community stroke services that provided a coordinating or liaison role termed the 'Stroke Care Coordinator'. Therefore the context in which the system of care was evaluated was, and continued to be, shaped by national initiatives attempting to improve community stroke services. Many of these initiatives were similar in nature to the system of care i.e. based around an assessment of need, care planning and follow-up objectives. There are a number of limitations when using the Randomised Controlled Trial to evaluate a complex intervention (such as the LoTS care system of care) inserted into a complex social system (such as a community health service), these are discussed in more detail in the following section.

2.8   Randomised Controlled Trials and complex interventions

As discussed in chapter one (section 1.7), a complex intervention in health services can be defined as '*interventions that are not drugs or surgical procedures, but have many potential 'active ingredients'. A complex intervention combines different components in a whole that is more than the sum of its parts*' (Oakley et al., 2006). The LoTS care system of care falls within this catergory, as do many other interventions e.g. the Stroke Liaison Worker. Randomised Controlled Trials of the Stroke Liaison Worker have resulted in inconclusive and sometimes contradictory findings (Forster et al., 2009, Forster and Young, 1996, Friedland, 1992, Allen et al., 2009, Dennis et al., 1997, Lincoln et al., 2003, Mant et al., 2000). More recently the results of the LoTS care trial found no significant difference between the intervention and control group in the outcomes of interest including the GHQ-12, the BI, the FAI and the LUNS. Explanations to account for these results include poorly defined interventions and the use of inappropriate outcome measures, the use of non-stroke specific outcomes, and the reliance on other community services (Ellis et al., 2010, Dennis et al., 1997, Boter and for the HESTIA Study Group, 2004, McKevitt et al., 2004, Tilling, 2005).

Explaining the results of clinical trials (success or failure) can be problematic, as the trial design prioritises outcome rather than process measures; therefore the intervention often remains a 'black box' (Rychetnik et al., 2002, Oakley et al., 2006, Stame, 2004, Pope and Mays, 1993). For this reason, if successful, the parts of the intervention that need to be replicated to produce a similar outcome remain unclear (Pope and Mays, 1993). An example often cited is that of the stroke unit, a complex intervention shown to be effective in reducing death and disability for all stroke survivors in clinical trials and subsequent meta-analyses (Stroke Unit Trialists' Collaboration, 2007). However, the active ingredients that worked to produce these outcomes have not been definitely established (Langhorne et al., 2002, Whyte and Hart, 2003). The literature on specific rehabilitative interventions, reviewed in chapter one, further emphasises this point. Most reviews highlighted a need to define the content, duration, frequency and timing of the intervention to understand what has produced the benefits identified. It is argued that the strengths of the trial design are particular to the evaluation of certain types of intervention, Berwick (2008) commented:

To study a linear, mechanical or natural tightly coupled causal relationship most efficiently an OXO design (such as an RCT) may be exactly correct. But with social changes, multicomponent interventions some of which are interpersonal all of which are non-linear, in complex social systems then other richer but equally disciplined ways are needed. (Berwick, 2008)

The 'OXO design', to which Berwick refers, describes the process of observe (O), introduce an intervention (X) and observe again (O) (Berwick, 2008), i.e. the 'successionist' view of causality described in chapter one (section 1.5) (Pawson, 2008). For example, in the Chinese Acute Stroke Trial (CAST), individuals were allocated to either the intervention (received aspirin) or to the control group (do not receive aspirin). The outcome observed (O) was recurrent stroke and this was significantly reduced in the intervention group i.e. aspirin worked to reduce the risk of recurrent stroke. Aspirin worked because of its affect on the blood platelets within the body. The mechanism of action was, therefore, physiological and more easily described than most at work in more complex rehabilitative interventions (Whyte and Hart, 2003). In comparison to aspirin, health care professionals were expected to interpret and implement the components of the system of care before it could impact on the patient outcomes observed in the LoTS care trial. The mechanisms of action assumed to be at work, as in many other complex interventions, were therefore social in nature and effectiveness depended on the ability to change human behaviour (Davidoff, 2009).

If the mechanisms of action are unknown, selecting an appropriate outcome to measure effectiveness becomes problematic. For example, in the meta-analyses of the Stroke Liaison Worker service, reviewed in chapter one, Ellis (2008) described that the interventions were developed on a pragmatic and intuitive basis and therefore lacked a clear underlying mechanism of action. For this reason, it was unclear which outcome, from the numerous targeted, would be effected most by the multifaceted intervention (Ellis, 2008). Defining a good outcome is also dependent on the perspective used e.g. commissioners might prioritise service costs, physiotherapists walking speed, whereas stroke survivors might prioritise their pre-stroke level of activities (McKevitt et al., 2004). Qualitative studies have indicated

that the benefits of receiving the Stroke Liaison Worker service might be less tangible i.e. not easily quantified using standardised measures prioritised by the trial design (Lilley et al., 2003, Dowswell et al., 1997).

In the evaluation of complex interventions the links between the intervention and the outcome of interest are not always apparent and usually form part of a much longer chain than those observed when evaluating less complex interventions. Further to this, the context in which complex interventions are implemented are also characterised as complex adaptive systems (Begun et al., 2003). Distinctive features of such systems include feedback loops that crucially shape how change occurs; behaviour, which emerges unpredictably from the interaction of the parts, and the system's ability to adapt through learnt experience (Begun et al., 2003). Community health services (the context for the LoTS care trial) could be described as complex adaptive systems, they change and adapt over time in response to national and local drivers of change. Therefore, contextual circumstances might also impact on the outcomes observed and need to be considered in the evaluation process. Instead of imagining the trial design as a comparison of 1) a site with intervention on and 2) to an identical site with intervention off, it has been suggested that a more appropriate comparison might be to consider that of, 1) a complex adaptive system thrust into a complex adaptive system and 2) another complex adaptive system (Pawson et al., 2004).

2.9   Opening the 'black box' in evaluation research

The Medical Research Council has made recommendations to inform the development and evaluation of complex interventions (Campbell et al., 2000, Craig et al., 2008). Among other things these recommendations advocate the use of theory in the development phase, feasibility testing and embedded evaluations of process (Craig et al., 2008). The system of care underwent a thorough development process including empirical work and literature reviews to inform its component parts and feasibility testing (Murray et al., 2006). The system of care was also evaluated using a 'pragmatic' design, therefore adaptations between localities was expected, as in routine practice (Macpherson, 2004). Some authors argue that complex

interventions can be evaluated using an experimental design, as long as the mechanism(s) of action underpinning the intervention are at work across the intervention sites (Hawe et al., 2004). However, others suggest that the complexity inherent in the intervention and in the context in which they are implemented, mean that the trial design is simply not appropriate in some circumstances (Mackenzie et al., 2010, Keen and Packwood, 1995, Blamey and Mackenzie, 2007).

Conceptualising the trial as a complex intervention inserted into a complex social system certainly requires approaches, other than an RCT, to understand how the intervention has worked to produce which outcomes. The use of theory-based evaluation in health services research is now widely advocated (Berwick, 2008, Davidoff, 2009). Blamey and Mackenzie (2007) describe that, '*for the theory based evaluator programmes are not monoliths, and people are not passive recipients of opportunities, to improve their health, wealth and social standing offered through various initiatives, and context is key to understanding the interplay between programmes and effects*' (Blamey and Mackenzie, 2007 p440-441). Realist evaluation is a form of theory-based evaluation that asks, what is it about the intervention that has worked, for whom, how and in what circumstances, in contrast to, does the intervention work, as in the trial design. A theory-based approach, which drew on the principles of realist evaluation, was adopted in this study. The aim was to complement the LoTS care trial through examining the implementation and impact of the system of care at participating stroke services.

2.10 Summary

Stroke survivors join a substantial group of people who require ongoing support post-discharge from hospital. This chapter has considered some national strategies that have attempted to coordinate care inputs on their behalf. The concept of case management has been extremely influential in this process; promoting a needs led assessment, care planning, and the use of follow-up objectives. Community stroke care has developed within this context and has been the recent target of an accelerated improvement initiative. The LoTS care system of care was delivered in this context i.e. within existing community stroke services. Like many policy initiatives the system of care was designed for use nationwide, but malleable to local

circumstances. Experimental research designs, such as the Randomised Controlled Trial, do not fully account for how complex interventions are embedded, implemented or work in local contexts. Without consideration of these factors it is often difficult to explain the study findings. The current study was designed to complement the LoTS care trial using a theory-driven approach to examine the inner workings of the system of care in context. The methodology is described in detail in the following chapter.

Chapter 3: Methodology and methods

3.1   Introduction

This chapter explains the purpose of the study and justifies the choices made in the research design. The broad objectives and the research questions addressed in the thesis are initially clarified reiterating that the study was evaluative in nature and aimed to complement the LoTS care trial. To examine the inner workings of the system of care a theory driven approach, drawing on the principles of realist evaluation, was applied. This approach was considered appropriate to illuminate the black box often found in experimental research. Two community stroke services were selected as case study sites. The sampling strategy will be clarified demonstrating that variation in context was initially sought. Following this, the multiple methods employed to perform the inquiry including observations of service practice, interviews with stakeholder groups, a review of service documentation and respondent validation will be described. Finally, the discussion will focus on the process through which the data was reduced and organised for the purpose of analysis and interpretation.

3.2   Research objectives and questions

The longer-term problems of community dwelling stroke survivors are well documented, but are not adequately addressed by existing community services (Murray et al., 2007). The Stroke Association family support worker was an early attempt to bridge the gap where formal services ended and informal care began (Pound and Wolfe, 1998). Interventions using specialist nurses and social workers have also been employed to address the longer-term problems of stroke (Claiborne, 2006, Forster and Young, 1996). Unfortunately a meta-analyses of these types of intervention found no significant difference between the intervention and control group in the outcomes of interest (Ellis et al., 2008). This study considers a more recent attempt to address post-stroke problems using the LoTS care system of care (referred to hereafter as the system of care). The system of care offered heath care professionals termed 'Stroke Care Coordinators' new resources and two training days to enhance their practice. The aim of this study was to examine how the

system of care enhanced the Stroke Care Coordinator (referred to hereafter as Coordinators) service using a theory-driven approach. The broad objectives were:

- To elicit the programme theory - to interrogate the assumptions behind the system of care to discover how and why it was supposed to work.
- To examine the implementation of the system of care and identify points at which the programme theory applied or failed to apply.
- To provide feedback on how future stroke care interventions could be designed, implemented and targeted.

Theory-driven evaluators argue that the explicit or implicit programme theory should be integrated into the inquiry process. For example, Pawson and Tilley (1998) describe programmes as 'theories incarnate'; if this is the case then evaluation should involve a test of these theories. Programme theory consists of a set of statements that explain how, why and under what conditions a particular programme or intervention (in the case of this study the system of care) will produce the desired effects, and describe what needs to be done to bring these effects about (Sidani and Sechrest, 1999). Evaluation by this mode examines the connections between provision of the programme resources and the anticipated outcomes. To fulfil the research objectives the overarching question asked in this study was, 'how does the system of care work to address post-stroke problems?' This question was broken down further into:

- How was the system of care's components implemented in routine practice?
- How and to what extent did the system of care enhance service delivery?

These questions focused the empirical inquiry on the inner workings of the system of care i.e. its contribution to problem identification and resolution. The intention was to complement the LoTS care trial (a methods driven approach) by examining how the system of care unfolded in practice and the changes it generated in service delivery. Theory-driven approaches, in particular realist evaluation, are increasingly used in health services research (Manzano-Santaella, 2011, Malone et

al., 2003, Byng et al., 2005, Greenhalgh et al., 2009). The following section describes how theory was used in this inquiry.

3.3 Programme theory evaluation

There are many types of theory but a commonality among them all is that they try to interpret phenomena, although at varying levels of generality. Social theory ranges from 'grand theories' that attempt to explain at a societal level, such as the Health Belief Model to empirical generalisations that are based on observed data and are unexplained observed patterns (Bass, 1995, Harrison et al., 1992). The terms theory-driven (Chen and Rossi, 1983), theory-based (Weiss, 1997), theories of change (Blamey and Mackenzie, 2007) and realistic evaluation (Pawson and Tilley, 1997) are all used in the literature to describe programme theory evaluation. Theory can be used for different purposes within these approaches, but all require that the theory underpinning the programme is elicited to inform the evaluation process, they consider programmes in context and utilize all methods appropriate for the empirical inquiry (Stame, 2004).

Two discrete conceptualisations of programme theory were considered in the current study. The first relates to the hypothesised links between the programme activities and its outcomes. Weiss (1998) describes this as implementation theory, Chen as prescriptive theory (Chen., 2005). Both assume that if activities are conducted as planned with sufficient quality, intensity and fidelity then the desired results will be forthcoming (Weiss, 1998). The second type of theory refers to the hypothesised causal links between the mechanisms released by an intervention and their anticipated outcomes (Blamey and Mackenzie, 2007). Weiss (1998) refers to this as programme theory, Chen as descriptive theory (Chen., 2005), and realist evaluators refer to this as the 'middle range theory'(Pawson and Tilley, 1997). Weiss (1998) terms the combination of both types of theory the 'theory of change'. This term was used in the current study to describe the theory elicited as both aspects were examined (see chapter four). However, the principles of realist evaluation, which explore the relationship between mechanism, context and outcome were largely drawn upon to guide the empirical inquiry (Pawson and Tilley, 1997).

3.4   Principles of realist evaluation

The principles of realist evaluation are based in theory-driven approaches but are rooted in scientific realism (Marchal et al., 2012). Realist ontology distinguishes between the real (generative mechanisms), the causal (the events which are produced) and the empirical (observation of events) (Ekstrom, 1992). Social regularities are explained as a result of underlying causal mechanisms that trigger the observed patterns of behaviour, but only in certain circumstances (Manzano-Santaella, 2011). Therefore the sucessionist view of causality established through experimental designs (described in chapter one) is replaced with a generative view, as Pawson notes: '*The causal explanation, in other words, is not a matter of one element (X), or a combination of elements (X$_1$.X$_2$) asserting influence on another (Y), rather it is the association as a whole that is explained*' (Pawson, 2008). Put simply this mode of inquiry aims to explain what has worked, for whom, how and in what circumstances.

The generative mechanisms described are not the programme's resources but what they offer to participants and how they are acted upon (or not) to produce the outcomes observed. An example provided by Weiss (1998) is as follows; in a programme of contraceptive counselling where the intention is to reduce the number of teen pregnancies (the outcome), the mechanism is not the counselling itself, however, it could be the knowledge that the participants gained through attending the sessions, or an increase in their confidence levels which enables them to assert themselves. Using realist principles, therefore, people are not passive recipients of new resources, Greenhalgh and colleagues (2004, p 598) noted they '*find (or fail to find) meaning in them* [the intervention]*, develop feelings (positive and negative) about them, challenge them, worry about them, complain about them, 'work around' them, gain experience with them, modify them and try to improve or redesign them*' . For this reason, an attempt is made to identify the ways in which the resources offered to participants permeate into their reasoning and compares this against what happens in practice (Pawson and Tilley, 1997).

In this study the principles were adapted slightly. The outcomes of interest were not those measured as part of the LoTS care trial (patient and carer outcomes), but the

changes in service delivery i.e. service enhancements (outputs) that were at the centre of the change efforts. The mechanisms considered, therefore, were those expected to generate change in professional practice and service delivery, not in the emotional or functional capabilities of the service users, as measured in the LoTS care trial. However, consideration was given to how changes in service delivery might have contributed to the patient outcomes observed.

Complex interventions are unlikely to work indefinitely, in the same way or in all circumstances, as Manzano-Santaella (2011, p21) described: '*They* (the programme) *bend because of differences in local conditions, funding contingencies, political impetus, staff turnover, policy fashions and so on. Above all they change because from the start they meet with varying success'*. Context is therefore fundamental when explaining outcomes and operates at a variety of levels. These levels are often categorised as micro (individual), meso (group/organisation) and macro (national/political) phenomena (Fulop et al., 2001). Figure 5, below, depicts the types of phenomena that might exert influence over community stroke services and consequently the implementation of the system of care.

Figure 5: Levels that influence service organisation and delivery
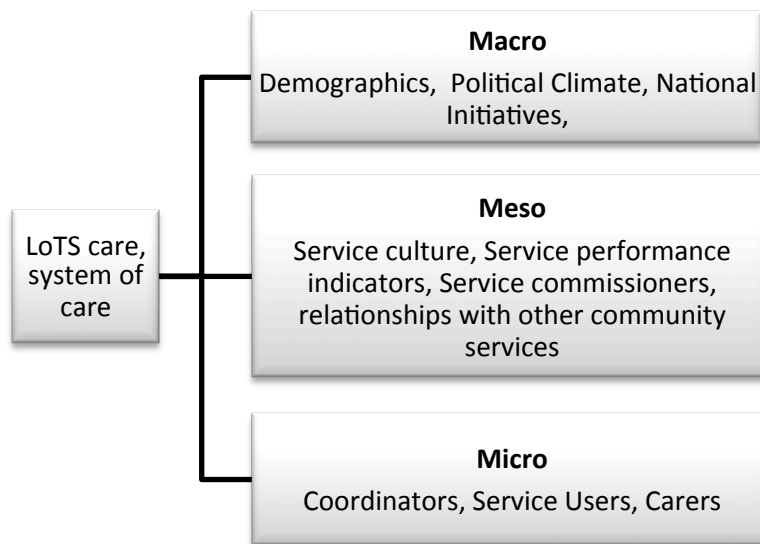
The system of care targeted the micro level, however, in the delivery of health services phenomena at all levels can exert influence e.g. politicians decide on the level of welfare funding and how this is distributed between areas (macro level), health authorities (meso level) will then make decisions about how to allocate this funding between local services, and health and social care services (micro level) at 'street level' have to manage the 'conflict and dilemmas' created by these decisions (Allen et al., 2004). For this reason, all levels are important considerations in the evaluation process. To cut through some of this complexity realist evaluation hypothesises the causal (M) and situational (C) triggers that will bring about alterations in behaviour, event or state regularities (O)(Pawson and Tilley, 2004). These are known as CMO configurations and are teased out from the wider programme theory for refinement through empirical inquiry, see figure 6 below for research cycle.

Figure 6: Realist research cycle

Refined CMO proposition

What might work for whom and in what circumstances (CMO proposition)

Data collection and analysis (Compare data against proposition)

Selection of appropriate methods and sample
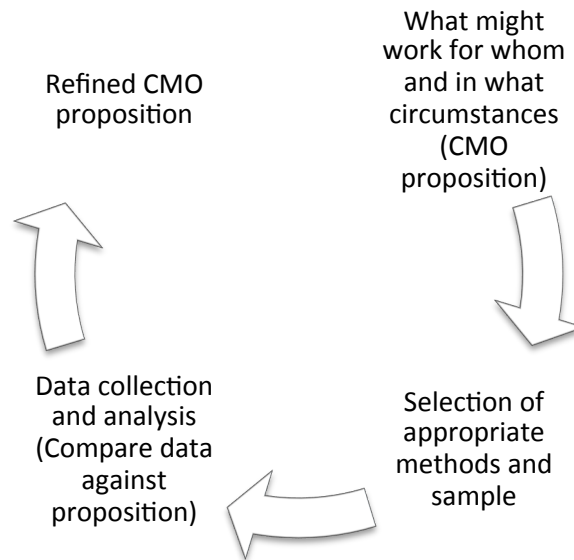
The principles of realist evaluation have gained some popularity in health services research, however difficulties have been noted in the application of the conceptual tools (Marchal et al., 2012). For example, the development of the initial CMO configuration requires knowledge of what contexts are likely to facilitate change, which is not always apparent (Marchal et al., 2012). Distinguishing context from mechanisms has also been noted as problematic (Marchal et al., 2012, Malone et al., 2003, Byng et al., 2005). Researchers have addressed these problems to varying extents by using multiple sources (including stakeholders) to identify relevant CMO propositions, and through acknowledging that multiple mechanisms can operate at different levels. Therefore it is the level of abstraction that helps to differentiate between mechanism and context (Malone et al., 2003, Byng et al., 2005). The process of theory elicitation and the starting CMO configurations used to guide this study are described further in chapter four.

3.5   Using a case study design

Yin (2009, p 18) defines the case study as '*an empirical enquiry that investigates contemporary phenomena within its real life context, when the boundaries between*

the phenomenon and context are not clearly evident; and in which multiple sources of evidence are used', and at least four applications have been described,

1. To explain complex causal links in real-life interventions
2. To describe the real-life context in which the intervention has occurred
3. To describe the intervention itself
4. To explore the situation in which the intervention being evaluated has no clear set of outcomes. (Tellis, 1997)

These applications are well suited to an evaluation using realist principles, which explore the relationship between context, mechanisms and outcomes using any method appropriate. The aim of the study was to explain how a complex intervention (the system of care) unfolded in a complex and dynamic context (a community health service) and to what effect. Case studies are acknowledged as particularly appropriate for this type of inquiry (Fitzgerald, 1989). For this reason, a small and focused empirical inquiry was designed using two community stroke services as research sites.

3.6   Defining the case

Defining the case has been described as one of the methodological issues of using this design. The decisive factor is the choice of the individual unit of study and the setting of its boundaries (Flyvbjerg, 2006). This task can be a complex as the case and context are intertwined and a single case may have several embedded units. For example, defining a hospital as 'the case' may involve looking at data from 1000 patients as the embedded unit (Kohn, 1997). Therefore the events, situations and informants that constitute a case need to be clearly defined. In this study the community stroke service was considered 'the case' and the system of care was the focus of the empirical inquiry within it. The individual units studied to examine how, why and to what extent the system of care enhanced service delivery included:

- The LoTS care team who designed the system of care's components and advocated the principles with which they should be implemented (their contribution is described further in chapter five as part of the theory elicitation process)

- The Coordinators who implemented the system of care on a day-to-day basis

- The managers who had volunteered their services to participate in the LoTS care trial.

- Processes and events that demonstrated the system of care's components at work.

The service was selected as the 'case', as opposed to the Coordinators, as the system of care aimed to enhance different aspects of service delivery i.e. the Coordinators knowledge and skills, and the processes of care employed by the service. The community stroke services had established processes for delivering the Coordinator role. For this reason, an attempt was made to capture how the system of care enhanced the service overall.

3.7   Selecting the research sites

The cases selected in this study were chosen from the services randomised to the intervention arm of the LoTS care trial. These services, therefore, had similarities as they fulfilled the LoTS care trial's eligibility criteria, which had three levels, 1) stroke unit, 2) stroke service and 3) Stroke Care Coordinator. Treatment in a stroke unit is the recommended care pathway for all patients after stroke. For this reason a service was only considered for participation if it included a stroke unit as defined by the Royal College of Physicians, i.e. the presence of four out of the five following criteria:

- Consultant physician with responsibility for stroke;
- Formal links with patient and carer organisations;
- Multidisciplinary meetings at least weekly to plan patient care;
- Provision of information to patients about stroke;
- Continuing education programmes for staff.

If the hospital from which service users were recruited to the LoTS care trial satisfied these criteria, the community stroke service was eligible to participate. A community stroke service was defined as either an individual community Stroke Care Coordinator or a community stroke team that includes one or more Stroke Care Coordinator. A Coordinator was classified as working in a team if they attended regular (i.e. weekly/fortnightly) community multidisciplinary meetings. The Coordinators were considered eligible for participation if they:

- Were a registered healthcare professional with documented experience in stroke care;
- Undertook a community based/liaison or coordinating role for stroke patients;
- Were in contact with patients and coordinated a range of longer-term care inputs on their and their carers' behalf (e.g. signposting, carrying out assessments);
- Worked within a stroke service as above.

These criteria were taken from the LoTS care trial protocol (V4.0 18-03-09). In total 32 stroke services satisfied the eligibility criteria and sixteen were randomised to deliver the system of care. The cluster randomisation performed stratified the sample according to 1) the quality of the stroke unit, 2) the referral rate to the service, 3) whether Coordinators worked alone or within a community multidisciplinary team and 4) strategic health authority, see table 3 below for overview of intervention services.

Table 4: Intervention services

NETWORK	No. of services	Individual	Team
North West	4	2	2
North East	2	0	2
Northern Ireland	1	0	1
Wales	2	1	1
West Midlands	1	0	1
Peninsula	1	0	1
Scotland	1	0	1
South East	1	0	1
Trent	1	0	1
No SRN	2	1	1
Total	16	4	12

Cases are usually selected based upon expectations about their information content (Silverman, 2001). Different strategies can be employed to inform this process e.g. single cases may be used to confirm or challenge a theory, or to represent a unique or extreme case (Flyvbjerg, 2006). Maximum variation is used to explore the significance of specified differences on the phenomena of interest (Flyvbjerg, 2006). Two services were selected in this evaluation based on the premise of maximum variation. This type of sampling was considered appropriate, as the intention was to examine the influence of context on the implementation of the system of care. Therefore it was of interest to look for differences that might impact on this phenomenon.

A survey completed by the services participating in the LoTS care trial revealed further variations than those used in the stratification process e.g. whether service users were subject to an eligibility criteria, and how often Coordinators visited service users. To identify services using maximum variation a meeting was held with the programme manager, the trial manager and the chief investigator of the LoTS care trial. During this meeting the survey was used to inform the selection process, however, pragmatic considerations were also involved in the final choice e.g. the

researcher was based in Leeds and had to access the services frequently, and within a designated budget and time frame. These considerations are a common feature of case study research and are sometimes necessary to maximise what can be learned in the period of time available for the study (Frankfurt-Nachmias and Nachmias, 2000). The variations sought were:

- Individual/ team stroke care coordinator – to assess the influence of team structure, interactions and resources on the delivery of the system of care
- Professional background of the stroke care coordinator – to assess the influence of different disciplines on the assessment and care planning processes.

Obviously these variations did not reflect all differences, but were those prioritised for investigation in the services that were accessible to the researcher. Two individual Coordinators and two community teams were selected for approach. This provided two 'back-up' services in case the first choices were unable to participate or had to withdraw from the study.

It must be noted that the sampling strategy employed in this study deviated from the traditional approach used by realist evaluators. Realist principles emphasise the role of programme theory in sample selection i.e. the sample should reflect the contexts that are thought to trigger the mechanisms of action, as articulated in the CMO proposition. Using this logic the theory is tested in contexts where it seems most likely to hold true. The theory can then be refined through empirical work, which will either support or refute that the mechanism was activated (or not) in that particular context. In this study the significant contexts concerned the characteristics of the Coordinators (articulated in chapter four). However, information about these characteristics was not available to the researcher at the time of sampling. For this reason, the sample choice was guided by the pragmatic considerations and contextual differences discussed i.e. those that were known to the researcher. However, empirical work considered context at the service and Coordinator level. Therefore, it was established whether the significant contexts were apparent in order to test and refine the starting CMO propositions.

3.8   Generalising from a case

The ability to generalise from one or a small number of cases is a common criticism of case study (and qualitative research) research. Statistical generalisation uses a sample from a wider population that is 'powered' to detect whether the results have occurred through chance (Bowers et al., 2006). However, it is suggested that the potential for learning from case studies is different and sometimes superior to being representative (Stake, 2000, Tellis, 1997). Other authors refute statistical generalisation in favour of 'analytic generalisation', Yin (2009) describes that; *'in analytic generalisation, previously developed theory is used as a template against which to compare the empirical results of the case study'*. For example, the Theory of Planned Behaviour (TPB) has been used to explain professional behaviour change in an inquiry on knowledge translation (Ramsay et al., 2010). If the empirical work supports the theory, the theoretical constructs should be used to inform future behaviour change strategies. The focus of the empirical inquiry in this study was to provide data to support/refute and ultimately refine the CMO proposition prioritised for investigation. These are also known as the 'middle range theories', defined as:

> *Theories that lie between the minor but necessary working hypothesis that evolve in abundance during day to day research and the all inclusive systematic efforts to develop a unified theory that will explain all the observed uniformities of social behaviour, social organisation and social language* (Merton, 1949, p 39)

Using the principles of realist evaluation explanatory theory becomes a mechanism that explains why an individual or group of individuals (within a particular context) respond in a particular and relatively predictable way to an intervention (or aspects of an intervention) (Manzano-Santaella, 2011). Successful CMO propositions can then be tested in future empirical work for further refinement i.e. it is the ideas that are transferable beyond the study context. However, a further aim of the study was to help interpret the LoTS care trial outcomes. Examining the 'black box' i.e. the implementation processes and the mechanisms of change was intended to provide insight into how the system of care contributed to problem resolution, and consequently the quantitative outcomes measured as part of the LoTS care trial.

3.9   Research methods

When using a theory-driven approach the individual units can be studied qualitatively, quantitatively, or using mixed methods. It is the nature of the problem and the theories of interest that should determine the methods used (Kohn, 1997). In this study the phenomenon of interest was the system of care and its implementation within two community stroke services. To understand how the intervention unfolded in this dynamic and multi-layered context a mix of qualitative methods were employed.   Qualitative methods are widely regarded as the most appropriate choice, when the question being posed is how and why something has happened, not just what (Sayer, 2000). Six primary sources have been identified; the strengths and weaknesses of each type are displayed in table 5 below.

Table 5: Strengths and weaknesses of data sources

Source of evidence	Strengths	Weaknesses
Documentation	• Stable- repeated review • Unobtrusive • Exact • Broad coverage	• Retrievability • Biased selectivity • Reporting bias • Access
Archival records	• Same as above • Precise and quantitative	• Same as above • Privacy might inhibit access
Interviews	• Targeted – focus on case study topic • Insightful – provides perceived causal inferences	• Bias use to poor questions • Response bias • Incomplete recollection • Reflexivity – interviewee expresses what interview wants to hear
Direct Observation	• Covers event in real time • Covers event in context	• Time consuming • Selectivity • Observer's presence might cause change • Cost
Participant Observation	• Same as above • Insight into interpersonal behaviour	• Same as above • Bias due to investigator's actions
Physical Artefacts	• Insightful into cultural features • Insightful into technical operations	• Selectivity • Availability

(Adapted from Tellis, 1997 pg 8)

The importance of multiple sources to the reliability of a study is well established (Keen and Packwood, 1995, Chamberlain et al., 2011, Tellis, 1997). Using multiple sources is often referred to as triangulation and minimises the reliance on one type of data, which can limit the scope of the findings (Frankfurt-Nachmias and Nachmias, 2000). Some researchers argue that triangulation provides multiple measures of the same phenomena (Andarde, 2009). The weaknesses of one method can be complemented by the strengths of another. However, researchers debate its purpose and whether it can validate research findings or simply provide a more holistic perspective of the phenomena under study (Chamberlain et al, 2011; Mays and Pope, 2000). In this inquiry multiple sources were used, as one method was not considered sufficient to capture all salient aspects of the system of care. For example, an interview would not reveal the nuances that marked the activities performed by the Coordinator on a day to day basis, and observations would not reveal how or why the activities observed had come to pass. The multiple sources used therefore contributed to an in depth understanding of the complex processes under investigation.

The methods used in this study included direct observations of service practice, interviews with the Coordinators, interviews with the service managers and a review of the relevant service documentation. Focus groups were also held at the end of data collection to present the preliminary findings to the Coordinators for discussion and feedback; this is referred to as respondent validation or data checking (Pope and Mays, 2000).

3.9.1 Observations of service practice

Observation has been defined as '*the systematic description of events, behaviours, and artefacts in the social setting chosen for study*' (Marshall and Rossman, 1989). However, they may also involve informal interviewing, learning through experience and using all five senses (Kawulich, 2005, DeWalt and DeWalt, 2002). One of the main advantages of observing service practice is that it allows the researcher to directly observe the social activities of interest in real time and in context (Frankfurt-Nachmias and Nachmias, 2000). Observations are described as well suited to the study of working organisations and how people within them perform their functions

(Mays and Pope, 1995). They can help to overcome the discrepancy between what people say and what they actually do (Mays and Pope, 1995). In this study observations were undertaken with a specific focus - to understand how the system of care was implemented and the influence it appeared to exert on professional practice i.e. as an evaluator exploring the contextual factors that mediated the intended outputs. An initial site visit was performed before formal data collection began; the researcher met with the Coordinators and explained the purpose of the observations. This visit provided an opportunity to discuss the activities that the Coordinators thought would be useful to observe, these included:

- The assessment process, which took place in patient's homes. It was decided to observe a similar number of assessments at each service to facilitate comparisons.
- Care planning processes i.e. decisions made in real time about how the coordinator would respond to the problems they had identified, and the documentation of these decisions.
- Multidisciplinary team meetings where the coordinators caseload and actions were discussed.

The meeting informed what observations were performed; however, observations were not limited to the activities initially prioritised e.g. interactions in the service offices and other events were also observed with permission from the team. Observations were performed intermittently (usually 2-3 days per week) over a period of six weeks at each service. The assessments observed were opportunistic i.e. all LoTS care assessments that took place during fieldwork that the researcher was invited to attend. This was in line with the recruitment procedure, which stated that observations would take place at times and places convenient to the Coordinators. However, an attempt was made to observe at least one assessment with each Coordinator, and the professionals supported the researcher to achieve this aim.

The assessment was performed within the patient's home (at both services). During this time an attempt was made to capture details considered significant to the theory testing process e.g. characteristics of the stroke survivor, discussion of the problems

identified and their resolution, whether a carer was present and their role in the assessment process, the extent to which the Coordinator addressed all assessment domains and how the assessment structure was used e.g. as a prompt or reminder. Evidence of the use of problem solving and goal planning was also recorded. Most other observations took place in the service building e.g. weekly multidisciplinary team meetings were held in the service office or another private room in the service building. At service one all professionals were expected to attend the weekly meeting, this included physiotherapists, occupational therapists, the stroke nurse, the speech and language therapists and the generic workers. At service two a representative from each professional discipline attended the meeting, which included the professional groups listed at service one and a psychologist. Observations of the assessment process provided most insight into problem identification and resolution and the role of the system of care in these endeavours, however, more general interactions between colleagues was also observed between formal assessments e.g. informal discussion of case load, telephone calls to external agencies. During fieldwork, observations were recorded as written notes, which are a significant way of representing just observed events (Mason, 2002).

As an observer it is possible to adopt a role on a continuum between complete observer to complete participant (Davies, 1999). In this investigation the researcher performed direct observations i.e. was not formally involved in any of the activities observed. However, it is accepted that the role of complete observer is hard to achieve, as interaction is likely to occur at some level particularly when the researcher is a stranger in the participant's environment. Interaction with the Coordinators often occurred in the form of casual conversations and discussions, which could also be considered informal interviewing (DeWalt and DeWalt, 2002). For example, after one assessment observed the Coordinator commented to the researcher that they would like to speak to the patient's carer (who was not present at the time), who might provide more details about the problems experienced than the individual had revealed. This example demonstrates how the Coordinators reflected on the activities observed, which provided useful insight into the complexities involved in problem identification and resolution.

3.9.2   Qualitative interviews

Qualitative interviewing respects how participants structure and frame their response (Warren, 2001). This is based on an assumption fundamental to qualitative research that the participants perspective on the phenomena should unfold as the participant sees it (Marshall and Rossman, 2006). However, interviewing varies in terms of a priori structure. In this study semi structured interviews were used. These negotiate a path between structured interviewing that use fixed responses to produce quantitative data, and unstructured interviews that allow participants to discuss a topic as they choose creating a narrative (Mathers et al., 2000). A semi structured approach was appropriate for this study; it enabled the theories of change to be explored in detail using the interviewee's own words whilst keeping the discussion focused and providing a basis for comparability (May, 2001).

3.9.2.1   Stroke Care Coordinators

Coordinators were considered key informants in this study as they had direct experience of implementing the system of care in day to day practice. Interviews with Coordinators were conducted at the end of fieldwork to provide an opportunity to clarify the processes observed. The interviews were performed in a private office in the building of the stroke service. The Coordinator and researcher were the only people present for this part of data collection. Every Coordinator was interviewed at least once (n=10). However, some Coordinators were asked for a second interview to clarify points from the first. For example, one Coordinator referred to an information file that had been developed to complement the LoTS care manual during their initial interview. This file had not been used during observations and most Coordinators were not aware of its existence. However, it had been developed in response to the introduction of the system of care. For this reason, the Coordinator who developed the file was asked for a second interview to provide insight into how and why it had been created.

An interview schedule was developed prior to data collection to guide the discussion. The questions focused on the implementation processes and the role of the system of care's components in problem identification and resolution (see

appendix ii). However, by the time the interviews took place the researcher was familiar with the implementation processes performed though the observations performed and casual conversations with the Coordinators. For this reason, the interview schedule was adapted as required and provided a framework rather than a rigid guide to data collection. During interviews the Coordinators were encouraged to reflect upon their practice and to describe the role of the system of care. The theories of change were made explicit to the Coordinators, so that they could comment upon these and offer their interpretations of how the system of care had worked to enhance their practice.

3.9.2.2 Service managers

The service managers were interviewed after observations and interviews had been completed. During this time, it became apparent that the Coordinators were unaware of details that were deemed useful to the investigation; such as the service's reasons for participation in the LoTS care trial. The service managers were approached for an interview to address these gaps. The managers described the service aims, why they had volunteered their services to participate in the LoTS care trial, and how the system of care's components had become embedded in routine practice. The manager at service one had also implemented the system of care in their previous role as team lead. Therefore, they had used the system of care's components in the Coordinator role, and could comment on the changes that they felt were introduced to their service as a result.

3.9.3 Review of service documentation

The service documentation reviewed included the assessment booklets used during fieldwork and the service case notes. The LoTS care assessment booklet included sixteen assessment sections and a care plan (see appendix iii). The information recorded in these booklets demonstrated how the Coordinators documented the assessment process. This information was useful as it highlighted whether all assessment domains were documented as addressed, the problems identified by the Coordinator and the service response employed to resolve the problem.

Therefore they indicated the extent to which some of the service outputs anticipated by the LoTS care team had been realised in practice i.e. whether a comprehensive assessment was documented, and the extent to which the service responses adhered to or deviated from the recommendations in the LoTS care manual. The data from the assessment booklets also produced some descriptive statistics i.e. the type of problems frequently identified by Coordinators, which enabled some comparisons to be drawn between the two services.

Documentation that was not part of the system of care, but was considered relevant to the investigation was also identified during fieldwork. For example, prior to participation in the LoTS care trial both services had used an assessment tool adapted from the Single Assessment Process to facilitate problem identification. Copies of these tools were provided to the researcher and their content was compared against the LoTS care assessment to reveal differences in their scope. The assessment tools previously used can be described as 'historical data', this type of data enables the researcher to track changes through time (Fitzgerald, 1999). Case notes recorded at each service also documented:

- The multidisciplinary team meetings
- Service users' progress notes
- The Coordinators liaison with other services.

These records were useful as they demonstrated that many activities were documented outside the LoTS care assessment booklet. Finally, the managers at both services reported working to a specification that was developed in collaboration with other stakeholders. These detailed the aims and objectives of the stroke services and how they were expected to meet these objectives. Service one was able to provide a copy to the researcher for review. However at service two the specification was being updated by stakeholder groups, therefore a copy was not provided.

3.9.4   Respondent validation

Respondent validation or 'member checking' refers to a process through which the researcher's interpretation of their data is compared against the participants' views (Mays and Pope, 2000). This can help corroborate the study findings, however, difficulties are also noted in the process e.g. participants might have defensive reactions to the results presented, they might agree with the researcher even if there are alternate explanations, and they might be presented with findings in a way that it is difficult for them to disagree (Emerson, 1988, Barbour, 2001). Further to this, respondent validation is also likely to generate new data, which in turn requires analysis and interpretation (Mays and Pope, 1995).

In this study the decision to perform respondent validation was prompted to further the researcher's understanding and refine the initial interpretations. This work was considered necessary, as 1) the system of care had been embedded and implemented to varying extents in each service, and 2) the Coordinators had varied backgrounds and experiences and had responded to the intervention components in different ways. For these reasons it was considered beneficial to clarify what changes the Coordinators felt had been introduced to the service and their individual practice.

Focus groups were used in this study to present the study findings to the Coordinators. Focus groups have been described as a carefully planned session designed to obtain several perceptions of a defined area of interest in a permissive and non-threatening environment (MacFie et al., 1994). The focus groups were held a couple of months after data collection had been completed and all Coordinators were invited to attend. The main findings were presented to the group, and the Coordinators were encouraged to discuss whether they agreed or disagreed with the interpretations. The group discussion was useful as the Coordinators could reflect on findings together, which provided insight into the extent to which their views differed from each other and the researcher. Individual summaries that described how the system of care had impacted on each Coordinator, based on their interviews and informal discussion were also developed (see appendix iv for example). The reason for this was that the group discussion was not an appropriate

forum to discuss individual experiences. The professionals were asked to add or amend the statements to further refine the explanation.

3.10 Reflexivity in the research process

Qualitative researchers acknowledge their role in the production of knowledge through reflexivity (Watt, 2007). In evaluation a distinction is often made between internal and external evaluation i.e. whether the evaluator is an employee of or an external to the programme (Worthen et al., 1997). This study could be described as an internal evaluation, as the researcher was employed as part of the LoTS care programme team.   This position could be seen as advantageous as the researcher had access to detailed knowledge about the system of care. However, in the field the Coordinators often referred to the intervention components as 'your' assessment/manual i.e. assuming the researcher had a vested interest in the performance of the system of care and possibly influencing what they were willing to reveal. However, informal conversation provided an opportunity to clarify that the researcher was not there to monitor the implementation of the system of care, and the Coordinators appeared to understand that the research aims of this study were separate from that of the LoTS care trial.

3.11 Ethical considerations and approval

Ethics approval for the study was sought from the National Research Ethics Service (NRES) using the Integrated Research Application System (IRAS).   NRES is responsible for assessing and granting ethical approval for all research in the United Kingdom that involves NHS subjects. Initially the research was submitted as a sub-study of the LoTS care trial, which is completed as a substantial amendment. However the ethics committee requested that the study be submitted as a new and separate application. A new application was submitted for review and approval was granted on 24-Sep-2010. Following this the four services selected as potential research sites were approached for participation in line with the recruitment procedures approved (see below). Research and Development (R&D) approval was then sought from the local NHS trust within which each site was located. This study

raises some ethical considerations in its procedures; for example, observations of professionals practice might cause anxiety for the Coordinator and the service user. The researcher attempted to address these concerns during the recruitment process.

3.11.1 Recruitment procedures

The participating services were telephoned and the purpose of the study was explained to them. During this discussion the researcher clarified that the system of care was the focus of data collection, not the individual Coordinators. Further to this, observations would take place at times and locations convenient to them and that these would be planned in advance. Their right to refuse participation and withdraw from the study at any point was also clarified. If the service was interested in participating in the study they were sent an information sheet with contact details of the researcher, who could answer any questions regarding their involvement. They were given at least twenty-four hours to consider their participation in the study and were then re-contacted. If they were willing to participate in the study an initial site visit was arranged where written informed consent was obtained.

Individuals other than the Coordinators were also observed during the course of fieldwork. The observations considered processes rather than people therefore written consent was not sought for every person involved in the observations. However, verbal consent was obtained from all professionals present at any meetings or processes observed. The Coordinator was also responsible for obtaining verbal consent from the service users whose assessment was observed. The Coordinators were asked to explain that the observer was an NHS researcher who was interested in the assessment process rather than the service user themselves. The service user had to provide informal consent before an assessment was observed.

3.11.2 Confidentiality and anonymity

The Coordinators were reassured when recruited to the study that all data would remain confidential and would be reported anonymously. To comply with the ethics committee approval, all data stored in electronic form was done so on encrypted devices (USB, laptops and computers). All paper copies of the data were stored in locked filing cabinets, in locked offices at the Leeds Institute of Health sciences at the University of Leeds. Participants were given a unique study identifier to ensure that the data could not be linked to any individual.

3.12 The research sites

The researcher approached the four services outlined in section 3.7 in line with the procedures agreed with the ethics committee and initially all were willing to participate in the study. Data collection subsequently began at the first choice sites, however, the individual Coordinator had to withdraw from the study for personal reasons. The 'back-up' individual Coordinator was then contacted, unfortunately they were no longer able to participate due to an increased workload. The LoTS care team were re-consulted and a third individual Coordinator was identified and approached. However, this site could not commit to the study due to other research obligations. The decision was made to approach the 'back-up' community stroke team as they had agreed to participate, R&D approval had been obtained and the researcher could easily access the site in comparison to many others. Therefore the 'back-up' community stroke team established the second research site. The two stroke services are referred to as service one and service two.

3.13 Data management

A large amount of data was collected from each research site, see table six below for overview. To add to the data presented in table 6 the service documentation reviewed included twenty-six LoTS care assessment booklets, and the associated patient case notes (including multidisciplinary team meetings and progress review notes), the assessment tools previously used by each service, and the service specification from service one.

Table 6: Data collected from each research site

Service	Interviews		Observations		Respondent Validation	
	SCC	Manager	Assessments	MDT meetings	Focus Group	Written feedback
1	12	1	14	7	1	7
2	6	1	12	6*	1	1
Total	18	2	26	13	2	8

* Includes 2 hospital MDT meetings

The interviews were digitally recorded and transcribed verbatim. Field notes and document excerpts were also transcribed. Interpretation, the process through which the researcher brings meaning, coherence and explanations to the findings is a fact of qualitative research (Sayer, 2000). To reduce the data and facilitate the analysis process the framework approach was used (Ritchie and Spencer, 1994). The framework approach was developed by social policy researchers at the National Centre for Social Research to manage and analyse qualitative data in applied policy research (Ritchie and Spencer, 1994). It has been described as appropriate for research that has specific questions, a limited time frame, a pre-destined sample, as in the current study (Srivastava and Thomson, 2009). However the organisational stages (see figure 8 below) allow emergent themes to be incorporated and used in the analysis process, therefore it is not purely deductive.

Figure 7: Stages in the Framework Approach

```
┌─────────────────────────────────────────┐
│            Familiarisation                │
│       Read proposal and transcripts       │
│     Review topic guide and field notes    │
└─────────────────────────────────────────┘
                    │
                    ▼
┌─────────────────────────────────────────┐
│       Identify descriptive categories     │
│   Develop working analytical framework    │
│      of key themes and sub-themes         │
└─────────────────────────────────────────┘
         │                        │
         ▼                        ▼
┌──────────────────┐   ┌──────────────────┐
│     Indexing     │   │  Pilot Charting  │
│ Apply numerical  │   │ Chart a few      │
│ series to        │   │ transcripts      │
│ framework, label │   │ using working    │
│ data sources and │   │ framework and    │
│ revise framework │   │ the revise       │
└──────────────────┘   └──────────────────┘
         │                        │
         └────────────┬───────────┘
                      ▼
            ┌──────────────────────┐
            │      Charting        │
            │ Summarise/synthesise │
            │        data          │
            └──────────────────────┘
                      │
                      ▼
            ┌──────────────────────────┐
            │ Investigation and        │
            │ interpretation           │
            └──────────────────────────┘
                      │
                      ▼
            ┌──────────────────────┐
            │  Reporting findings  │
            └──────────────────────┘
```

The Framework approach has been applied in several policy studies (Ritchie and Spencer, 1994) and is also gaining popularity in health services research (Smith and Frith, 2011). It was chosen for this evaluation, as the stages enable the researcher to explore the data in depth while simultaneously maintaining an effective and transparent audit trail (Furber, 2010). This enhances the rigour of the analytic process and the credibility of the findings (Smith and Frith, 2011). The framework also enabled a focus to be maintained on the theories of change prioritised for investigation.

3.14 The analysis process

The LoTS care trial considered outcome measures completed by the patient and carer participants. This study considered the changes in service delivery expected through the provision of new resources and training i.e. the outputs that if realised might impact on the patient and carer outcomes. The outputs were explored in two ways 1) by comparing the implementation activities performed in day-to-day practice against those anticipated by the intervention architects, and 2) by testing two CMO propositions.   Data from the observations, interviews and service documents reviewed were brought together to provide a detailed account of the extent to which the system of care produced the desired outputs i.e. enhanced service practice.

Data from observations and informal discussions were organised into frameworks at two levels, 1) the service and 2) the Coordinator. At the service level the analysis framework categorised contextual differences in the structure and organisation of the teams e.g. their eligibility criteria, the allocation of the Coordinator role, the number of stroke reviews performed and details of the assessment tools used prior to the LoTS care system of care. This framework also recorded details of how the LoTS care components had been embedded in service practice established through observations. These areas are described further in chapter five. At the Coordinator level the frameworks highlighted the professional's background and experience, and details of their assessment observed e.g. their use of the client checklist, assessment booklet, the LoTS care manual and their approach/ interaction with the service user.

Interview data was organised separately. A tentative analysis framework was developed based on the questions guiding the research, and the theories of change prioritised for investigation. For example, 'the implementation process' was an overarching theme within which a further three sub-themes were identified from the theory elicitation process; 'provision of reviews', 'monitoring processes', and 'care planning'. The themes and sub-themes were refined, where necessary, through data collection and allocated codes. The codes were then applied to the transcripts and

the coded chunks were cut and paste into a data matrix developed using Microsoft Word.

The frameworks organised the data and facilitated the exploration of themes within and across each case. The analysis process compared the theories of change prioritised for investigation (described further in chapter four) against service practice. The implementation of the system of care was examined first. Data from observations and informal discussion during fieldwork quickly revealed that the services' monitoring and review processes differed from the expectations of the LoTS care team (these findings are described in detail in chapter six). Interview data provided evidence that explained the observations and supported the informal explanations provided during fieldwork.   The different sources were used to describe how and why the implementation of the system of care differed from the expectations of the intervention architects. This analysis provided insight into the extent to which the system of care enhanced the amount and type of contact provided to the service user by the Coordinator.

The realist propositions explored focused on the extent to which the system of care promoted evidence base service responses and a comprehensive post-stroke assessment (clarified in chapter four). The first step in the analysis process was to establish the extent to which these outputs were realised in practice. Data from the LoTS care assessment booklet provided some insight into this. The assessment booklets recorded whether an assessment domain had been addressed, the type of problems identified by the Coordinator, and the service response employed. The data revealed whether the Coordinators had documented a comprehensive assessment (according to criteria established by the LoTS care team) and the extent to which their service responses adhered to or deviated from the recommendations in the LoTS care manual.

Establishing the extent to which the outputs of interest were realised in practice, the next point of inquiry was whether these linked to the hypothesised causal mechanisms underpinning the intervention. Observational data provided insight into the extent to which the LoTS care components were used in day-to-day practice and

for what purpose. Interview data provided insight into the extent to which the Coordinators felt they had been informed by the system of care's components, which was not observable. This part of the analysis was undertaken with consideration of the particular contexts (service and Coordinator level) that were thought to trigger the desired mechanisms i.e. to refine the starting CMO proposition.

The multiple methods provided a detailed account of how the system of care was implemented in practice, the influence its components exerted on the Coordinators practice and the extent to which these factors represented an enhancement in service practice. The preliminary analysis was discussed with the Coordinators as part of respondent validation. Extracts from the focus group discussions are presented in boxes throughout the thesis and were used to elaborate upon the findings from the initial stages of fieldwork.

3.14.1 Interpreting trial outcomes

Exploring the implementation of the system of care and the mechanisms of change provided insight into the contribution it made to the outcomes measured as part of the LoTS care trial. This provides: *'an increased understanding of why observed results have occurred (or not) and the roles played by the intervention and other factors'* (Leeuw and Vaessen, 2009). The role of the system of care in identifying and addressing post-stroke problems was reflected upon in each of the findings chapters.

3.15 Summary

This chapter has described the methodology and methods used to answer the research questions. An overview of the methodology is provided in figure 8 below, for clarification. To address some limitations in the trial design a theory-driven approach was applied drawing on the principles of realist evaluation. The aim was to examine the implementation of the system of care in context and whether the system generated changes that enhanced service delivery. Two services were

selected as case studies based on the premise of maximum variation, and multiple methods were employed to provide a detailed account of the complex processes under examination. The study was small and focused on a set of sub-theories prioritised for investigation from the wider theory of change; these are clarified in the following chapter.

Figure 8: Methodology Overview
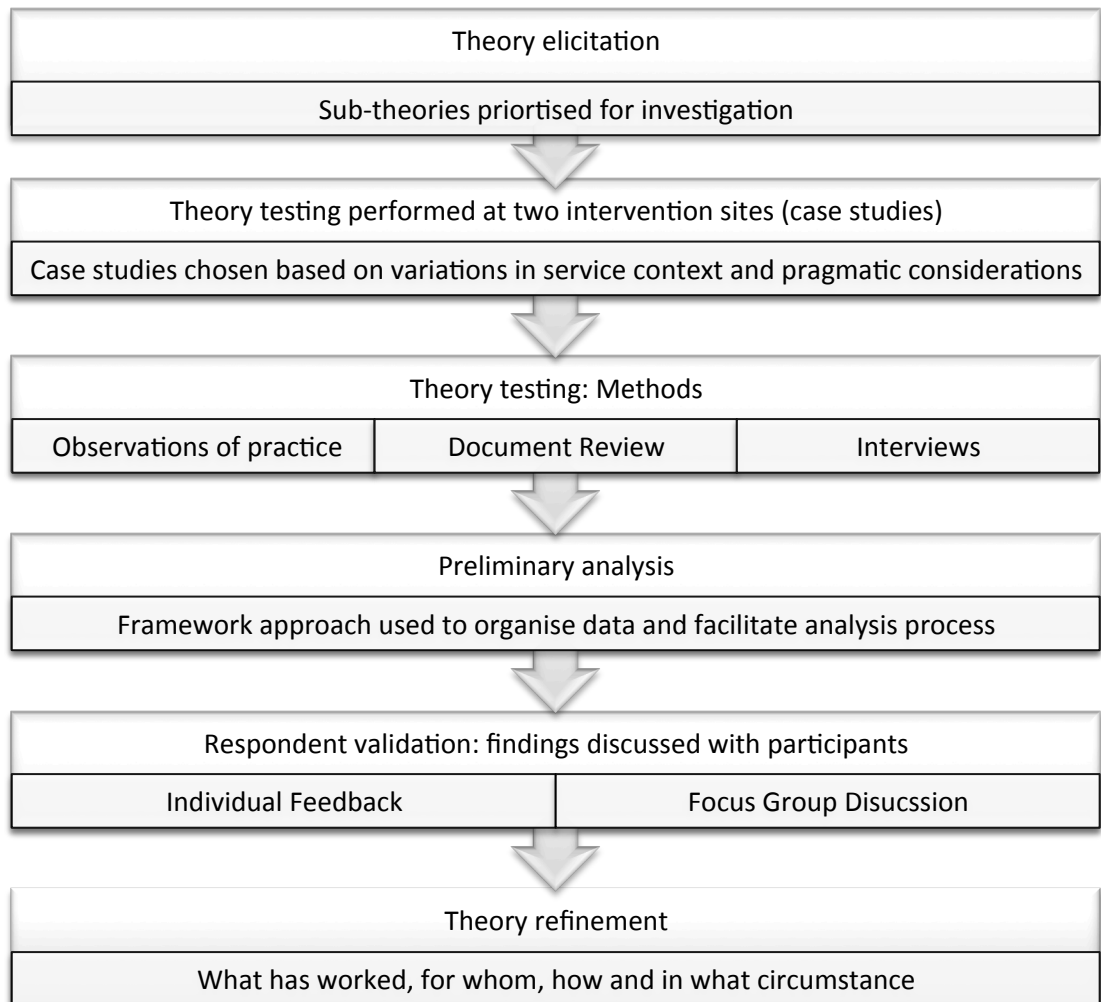
Chapter 4: Eliciting the theory of change

4.1   Introduction

Theory-driven evaluation attempts to establish the extent to which observed processes and events match a predicted set of ideas (a theory). Therefore, the theory of change underpinning the intervention needs to be articulated to guide the empirical inquiry. This chapter describes how the theory of change underpinning the LoTS care system of care was elicited. The sources used to inform the elicitation process will initially be clarified. These sources were used to explore three questions - 1) why were post-stroke needs unmet by existing community services? 2) What was the aim of the system of care? and, 3) how was the system of care expected to achieve its aim? Exploration of these questions culminated in the development of a logic model that depicted the theory of change. The logic model acted as the overarching theoretical framework for the study from which sub-theories were prioritised for testing during fieldwork.

4.2   Sources used to elicit the theory of change

Numerous sources can contribute to the theory elicitation process e.g. the intervention architects, the practitioners who implement the intervention, service users who receive the intervention, and literature that documents past experiences can all provide insight into how the intervention is expected to affect/ is affecting / has affected target groups (Leeuw and Vaessen, 2009). Many documents were produced during the development of the system of care, for example, published papers, the programme grant application, the project protocol, and the LoTS care manual (a component of the system of care). These documents were reviewed for the purposes of theory elicitation; however the links between the provision of the system of care's resources, the changes expected in service delivery and the impact of these changes on patient outcomes were not made explicit in these documents. For this reason, the stakeholders who produced the documentation, based at the Academic Unit of Elderly Care and Rehabilitation (AUECR), University of Leeds, were interviewed to provide clarity on the processes of change expected, see table 7 below for overview of stakeholders.

Table 7: Stakeholders interviewed

Identifier	Role
Stakeholder 1	Professor of Elderly Care, Member of the Programme Management Group Involved in developing the system of care 1992-present
Stakeholder 2	Senior Research Fellow Member of the Programme Management Group Involved in developing the system of care 2000 - 2008
Stakeholder 3	Chief Investigator of the LoTS care Trial Professor of Stroke Rehabilitation Member of the Programme Management Group Involved in developing the system of care 1992-present
Stakeholder 4	LoTS care trial Manager Joined the AUECR in 2007
Stakeholder 5	Professor of Liaison Psychiatry Member of the Programme Management Group Delivered problem solving sessions at the LoTS care training days

The role of stakeholders in building programme theory is debated. Patton (1989) emphasises the role of programme personnel whereas Chen and Rossi value the evaluator, social science theory and knowledge (Stame, 2004). In this study the stakeholders ideas and assumptions were prioritised, as they described a 'pragmatic approach' to the problem they perceived. However, assumptions often reflect more established theories. The system of care consisted of a number of components, which could be considered discrete interventions. Typologies have been developed to categorise interventions designed to promote professional behaviour change (Walter et al., 2003, Michie et al., 2011). These interventions are usually implicitly or explicitly underpinned by established theories. For example, adult learning theories assume practitioners are personally motivated and will keep up to date with research findings as a means of professional development (Walter et al., 2003). Designing an intervention to promote behaviour change based on these assumptions might involve the dissemination of educational materials, a strategy which has often been employed in health services (Thomas et al., 1999, Giguere et al., 2012).

4.3   Surfacing the stakeholder's assumptions

During interviews the stakeholders were given an A4 sheet of paper with a line drawn through the centre. The start point was titled 'patient recruited to trial' and the end point was titled 'improved outcomes'. The line represented the period of time in which the system of care was delivered to service users. Interviewees were asked to mark on this line the processes that they believed were important in achieving the end point and to explain each process in turn. The aim was to encourage the stakeholders to articulate the properties of the system and the processes involved in its implementation. A further aim was to establish why the system of care would promote these changes in practice, and consequently improve patient outcomes. The interviews were recorded, transcribed and reviewed to unearth the respondents' assumptions, which were summarised as a preliminary logic model, later refined after feedback from the stakeholders.

Some difficulties have been noted in eliciting the programme theory. For example, the core programme theory can sometimes fail to surface in the interview as it is seemingly so obvious, or it can be buried tacitly in the minds of the programme architects (Pawson and Tilley, 1997). Similar problems were encountered during this study. The initial interview focused on the processes involved in implementing the system of care, not how it would generate change in professional practice or how this would impact on patient outcomes. However, the researcher worked in close proximity to the stakeholders, therefore, informal conversation clarified details not formally discussed during the interviews. The researcher also attended the official LoTS care training days as an observer. These observations were useful as they provided insight into how the LoTS care team attempted to impart knowledge and skills to the Coordinators.

Theory development often begins with an attempt to clarify the problem perceived by the stakeholders (Pawson and Sridharan, 2009). Understanding the cause of the problem provides insight into which contextual level(s) (macro, meso or micro) might be targeted by the intervention. This formed the starting point for theory elicitation in this study. Chapter one described the range of longer-term problems experienced post-stroke, which encompass social, emotional, psychological, physical and

functional domains. Chapters one and two described specific interventions in stroke rehabilitation and policy initiatives that have attempted to meet the needs of community dwelling stroke survivors. Why then do stroke survivors continue to report unmet needs? Two points surfaced in response to this question, 1) there was an assumption that previous services were not based on the 'expressed needs' of stroke survivors and their carers, and 2) the development of the system of care spanned two decades; this period saw significant changes in the provision of community stroke care i.e. the context in which the system of care was evaluated was different to the context in which it was conceived.

4.4   The problem in longer-term stroke care

Researchers in the AUECR began exploring ways to improve outcomes for stroke survivors as early as 1992. At this time there were few recommendations that guided health or social care provision specifically for the community dwelling stroke population. Four years earlier the Kings Fund Consensus had highlighted major deficiencies in primary and secondary stroke care (Kings Fund, 1988). The years that followed witnessed an increase in stroke rehabilitation research (Langhorne and Rudd, 2009). The AUECR developed two interventions during this period, which stakeholders 2 and 3 referred to as the origin of the system of care. The first was the Bradford Community Stroke Trial, published in 1992 (Young and Forster, 1992). This trial compared domiciliary physical rehabilitation with day hospital attendance. The study demonstrated that the intervention was successful in improving function, but did little to impact on social reintegration, as measured by the Barthel Index, Functional Ambulatory Categories, Motor Club Assessment, Frenchay Activities Index, and Nottingham Health Profile (Young and Forster, 1992), stakeholder 1 commented:

> *Stakeholder 1: 'We found that neither of those two service models* [domiciliary or day hospital] *adequately addressed what we called psycho-social functioning after stroke, and at that time people weren't very interested in psychosocial function because rehab was primarily focused on physical function, but because we chose to measure psychosocial outcome*

we found that we rehabilitated patients really well in the sense that they could walk around the home but they did nothing with that walking. They didn't go outside or to churches, or post offices or shops. So they seemed to have good physical outcome but very poor social outcome. So we started thinking about how we could achieve that and the more we looked the more we realised that that was what patients wanted.

The intervention was able to improve physical function, but this was not translated into social activities or participation i.e. the areas valued by stroke survivors. The next intervention, delivered by a specialist nurse, intended to address this gap. The specialist nurse provided information, advice and support to stroke survivors with the hope of impacting on their psychosocial function. The results of the trial indicated that there was a small improvement for mildly disabled patients, however the authors concluded that there was no proven strategy to address psychosocial problems for all stroke survivors (Forster and Young, 1996). The specialist nurse was similar in nature to the Stroke Association's Family Support Worker introduced in the early nineties i.e. it provided a multifaceted role that targeted numerous problems (Dennis et al., 1997). In regards to the Family Support Worker, stakeholder 1 noted:

Stakeholder 1: *'At the time the main mechanism for trying to help people in the longer-term was the Stroke Associations Family Care Worker and around that time there were various RCT's done that cast doubt as to whether that role produced any health gains or not, and subsequently there has been a systematic review and that has confirmed a weak intervention doesn't really attend to what the patients want at all.'*

The systematic review, to which the stakeholder refers, was the meta-analysis of the Stroke Liaison Worker service discussed in chapter one and two (Ellis et al., 2010). The role was defined as a practitioner (nurse/therapist/social worker or volunteer) who provided a multifaceted service to stroke survivors' i.e. providing education and information as well as social support and/or liaison with other services. The meta-analysis included the evaluation of the specialist nurse performed by the AUECR and various trials evaluating the Stroke Association's family support worker. Ellis et al (2010) provided explanations to account for the study findings (see chapter one); however, long before the publication of this review the researchers at the AUECR postulated their own reasons for disappointing results, for example:

Stakeholder 2: *one belief was that the reason why these trials were negative was because they weren't developed through a very clear understanding of the nature of problems that patients and carers were experiencing and they weren't based on the best available evidence.*

The stakeholder explained that the interventions were not well informed about the nature and type of post-stroke problems experienced, as a result they were somehow 'weak'. The resolution to this problem required the development of a comprehensive system of care that was based around the post-stroke problems reported by patients and their carers (Murray et al., 2003a). However, development of the system of care took place alongside significant changes in health and social care policy. From 2001 onwards the management of long-term conditions, including

stroke, was prioritised on the policy agenda. Figure 9 below, depicts some government strategies that have influenced the provision of community stroke care in the formative years of the system of care's development.

Figure 9: Milestones in the development of the system of care

Year	Milestone
1990	• NHS and Community Care Act - introduces care managment and assessment
2001	• National Service Framework for Older People - introduces the Single Assessment Process
2003	• AUECR performs systematic reviews of the qualitaive and quantitative literature that report the longer-term problems expereinced by stroke survivors
2004	• Royal College of Physicians (RCP) Clinical Guidelines for Stroke (2nd edition) published
2005	• Model for supporting people with Long-Term Conditions - Case management, Disease Managment or Supported Self Care
2006	• Feasibility study of the LoTS care system of care published
2007	• National Stroke Strategy published - chapter dedicated to 'life after stroke' • Recruitment to the LoTS care trial begins (community stroke services)
2008	• RCP Clinical Guidelines for Stroke (3rd edition) published • Survey to investigate the role of the Stroke Care Coordintor published
2009	• Stroke Care Coordintors recieve LoTS care training • Recrutiment to the LoTS care trial begins (Patients and Carers)

These strategies are discussed in more detail in chapter two; to recapitulate in 2001 the National Service Framework for Older People introduced the Single Assessment Process for people aged sixty-five and over. This process included a comprehensive Overview assessment that was expected to cover certain domains as standard practice (Department of Health, 2001b). In 2004 the National Clinical Guidelines for Stroke (2nd edition) advocated the use of a Stroke Care Coordinator and timely reviews for stroke survivors (Intercollegiate Stroke Working Party, 2004). In 2005 a model of care was advocated that stratified individuals according to their level of need to receive either case management (delivered by a community matron), disease management (delivered by a multidisciplinary team) or be supported to self manage their condition (Department of Health, 2005b). These policy initiatives were underpinned by ideas of needs led assessment the appropriate allocation of community resources and follow-up objectives (Department of Health, 2007, Department of Health, 2001b, Department of Health, 1989).

In 2007 the National Stroke Strategy set quality markers to drive forward improvements in the entire stroke care pathway, with a chapter dedicated to life after stroke (Department of Health, 2007). This chapter stated that stroke survivors should have ongoing access to specialist therapy and nursing, and that their needs should be reviewed at six weeks, six months and annually thereafter. The Single Assessment Process was referenced as an example of how this might be achieved (Department of Health, 2007). In response to these policy initiates new roles have emerged in community care, one of which was the Stroke Care Coordinator (Murray et al., 2008). However the national guidance was said to lack clarity: '*the structure content and process of a primary care based strategy to address the longer-term problems of stroke were poorly defined*' (Murray et al., 2003b). The LoTS care system of care was designed to address this gap defining the role in greater detail.

4.5   The aim of the LoTS care system of care

The system of care provided health care professionals termed 'Stroke Care Coordinators' with components designed to enhance their established practices. The overarching aim was to, '*address the longer-terms needs of stroke survivors in the community*' (LoTS care Protocol). The success of the system of care in achieving its aim and improving patient outcomes was measured, as part of the LoTS care trial, with standardised patient outcomes including the GHQ-12, the FAI, the BI and the LUNS (a checklist of unmet need post-stroke). The LoTS care team hypothesised that emotional and functional outcomes would be significantly better in individuals who received the system of care in comparison to usual care. However, to improve these patient outcomes the system of care intended to enhance an existing service. In order to complement the LoTS care trial, this study considered the outputs (service enhancements) anticipated; these included:

1. A focus on ***problems of central importance*** to patients and their families

2. The promotion of a ***systematic*** approach to the assessment of longer-term needs for stroke survivors and their carers

3. ***Client centred care*** according to collaborative problem solving approaches and goal setting

4. Service responses that are based on the best available ***evidence of clinical effectiveness***

5. The promotion of ***continuity of care*** through a process of assessment and review according to patient need

These outputs were documented in the LoTS care manual (The LoTS Care Team, 2009); they represent the system attributes that would work together to address the problems experienced by stroke survivors and their carers. They extend beyond practitioner knowledge of post-stroke problems, which was the problem initially highlighted, and include assessment skills (e.g. problem solving) and the processes of care (e.g. review systems) employed. These additions demonstrate how the initial assumptions changed i.e. it was not only practitioner knowledge that needed

enhancing, but also their skills and the processes of care employed by their service. The next section describes the framework on which the system of care was built and its component parts, before establishing how these components would bring about the outputs anticipated.

4.6   The System of care's framework and components

To focus on the problems of 'central importance' to patients and their carers the LoTS care team undertook systematic reviews of the qualitative and quantitative literature that reported the longer-term problems of stroke (Murray et al., 2003a, Murray et al., 2008). To develop a 'better' intervention Stakeholder 1 described that the reviews intended **'***to try and draw together the things that were important to patients, tease out from the qualitative interviews that had been done the things that patients thought were very important to them in the longer-term'.* The system of care would then be mapped on the 'expressed needs' of stroke survivors rather than particular services or professional expertise. This echoes the ambitions of policy initiatives that advocated the provision of 'needs led' as opposed to 'service led' assessments (Stewart et al., 2003). In total ninety-two problems were identified, the majority of which were found to be highly prevalent, see chapter one for further details. The problems were re-categorised into sixteen domains:

1. Transfer of care
2. Communication and information
3. Medicines and general health
4. Pain
5. Mobility and falls
6. Driving and general transport
7. Continence
8. Sexual functioning
9. Shopping and meal preparation
10. House and home
11. Finance and benefits
12. Personal hygiene and dressing
13. Cognition
14. Patient mood
15. Patient social needs
16. Carer social and emotional needs

The system components were mapped against these domains to ensure they incorporated the problem areas relevant to stroke survivors and their carers. The components included an assessment booklet, a manual, a client checklist and implementation principles. Table 8 below provides a brief summary of the content of each component.

Table 8: Components of the system of care

Component	Content
Assessment booklet	• Sixteen post-stroke assessment domains • Twelve carer assessment domains • A care plan to document problems identified and service responses
LoTS care Manual	• Educational text including a definition of the problem area, a synopsis of the latest research, suggestions about how each problem might be addressed • Algorithms that lead, where possible, to evidence based or recommended treatment options • Frequency tables to show the prevalence of problems after stroke • A service directory with national contact details and space to record local service details.
Client checklist	A4 summary of the areas in the LoTS care structure that can be sent out with any appointment information or given to the patient in hospital if appropriate in advance of the assessment.
Implementation Principles	1) The system of care is patient-centred i.e. comprehensive coverage of problems identified as important by patients and carers 2) All assessment questions should be asked of each individual 3) The Stroke Care Coordinator should follow-up on actions and review goals that are documented in the care plan. (Taken from LoTS care manual)

Coordinators in services randomised to the intervention arm of the trial were provided with these components and attended two days of training. The training days provided an opportunity for the LoTS care team to emphasise to attendees how they believed the components should be implemented as a system of care. The

implementation principles were formalised in 12 points that were considered the 'take home' message of the training (see appendix v). The representatives who attended the training were asked to disseminate these messages to Coordinators who were unable to attend. However the LoTS care manual and a DVD of the training sessions (also provided to the intervention services) reiterated these messages. The LoTS Care team employed several strategies to ensure that the attributes of the system of care were realised in practice. The next sections explore these strategies in more detail, starting with those that aimed to focus the system on the problems of 'central importance' to patients and carers.

4.7   Focusing on problems of central importance to service users

The framework described in section 4.6 was intended to be comprehensive of the problems experienced post-stroke. Stakeholder 1 commented that the framework could inform a training package for professionals performing the role of Coordinator: '*I hope it would reflect that and it wouldn't matter if you were a physio or an OT, or doctor or nurse, or social worker at the end of the training programme you would be competent in assessing all the areas of interest for stroke patients.*'   The strategy was a training programme where professionals would learn how to address each domain competently. However, the LoTS care training did not educate the Coordinators about each domain, the training included 1) an introduction to the system of care, which provided a rationale for its development and described the content of its components, 2) a workshop that demonstrated the practical applications of the LoTS care manual using fictional scenarios, and 3) a session on the use of problem-solving techniques. The second day provided an opportunity for the Coordinators to discuss their experience of using the components, and to provide feedback to the LoTS care team on their utility. Two lectures were also delivered on, 1) pain after stroke and 2) finance and benefits. Stakeholder 2 commented:

Stakeholder 2 *The* [LoTS care] *manual is ok but it needs to be backed up with more comprehensive training**. So it's ok to provide questions on sexual functioning, but you could have done with some back up training. I mean it would have been ideal to have a longer training session, but I mean really a lot of the training is about introducing the manual with only really the benefits and the pain management plucked out*

Stakeholder 2 refers to LoTS care manual, which was also provided as an educational tool to Coordinators. The reference guides included in the manual linked directly to the assessment domains in the LoTS care structure and included a problem definition, a brief synopsis of current research knowledge, and hints and tips about approaching sensitive topic areas (see appendix vi for example). This information was expected to impart knowledge to the Coordinators about each assessment domain. For example, the activity of shopping might be impeded by physical barriers (mobility/ lack of suitable transport), cognitive problems (poor comprehension, short term memory loss), or psychological problems (fear, embarrassment) (The LoTS Care Team, 2009). If referred to, the reference guides could support the Coordinator in the accurate identification of the problem. However, stakeholder 2 indicated that whilst the manual was 'ok' more formal training was needed to support the comprehensive assessment of each domain.

Stakeholder's theories can include positive and negative reflections on the intervention and in this case the stakeholder was critical of whether the training provided was adequate to trigger the changes anticipated. However, the system of care did not rely solely on the training as a strategy to extend the scope of the assessment. Use of the LoTS care assessment booklet was mandatory as part of the intervention group and was accompanied by the implementation principle '*all assessment questions should be asked of each individual'*.   Therefore, the assessment structure and implementation principles were also expected to enhance the assessment process, as Stakeholder 1 commented:

Stakeholder 1: *The principle we're trying to get away from is that they* [health care professionals] *tend to assess on the basis of their own personal discipline. What we found in the original pilot work years ago, if you get a physiotherapist to assess they'll do a regular assessment of mobility but not continence, whereas if you get, if you get a district nurse to do an assessment of a patient they'll do an assessment of continence, but not of mobility. So people are a bit blinkered by their professional discipline and focus on the things that they're comfortable in and have had training in.*

The LoTS care assessment structure was expected to extend the scope of the assessments performed by professionals 'blinkered' by their discipline. The assumption was that professionals who assessed the needs of stroke survivors, focused on areas that they traditionally addressed as a therapist or nurse. Therefore problems outside their professional remit were not adequately addressed as part of standard practice. The mandatory use of the stroke specific structure, therefore, would raise the Coordinators awareness of other domains that needed addressing, the structure would not only extend the scope of the assessment but also promote a systematic approach to problem identification.

4.8   Promoting a systematic approach to the assessment

The LoTS care assessment structure was considered holistic (encompassing functional, physical, psychological, emotional and social domains) and comprehensive of the range and types of problems experienced post-stroke. Each domain included questions and prompts to guide the professional's assessment (see appendix iii). Working through this structure was described as a key attribute of the system of care, as Stakeholder 1 commented:

Stakeholder 1: I think that professionals need to work in a structure and I think this provides a structure and by a structure I mean not just going in cold to some one's house and saying what can I do for you today, although I do think that is an important question, but having an approach that goes through these key areas that we know are important to stroke patients, so I think imposing a structure is important

The assumption was that services were not currently using such a structured approach to their assessment. Therefore, areas that were addressed with one service user might be overlooked in another context. The provision of an appropriate structure would ensure that each domain was consistently addressed at each assessment i.e. promoting a systematic approach. The pilot study of the system of care supported this assumption, as the professional's who acted as Coordinators appreciated the structured approach offered by the intervention (Murray *et. al.*, 2006). However, the LoTS care assessment was not the only structure used in stroke care at this time. The introduction of the Single Assessment Process (SAP) in 2001 instigated the development of a holistic Overview assessment that were designed for use with the elderly population (those aged sixty-five and over)(Department of Health, 2001b). The LoTS care team reviewed these tools whilst developing the LoTS care assessment structure, stakeholder 2 commented:

Stakeholder 2: When we looked at the tools provided by the SAP we examined them the ones that are available on the DH website, Easy-Care the FACE the Camberwell then we looked at the content. They didn't map very well onto the 12 or 14 domains of need that we identified through the qualitative literature so it didn't seem a very good fit with the existing SAP instruments.

Some questions in the Single Assessment Process tools were considered too simple for a post-stroke assessment, others did not match the type of problems experienced, and some problems were completely absent from the tools.

Stakeholder 2 provided 'sexual function' and 'getting back to work' as examples. Many stroke survivors are under the age of sixty-five (the age targeted by the Single Assessment Process) therefore sexual problems and re-entering the workforce might be relevant to the individual, but perhaps not consistently addressed using the Single Assessment Process tools. For this reason, questions deemed appropriate from the Single Assessment Process tools were included in the LoTS care assessment structure, others were modified and new questions were developed for problems completely absent from the elderly care tools.

The amalgamation of LoTS care with the Single Assessment Process signifies a further theory; that the LoTS care assessment structure would provide a superior guide for the assessment and consequently lead to the identification of a wider range of post-stroke problems. This demonstrates how the original theory evolved and became more fragile i.e. it was not the provision of a structure, but the provision of a better structure that would enhance the assessment process. The assumption was that professionals might identify a similar range of problems, but the identification of certain stroke specific problems required a structure that was tailored to the condition, as stakeholder 4 indicated: '*I think the SAP in particular, although it does cover a lot of areas it leaves out some areas that are an issue for stroke patients*.'

The system of care employed numerous strategies to enhance the assessment process including educational lectures, the provision of educational materials in the LoTS care manual, mandatory use of a stroke specific assessment structure, and implementation principles. These were intended to promote the comprehensive and systematic identification of post-stroke problems. The system of care also intended to promote the provision of 'client centred care' through the use of problem solving approaches and collaborative goal setting (see section 4.5). The strategies to promote this output are discussed below.

4.9   Promoting patient-centred care

The term patient-centred is defined in different ways depending on the perspective used (professional / service user) (Robinson et al., 2008). The framework on which the system of care was based was described as promoting a patient as opposed to professionally centred system of care, stakeholder 2 commented: '*The idea is that if you're actually developing a system of care that is mapped onto the expressed needs you're more likely to deliver patient-centred care*'. However, the framework targeted stroke related needs and some would argue that the system is, therefore based around the condition (stroke) as opposed to the patient (Stewart, 2001). However, patient-centred care is also characterised by the type of interaction that occurs between the professional and the patient (Stewart, 2001). According to the system of care patient centred care would be promoted through a problem solving approach and goal planning.

Problem solving, as a therapeutic intervention, is based in the Cognitive Behavioural Therapies and has been traditionally used with individuals with depression or other emotional disorders (Mynors-Wallis, 2001, Cuijpers et al., 2007, Mcauliffe et al., 2006, Townsend et al., 2001). During the LoTS care training, two sessions were delivered that promoted the use of problem solving techniques when implementing the system of care. These sessions were discussed with the training provider (stakeholder 5), who clarified the purpose:

Stakeholder 5: The Idea of problem solving therapy is to teach people how to solve their own problems and the general view is that when you see people with problems, everyone has problems, and the people who get weighed down and into trouble with them is typically not that they have more problems than most people but they have fewer problem solving skills and don't know what to do about them. So the idea of the therapy is that you teach people a generalisble approach that they can then apply in other settings, in any setting really

The approach involves linking the individual's mood to their life problems, identifying the cause of the problem and listing potential solutions collaboratively with the service user (Mynors-Wallis, 2001, May et al., 2007). Mood disorders are prevalent post-stroke, and survivors also contend with numerous other problems that might result from their incident (Murray et al., 2007). Problem solving therefore had the potential to impact on the individual's mood and consequently on the primary outcome measured as part of the LoTS care trial, the GHQ-12. The training was intended to teach the Coordinators problem solving techniques i.e. new skills that they would apply in practice. Service users would consequently learn these techniques enabling them to take control over their life problems, which is thought to impact on their overall mood (Mynors-Wallis, 2001, May et al., 2007). However, problem solving was not formally taught to the attendees, as the stakeholder clarified:

Stakeholder 5: None of them are going to be using problem solving in a formal way because they haven't been trained. The idea is to shift the style a bit. You know be less like Brunhilda the physiotherapist and being jolly and I'll do this, and be a bit more like what are you going to do next, so shift that a little bit.

To deliver this type of therapy 'formally' was said to require two full days of training. Once a professional is trained, the service user is usually provided with at least 6 forty-five minute sessions to develop their own problem solving skills (Mynors-Wallis, 2001, Cuijpers et al., 2007). For this reason, problem solving in a 'formal way' was not anticipated as a direct output of the LoTS care training sessions. However, a problem solving approach might be prompted where the Coordinator engaged more with the service user, encouraging them to take ownership over their problems where appropriate, as stakeholder 4 commented: '*it's not just going in and asking questions and taking those problems away and sorting them out, it's trying to encourage them to engage more with the patient and encourage them to help themselves more. So I think the training would enhance their own clinical profession'.* The assumption was that professionals were currently taking responsibility for solving most problems identified during the assessment. Therefore

the problem solving sessions might shift their style and 'enhance' their practice as a Coordinator.

According to the LoTS care manual patient centred care would also be achieved through goal planning. However, there was no clear strategy to promote or guide the formulation of goals in practice apart from those linked to the problem solving approach. The LoTS care manual describes that the care plan would provide a document of what the professional and the patient were attempting to achieve and that this would '*encourage review of previously agreed actions and goals in line with the principles of goal planning*' (The LoTS Care Team, 2009). This indicates that there was an explicit assumption that goals would be documented in the care plan. Goals were also described to contribute to a successful period of rehabilitation, as stakeholder 2 commented**:** '*the more closely patients are involved with their medium and longer-term goals the more successful those goals are going to be.*' The LoTS care manual included a section describing the principles of goal planning as advocated in the National Clinical Guidelines for Stroke (see appendix vii). The assumption was that, as health care professionals the Coordinators would be familiar with the concept of goal planning and would incorporate this easily into their care planning process.

The system of care intended to enhance the role of Coordinator by promoting a patient centred approach, which the intervention architects linked to problem solving and goal planning. However, the strategies employed to promote problem solving and goal planning, as part of the system of care, were less clearly linked than the mandated use of the stroke specific assessment structure to extend the scope of the assessment. For example, the LoTS care training did not deliver training intended to establish 'formal' problem solving as part of the intervention, and goal planning principles were simply listed in the LoTS care manual with the hope that Coordinators would read, understand and implement these. Evidence suggests that there are many barriers to changing professional behaviour e.g. clinical uncertainty and a sense of competency (Baker et al, 2010). Further to this, research indicates that health care professionals may have reservations about actively engaging patients in the goal planning process, if they believe the individual is unable to participate due to cognitive, or communication barriers (Rosewilliam et al., 2011). Alternatively patients might pass goal planning responsibilities over to the health

care professional if they believe they are unable to actively engage in the process (Rosewilliam et al., 2011). The strategies employed by the intervention architects to promote patient centred care reflect policy documents that use similar rhetoric without clarifying the term or how it will be achieved in practice (Parry-Jones and Soulsby, 2001). Therefore, it is possible to be critical of the links between the intervention and the promotion of patient centred care.

4.10 Promoting evidence based service responses

Evidence-based practice is defined as: '*The conscientious, explicit and judicious use of current best evidence in making the decisions about the care of individual patients. The practice of evidence-based medicine means integrating individual clinical expertise with the best available clinical evidence from systematic research*' (Sackett et al., 1996). Implementing evidence based service responses requires both professional expertise and research evidence. To promote the use of research evidence the system of care offered the LoTS care manual. The LoTS care manual included reference guides that consolidated recommendations from clinical guidelines, systematic reviews and randomised controlled trials i.e. evidence that was considered to be the 'gold standard' of health services research. The dissemination of printed educational materials, such as the LoTS care manual, has been employed frequently in health services, as a strategy to promote professional behaviour change. Examples include research articles published in peer-reviewed journals, clinical guidelines and the National Service Frameworks. These materials are usually disseminated to promote the use of practices of proven benefit and to discourage ineffective procedures (Giguere et al., 2012).

Three characteristics can be used to describe the LoTS care manual in more detail 1) the format 2) the channel, and 3) the message (Giguere et al., 2012). The format refers to way in which the materials are presented. The 16 educational reference guides were presented in one booklet (the LoTS care manual), which also included frequency tables, a service directory and an introduction to the system of care; in total this amounted to 124 pages. The channel refers to the mode in which the written materials were presented to recipients e.g. whether they were posted, hand delivered and how frequently the message was received. The LoTS care manual

was passively disseminated to the intervention services but there was no strategy to facilitate or enforce the implementation of its recommendations. However, the Coordinators who attended the LoTS care training completed a workshop in which they used the manual in fictional scenarios. Therefore some Coordinators were aware of its content and how this information could be applied in practice.

The 'message' of the materials can be sub-divided into a further five categories, these are a) clinical area, b) type of targeted behaviour, c) purpose, d) level of evidence and e) the educational component of the material. The clinical area was stroke, however the sixteen reference guides targeted different problem areas e.g. pain, mobility, finance and benefits. The type of behaviour the manual sought to modify were the service responses employed by the Coordinators, this included their onward referrals, the information and advice provided to patients and the monitoring of certain problems (see appendix viii for example of algorithms).   The purpose of the manual was to bring service responses in line with the evidence base or expert opinion where possible. However, the level of evidence to support the recommendations in each domain varied. For example, the reference guide 'Mood' was informed by evidence from clinical trials that evaluated the use of pharmaceutical drugs and psychotherapies (although the evidence about an optimum treatment choice is not conclusive). In comparison to mood, there were no clinical trials identified to inform the reference guide 'Finance and Benefits'. This reference guide was informed by expert opinion and national policies. The educational component was described in the manual's introduction, which stated that the intention of the manual was to:

> *Provide new ideas to people who may be already very familiar with the content. For some areas e.g. the management of depression where evidence base is already strong the model will be more of a prompt of good practice. In other areas the identification and promotion of effective interventions incorporated into the model may serve to change the clinical behaviour of primary care professionals.*
> (The Lots Care Team, 2009)

The impact of the educational material in the manual therefore was expected to vary depending on the knowledge of the professional acting as Coordinator. The dissemination of the LoTS care manual to the intervention sites facilitated access to educational materials that linked directly to the assessment domains. The assumption was that professionals would refer to the LoTS care manual as a source of support when performing the Coordinator role. Reference to the LoTS care manual would inform them of how to address post-stroke problems using the latest evidence and expert recommendations. These recommendations would then be applied in practice to resolve the problem identified, where possible. The LoTS care manual had the potential to enhance the service responses employed by the Coordinators; however it was also acknowledged that service availability varies between localities. For this reason, adaptation would be appropriate and necessary in some contexts and this was reflected in the implementation principles that stated the system of care should be implemented according to local resources and services (see appendix v).

Again it is possible to be critical of the intervention and its links to the anticipated output. The manual contained a vast amount of information to inform and consequently change practice. However, barriers to the implementation of the manual's recommendations were apparent, as noted by stakeholder 4: *I think the Coordinator could be brilliant in themselves, but if they haven't got the services to refer on to, say if the patient has got psychological problems, if there's no psychiatrist for them to refer on to it would be difficult for that problem to be addressed*. Therefore, the manual might be used as a source of support, but this would not necessarily lead to the implementation of its recommendations, as this was dependent on local resources. This barrier has also been noted in the wider literature that described that a '*lack of (access to) hardware or human resources hindered implementation*' of clinical guidelines (Rashidian et al., 2008 p.154). There is also evidence that guidelines, which are perceived as complicated, or those considered time consuming might be avoided in practice; a lack of trust in the evidence presented might also influence their use (Spallek et al., 2010, Forsner et al., 2010). The manual was an efficient way to disseminate a large quantity of information as part of the intervention, but there was also evidence to suggest that the Coordinators might not respond to its recommendations in the way anticipated.

The final output explored was 'continuity of care', what this referred to and how this would be achieved is explored further below.

4.11 Continuity of care

Three types of continuity of care have been identified in a review of the relevant literature, these are information continuity, management continuity and relational continuity (Haggerty et al., 2003). The LoTS care manual emphasises 'management continuity', which is defined as: 'a consistent and coherent approach to the management of a health condition that is responsive to a patient's changing need' (Haggerty et al., 2003). The system of care aimed to promote 'continuity of care' through a process of assessment, care planning, monitoring and review. These were the implementation activities expected in the delivery of the system of care's components. The assessment booklet included the care plan, which was expected to link the problems identified with appropriate service responses, as stakeholder 1 commented:

Stakeholder 1: *If all you ever do is do an assessment then you're not making a difference to the patient. So you've got to link the assessment with an action plan or goals that you negotiate with the patient that mean you're going to change something for the patient, or help the patient change things for themselves. So they're two sides to it really. There's the assessment and then what does that trigger'.*

The conclusion of the comprehensive and systematic assessment was the documentation of a care plan that described what the service user wanted to achieve (their goal) and what the Coordinator and patient intended to do in order to achieve this goal (actions). Continuity of care would be promoted through the use of the care plan that would record the monitoring processes (follow-up of actions and review of goals) and the number of reviews (repeated assessment) performed over the period of one year (the LoTS care trial's duration). The study protocol, stated that *'the Stroke Care Coordinator will undertake a primary assessment of patients (and carers*

if appropriate) and instigate service responses, with additional follow-up and monitoring visits as considered appropriate to the needs of individual patients,' Monitoring was to be provided '*as needed*', however it was anticipated that this would involve at least two/three visits, which was also stated in the project protocol. The importance of monitoring the care plan was established during earlier studies performed at the AUECR (Murray et al., 2006, Dowswell et al., 1997), stakeholder 1 commented:

Stakeholder 1: *What* [the qualitative study] *showed was, and I think this is quite good really, if you take an average group of stroke patients and you see them at six months they have a range of different problems and you intervene and you help them hopefully to solve their problems, if you go back and see them at nine months you found that you have ameliorated some of the problems but now there are some new problems that have emerged,[…] You may be solving one problem, for example, you may be able to get a stroke patient to be more active socially going off to a local day centre but then that raises their expectations and they may have a higher horizon for doing something new and different. So I think that's why we need to do a review and almost be working with them and really try and promote their recovery over quite a long period.*

Previous empirical work demonstrated that addressing the needs of stroke survivors required a 'long-term perspective' as their needs changed over time (Dowswell et al., 1997). The feasibility study of the system of care supported these findings although for a different reason. This study surveyed participants' three-months after their assessment to identify unmet needs (Murray et al., 2006). The survey indicated that some problems, which had been identified by the Coordinator, persisted. The research team established that the Coordinator had identified and addressed the problem by referring to an appropriate service. However, the Coordinator had not clarified whether the service user had subsequently received that service, stakeholder 2 commented: '*if no-one is chasing these things* [referrals] *up then no one is tying up the loose ends in the system and problems are not being addressed, I think the process of care has to be a series of circles*.' The stakeholder emphasises that in order for a problem to be addressed through the system of care

an iterative process of monitoring and review needs to be performed. A follow-up telephone call was built in to the system of care during the feasibility study to address this gap in service provision.

During the LoTS care trial, the recruitment process clarified that the services visited individuals more than once, as stakeholder 4 clarified: '*were not saying they have to see the patients at six months and a year. It's when they would normally do a follow up anyway but before they are recruited to the trial we make sure that there isn't just a one off assessment and that's it*.' Therefore, there was an assumption that some follow-up processes would be performed as part of the Coordinators' standard practice. Further to this, the twelve points advocated at the LoTS care training days included three points that promoted contact with service users over an extended period of time, these were

- Follow-up should be conducted on actions that have been referred out.
- Review goals that have been made with the patient.
- Timing/duration of intervention in line with RCP Clinical Guidelines for Stroke & National Stroke Strategy**.**

Although not stipulated, the duration of the intervention was also expected to reflect national guidelines. The most recent guidelines were in the National Stroke Strategy, which recommended that a review take place at six weeks, six months and annually thereafter. Five 'contacts' (assessment structure and care plan documentation) were provided in one LoTS care assessment booklet. These contacts would facilitate the implementation of reviews where new problems could be identified, as stakeholder 4 commented: '*it would be useful for them* [the Coordinators] *to do the whole assessment so they could review any new problems that had come up since the last visit, particularly if the first visit was quite soon after going home as the patient may not have realised some problems.*' Although reviews and monitoring were described as important components of the system, there were no strategies employed to ensure these processes were performed. The assumption was that the Coordinators would incorporate the follow-up processes necessary to

ensure that the problems identified were addressed i.e. achieving the system of care's aim.

4.12 The LoTS care logic model

A number of assumptions about how and why the system of care would enhance service practice have been identified. However, the assumptions described are not an exhaustive list. There is no finite number of theories to be elicited, particularly as theories are subject to change over time (Barnes et al, 2003). The aim was to understand the system of care in enough detail to focus the empirical inquiry. In the case of this study the aim was to understand how change would be generated in professional practice to enhance service delivery. The information elicited was used to map the predicted path from the provision of system of care's components (inputs) to achieving the system of care's aim (the outcomes). The information was presented in a logic model, which Bickman (1987) refers to as '*a plausible and sensible model of how a program is supposed to work*.' Logic models have been described as key tools in programme theory evaluation, as they expose the links between, the input, activities, output and outcomes (McLaughlin and Jordan, 1999), see figure 10 below.

Figure 10: The LoTS care theory of change

OUTCOME: Service user's needs addressed
OUTCOMES MEASURED: GHQ-12, FAI, BI, LUNS

INTERMEDIATE OUCTOMES:

Post-stroke problem accurately identified

Service user accesses Health, Social, Voluntary and Housing services

Service user accesses Information and advice

Service user develops problem solving skills

SERVICE OUTPUTS:

- Coordinators address areas of central importance to stroke survivors

- Systematic approach to the assessment

- Evidence based / recommended service responses employed

- Patient centred care (collaborative problem solving and goal planning)

- Problem solving techniques applied in practice

- Continuity of care promoted through processes of assessment, monitoring and review

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System of care's components and principles embedded in routine practice

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Strategies to promote changes in practice:

- **2 Training Days**
Manual Workshop
Lectures (Pain and Finance and Benefits)
Problem solving techniques
12 implementation principles emphasised

- **Recruitment procedures for trial**
- **Mandatory use of LoTS care assessment booklet**
- **Dissemination of Manual to intervention service**

Resources provided by the system of care: Checklist, Assessment Booklet, LoTS care Manual, Information File

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ASSUMPTIONS

The logic model emphasises the communal theory of change discussed with the LoTS care team. However, logic models do not reflect every idea or eventuality involved in the process of change in a complex adaptive system (Barnes at al 2003). This task would prove difficult considering change is thought to emerge unpredictably from the interaction of the system parts (Begun et al., 2003). The model therefore is a simplified representation of the change process and reflects the ambition of the intervention architects, which were sought to focus the empirical inquiry.

When selecting theories to test, a judgement needs to be made on what ideas are dominant and considered worthy of evaluating in their own right (Pawson and Sridharan, 2009). With limited resources it is impossible to explore every salient aspect of a complex intervention, as Pawson (2006) notes, '*the only way to get to grips with complexity is to prioritise'*. The logic model summarises the strategies employed to generate change and enhance service delivery. It was the combination of these changes that were expected to achieve the system of care's aim and this was considered when prioritising a set of sub-theories for investigation. For this reason, two aspects were explored; the implementation of the system of care's components and a selection of the programme theories.

4.13 A focus on the implementation process

The system of care was designed for use nationwide; however there was enough flexibility for sites participating in the trial to adapt their delivery to local circumstances. This was reflected in the twelve points advocated at the training, which stated that the system of care, 1) was not prescriptive, and 2) could be implemented according to local service/resources. For this reason, there was a need to clarify what activities were performed when implementing the system of care. This clarification was directly linked to the research question articulated in chapter 3 - How were the components of the system of care implemented? This question became focused through theory elicitation on two aspects, these were:

a) The iterative process of assessment, monitoring and review described as a key attribute of the system of care, and;

b) The activities involved in care planning i.e. whether these reflected the problem solving techniques and goal planning advocated.

The processes of assessment, monitoring and review were prioritised in this study, as they were considered key in addressing the longer-term needs of stroke survivors. Enhancing the Coordinators' practice was one intention of the system of care; however the activities they performed needed to be repeated until no further problems were identified. Therefore the aim of empirical work was to trace the path of the system, as it unfolded in different contexts, capturing the points where it adhered to or deviated from the theory of change and the reasons why (Patton, 1987). The care planning processes were also examined, as these directly linked to the processes of monitoring and review i.e. indicated when monitoring and review should take place. The combination of these activities provided insight into the extent to which the Coordinator was involved in resolving the problems identified.

4.14 A focus on programme theory: Mechanisms and Outputs

Propositions consisting of a mechanism of change and an anticipated service output focused the second research question; how and to what extent did the system of care enhance service delivery? Sidani and Sechrest (1999) describe 'critical inputs' that are sometimes required to activate the 'mediating processes' or mechanisms of change   In this study the inquiry focused on the strategies employed to generate change in professional practice. The critical inputs therefore refer to the provision of the system of care's resources, and the training received by the Coordinators. Some of the links between the system of care and the service enhancements anticipated were less clearly embodied in the change strategies than others. For example, goal planning was expected to contribute to patient centred care (an anticipated output). However, the Coordinators were not provided with training or practical support to formulate goals as part of the intervention; therefore, this was not explored further as a proposition. The mechanisms selected were those that linked to the provision of the LoTS care manual and the assessment booklet, these were:

- Use of the stroke specific assessment structure was made mandatory as part of the intervention group. The structure would inform the Coordinators of the areas of central importance to service users and their carers (M). This mechanism would extend the scope of their assessment, promoting a comprehensive post-stroke assessment (O), depending on the context (C).

- Copies of the LoTS care manual were disseminated to the community stroke services, which facilitated access to educational texts. The Coordinators would refer to the LoTS care manual to inform their implementation of the system of care (M). This mechanism would promote the use of, where possible, evidence-based or recommended service responses (O2), depending on the context (C).

The propositions identify the mechanisms that were expected to enhance professional practice. These propositions were prioritised for investigation as they were expected to enhance two processes fundamental in addressing post-stroke problems; their identification and their resolution. They were also targeted as the intervention resources (the assessment booklet and the manual) were available to all Coordinators, regardless of whether they had attended the LoTS care training, and use of the assessment booklet was made mandatory i.e. the mechanisms relied on components that appeared most likely to be used in practice and therefore produce some (expected or unexpected) change as a result. Therefore, the propositions were prioritised as they were considered significant in achieving the system's overall aim and the mechanisms relied on the more tangible intervention resources. Examining these aspects in conjunction with the implementation activities was intended to draw a detailed picture of how the system of care worked to address post-stroke problems. Further to this, they linked to resources that were accessible to the Coordinators for the duration of the trial, and could be used practically in day-to-day practice.

4.15 Study Context

Theory elicitation indicated that the contexts in which the propositions were expected to work were where Coordinators had previously focused on specific areas due to their professional background, or where they used non-stroke or non-

structured assessments. The tools were essentially designed to address any gaps in the professional's knowledge i.e. enhance their practice. These proportions were explored with Coordinators based within two community stroke teams. The use of two teams removed some of the variation initially sought i.e. Coordinators who worked alone (see chapter three). However, it was hoped that all services would contain internal variations that could contribute to theory refinement. The two services selected as research sites, for example, were known to differ in their size and in the service users they targeted. These service level variations were not those initially sought, however they allowed different, but perhaps equally important comparisons to be drawn between the two services.

4.16 Summary

This chapter has elicited the theory of change underpinning the system of care. The problem perceived by the LoTS care team was that current community stroke services were not based on the expressed needs of stroke survivors. The LoTS care team targeted this problem (at the mirco level) by developing components that were mapped onto a framework considered holistic and comprehensive of the problems experienced post-stroke i.e. extending the scope of the assessments performed. However, the LoTS care team also sought to impact on the Coordinators skills and the processes of care they performed. Interrogation of the assumptions underpinning the system of care led to the development of a logic model that depicted the theory of change in a simplified format. This enabled a number of sub-theories to be prioritised for testing, and has provided a benchmark against which to compare empirical work. The next chapter will examine the context of each research site and begin to trace the path of the system of care within each service.

Chapter 5: Embedding the system of care's components

5.1   Introduction

This chapter describes the contextual characteristics of each research site and how the system of care became embedded within two established community stroke services (service one and service two). The service locality, their target population, the composition of the multidisciplinary teams and the allocation of the Coordinator role are all described to provide understanding of the structure and organisation of each site. The chapter proceeds by explaining why the services volunteered to participate in the LoTS care trial and the processes through which the client checklist, the manual and the assessment booklet were integrated with, or replaced, existing resources. Explanations draw on the premise that local facilitators and barriers shape how complex interventions unfold in practice. The components were absorbed in different ways and adapted to meet the specific needs of each service. The chapter concludes by reflecting upon the findings presented and their significance to the theory of change.

5.2   Local context and service users

Service one and service two were located in urban areas of regions (region one and region two) in the North West and West Midlands of England respectively. Both regions have higher levels of deprivation, lower life expectancies for men and women and earlier death rates from cancer, heart disease and stroke than the rest of England (Public Health England, 2013). Region one has some of the highest stroke admission rates compared to the national average, whereas admission rates for stroke in region two are not higher than the national average (Public Health England, 2013). Sixty four percent of the population in region one live in the most deprived national quintet (according to the English Indices of Deprivation), in region two the figure is 45% (Public Health England, 2013). Both services were based in the more deprived areas of their regions, with more strokes being registered from people living in these areas than any others (Public Health England, 2013).

Both services were dedicated community stroke teams. They had been established in their local communities for over twenty years and were commissioned by Primary Care Trusts (PCT)1. The service commissioners provided guidance on what the teams' should deliver and to whom. At service one a 'specification' outlined eligibility criteria and the patient pathway through the service. According to these criteria referrals would be accepted if, a) a health or social care professional (in hospital or the community) had completed the referral form and b) the individual's General Practitioner (GP) resided within the team's locality. Further to this, the service user had to fulfil the following criteria:

- Be over the age of 16
- Suffered a recent stroke, or have ongoing needs as a result of a previous stroke
- Medically stable and fit to participate in the rehabilitation process
- Would benefit from rehabilitation at home or in their local community,
- Motivated to participate in the rehabilitation process.

Individuals were excluded from becoming service users if:

- They are under 16 years who would access paediatric services
- Their problems were not stroke related
- They required rapid response intervention
- They were medically unstable

The criteria indicate that, in the context of service one, stroke survivors could access the Coordinator if they required ongoing rehabilitation provided by the Community Stroke Team. In comparison to service one, service two proactively identified every individual diagnosed with stroke to receive the Coordinator role. Service users were identified through attendance at the multidisciplinary team meetings held on the acute stroke unit. The only criterion applied at service two was that the stroke survivor's GP should reside within the team's locality. Service two also used a specification to guide service delivery. However during fieldwork this document was under review by the service commissioners and stakeholder groups and a copy was

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[1] The Acute Trusts and Primary Care Trusts recently merged to form NHS trusts, however this did not impact on the delivery of the LoTS care system of care.

not provided to the researcher. The service manager (S2SM) clarified the team's target population:

S2SM: The primary focus is around early supported discharge in terms of being able to really facilitate, for those obviously, patients that are applicable, it is about the ongoing therapy once they leave and the continuation, avoiding any gaps from when they're transferred from hospital into the community. So it's not only about, obviously a big part is around the rehabilitation, but for those patients that don't have any rehab needs obviously we pick those patients up for review, so regardless of what their needs are, if there is a confirmed stroke then they come to us for ongoing support review, whatever's needed for that individual.

The manager clarified that the service aimed to provide continuity in the provision of rehabilitation across the acute and community boundary. However, the service aim was also to support all stroke survivors regardless of their physical rehabilitation needs. The difference in eligibility criteria was reflected in the service caseloads e.g. on average each month in 2011 service one received seventeen new referrals, whilst service two identified one hundred and seven individuals to receive their service. This comparison provides some insight into how local circumstances (eligibility criteria) shaped the Coordinator role, resulting in a considerable difference in the size of their caseload. Accordingly service two employed a much larger team, the members of which are described below.

5.3 Members of the of the multidisciplinary team

Each service employed a range of health care professionals, these included occupational therapists, physiotherapists, speech and language therapists, and stroke nurses. The professionals were based in the same office (at both services) and shared a building with other community services. For example, service one

were based in the same building as the community continence nurses and service two shared their building with welfare rights, who provided advice about finance and benefits. Table 9 below provides an overview of the members of each team.

Table 9: Members of the Multidisciplinary Team

Role	Service one (S1)	Service two (S2)
Service manager (SM)	1	1
Occupational Therapist (OT)	2	3
Physiotherapist (PT)	2	5
Nurse (Specialist / Liaison) (SN / LN)	1	3
Speech and Language Therapist (SLT)	2	1
Psychologist (PSYCH)	0	2
Generic Worker (GW)	2	1
Technical support	0	2
Stroke Association Family Support Worker (SAFSW)	0	1
Total	10	19

It is apparent from the table that service two was more substantial and offered an additional two services - Psychologists and a Stroke Association Family Support Worker. As discussed in chapter two, psychological and emotional problems are common post-stroke (Hackett et al., 2005, Mukherjee et al., 2006). However access to psychological services in the community is often limited (NAO, 2010). For this reason, the psychologists at service two were acknowledged as a valuable resource. The Stroke Association Family Support Worker focused on the problems experienced by family and the informal carers of stroke survivors. This focus distinguished them from the Coordinators who concentrated on the needs of the stroke survivor.

The professionals were brought together to address the needs of their local stroke population. Direct intervention for many post-stroke problems could be provided by the skill mix within the team e.g. problems with mobility, cognition, speech, language and swallowing could be addressed by the physiotherapists, occupational therapists and speech and language therapists. However, the longer-term problems experienced post-stroke extend beyond the remit of these professionals. The system of care intended to enhance the role of the Coordinator, promoting a comprehensive assessment of all post-stroke problem areas. During fieldwork, insight was provided into how the Coordinator role was established prior to the system of care, this is discussed further if the following section.

5.4   The role of Stroke Care Coordinator

The LoTS care team defined the role of Coordinator as a health care professional who undertook a community based liaison or coordinating role, and who organised a range of care inputs for stroke patients in the community. Providing this role was an entry criterion for stroke services participating in the LoTS care trial. Service one and service two fulfilled this criterion, but the duties and responsibilities associated with the role were embedded within the multidisciplinary team structure. In the context of service one this meant that every professional in the team acted as a Coordinator, see figure 11 below for overview.

Figure 11: Coordinators at service one
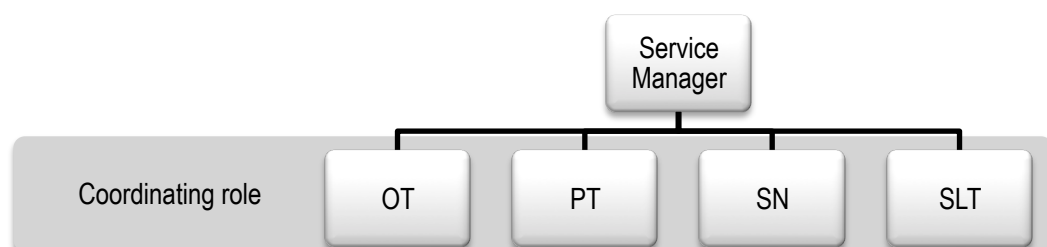
The allocation of the coordinating role was usually dependent on the service user's needs, as documented in their referral form. To clarify, referrals received by the service were screened to identify, a) if the individual was eligible to receive the service, and b) the reason why they had been referred. The latter indicated which professional was likely to provide intervention as a therapist or nurse and was therefore the most appropriate to act as the Coordinator. However, rather than 'Coordinator' the professionals referred to this as the 'MDT assessment'. The purpose of this assessment was to link the stroke survivor to appropriate services (within and outside the team) based on the problems identified. The adequacy of the tool used to perform this assessment was a factor that had motivated participation in the LoTS care trial, as the manager at service one (S1SM) explained:

S1SM: *'It* [the LoTS care trial] *looked like a good piece of work and I was looking at how we could develop a more cohesive service. So at that time we were using the SAP* [single assessment process] *Overview document, which met part of what we wanted, but wasn't quite specific enough. I knew I wanted to develop something, and it was there that I wanted to move on with it, and that's when I became interested in the LoTS care trial really'*

The Single Assessment Process Overview document, to which the manager refers, was the Easy-Care assessment. As described in chapter two, the single assessment process was initiated as part of the National Service Framework for Older People (Department of Health, 2001b). The Easy-Care assessment was a Department of Health accredited tool developed to provide a holistic overview of the service user's needs (Clarkson et al., 2009). The assessment domains contained within the Easy-Care are provided in appendix ix. Use of the Easy-Care tool indicated that the MDT assessment performed at service one used a structured and holistic approach. Unfortunately the Easy-Care did not meet the needs of the service as a dedicated stroke team i.e. supporting the assumptions of the LoTS care team described in chapter five. The system of care offered a potential solution in the form of the stroke specific assessment structure. In comparison to service one, at service two, 2 Stroke Nurses and a Generic Worker performed the Coordinator role, see figure 12 below.

Figure 12: Coordinators at service two
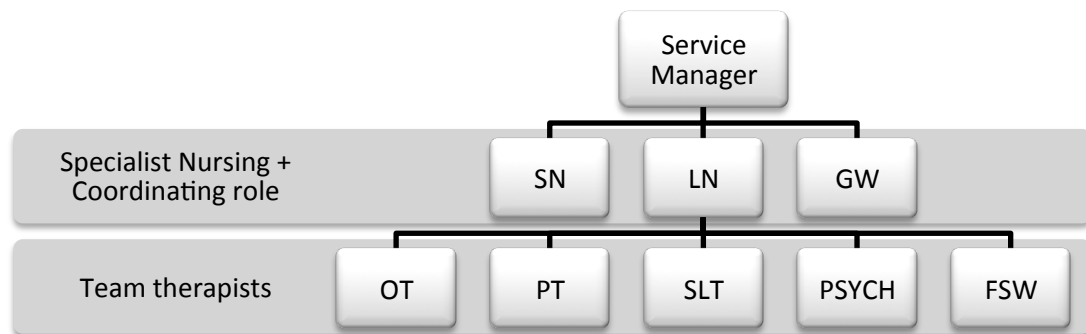
The Coordinators formed a stroke review team within the wider multidisciplinary team. Their duties included, 1) performing an initial assessment to link individuals to appropriate services, 2) reviewing their service user's needs intermittently over a three-year period, and 3) providing specialist nursing at each review. The specialist nursing provided included health promotion, blood pressure monitoring and medication management. Similarly to service one, the assessment tools used at service two to perform the stroke reviews had motivated their participation in the LoTS care trial. The service manager (S2SM) explained:

S2SM: 'We have to use this generic SAP document and we found that actually from a specialist service point of view it wasn't detailed. It wasn't detailed enough and it didn't evidence the work that we do so we found that with using the document [LoTS care], *you know, saves us a job as well doesn't it, you know. If somebody else has done the hard work, if we can demonstrate and it works well for us and the patients then obviously that's gonna be better for everyone.'*

Single Assessment Process tools were also used in the context of service two; however these had been developed in the local area. An Overview assessment, similar in content to the Easy-Care, was used to perform the initial assessment (see appendix X for domains). Specialist Nursing documentation was used to perform every subsequent stroke review, in line with the Single Assessment Process. Two

problems were reported with these tools, 1) that the assessment was not detailed enough, and 2) that it did not evidence the work of the Coordinators. The new system of care could address these problems and improve the documentation used by the Coordinators. However, stroke survivors only received the new system of care if they were identified in hospitals that recruited to the LoTS care trial. The service continued to review other stroke survivors using the Single Assessment Process, to remain consistent with other professionals in the area where possible. For this reason the two systems were implemented in parallel.

The Coordinator role had been established in different ways within each service. The Coordinators at service one wore two hats, one to perform the 'MDT assessment' and the second to provide intervention as a therapist or nurse. In the context of service two the review team combined their duties, they provided specialist nursing and a holistic assessment as part of each review. The LoTS care system of care was introduced at a timely point in the history of both services. The manager at service one was considering developing a new tool to improve the MDT assessment. However, the introduction of the system of care would potentially negate their need to do this. The Coordinators at service two were required to implement the Single Assessment Process. However, participation in the LoTS care trial provided the opportunity to use a stroke specific tool that would evidence the Coordinator role.

Participation in the LoTS care trial was partly motivated as the two services were enthusiastic to improve their existing practice. These findings reflect that of other studies that have described 'system readiness for change', as a factor contributing to the successful diffusion of innovations (Barnett et al., 2011, Greenhalgh et al., 2004). This readiness for change could facilitate the implementation of the new system of care. However, the different service structures and the emphasis (at both services) on improving the assessment tools used rather than their processes of care, suggested that the theories of change might be absorbed in different and unexpected ways. The next point of inquiry was to establish how the system of care's components (the checklist, the LoTS care manual and the assessment booklet) were received and interpreted by each service. The service managers and

a Coordinator from service one (S1OT1) had taken a lead role in assimilating the new components, and they were able to provide insight into how this was achieved.

5.5 Administering the Client Checklist

The checklist was an A4 summary of the LoTS care assessment sections, the purpose of which was to enable service users to prepare for their assessment. Both teams were keen to introduce the checklist into routine practice because of the benefits anticipated from its implementation. For example, an occupational therapist at service one commented that some individuals described the assessment as an '*interrogation*' (S1OT1), as the process was lengthy and covered many areas. For this reason it was considered good practice to inform service users of the content of the assessment prior to the Coordinator's visit. The manager at service one (S1SM) noted: '*With the number of questions you're asking them* [service users]*, for them to have jotted things down and have thought about them and knew what was coming we thought that, that was quite a good tool really*', and this opinion was also shared by the manager at service two:

S2SM: *It* [the checklist] *was something that we wanted to do in terms of communicating and preparing the patients for the visit, so we kind of picked up on some of the things that had been started through the LoTS, in terms of at least being able to, at least when you come, you know, they're not sort of hounded, they've had time to think about some of the issues or concerns for them so they can be prepared for the review in advance rather than being bombarded with lots of questions, and it also makes sure that actually you're getting things from their perspective as well, rather than having things thrusted upon them, do you know what I mean?*

Both services recognised that the assessment could be a negative experience for the service user if they felt 'hounded' or 'interrogated' during the process. Provision of the checklist could potentially alleviate these negative aspects through offering

service users an opportunity to prepare responses in the relevant domains. A further benefit of preparation, suggested by the manager at service two, was that the checklist might prioritise the 'patient's perspective' i.e. if the individual had documented their concerns the Coordinator could focus the assessment on these points. Provision of the checklist was also valued as a source of support for the Coordinators. The senior occupational therapist (S1OT1) at service one (who had taken a lead role in embedding the LoTS care components) commented:

S1OT1: There were some teething problems with it [using the system of care]*, that people didn't like asking about sex. That was a big one. So, from that, we decided we were going to send out the patient questionnaire, although I did feel like I was the only person banging on about sending that out to be honest, as it's all like, there is no admin, and it was just more work, but we should be doing that really and sending out a letter to someone to say, when we had a big waiting list, we need to write to the GP to tell them that we know about this patient as quite often we'd be in before they got their discharge letter from the hospital, or sometimes we'd be much later and people would be ringing up, and it's important to communicate where you're up to, so it made us be a bit more efficient.*

Administration of the checklist may work to legitimise the coordinators' coverage of the sensitive assessment domains i.e. sexual function, as service users would be aware that these questions were addressed as part of a standard assessment. The Coordinator (S1OT1) also revealed that there were some concerns over the administration of the checklist and that they had driven this change to improve communication with their service users. At the time of fieldwork, the waiting list for individuals to be seen by a Coordinator was up to eight-weeks. The occupational therapist commented that this led to uncertainty about whether the team had accepted the individual for a period of care. For this reason, a letter informing service users that their referral had been accepted and that they were on the waiting list to be seen was established. This provided a vehicle with which to administer the checklist. This finding also reflects the wider literature on diffusion of innovations, which describes that certain people can act as 'champions' of an intervention

facilitating their implementation in practice (Greenhalgh et al., 2004). In comparison to service one, service two corresponded with their service users to notify them of the date and time of their stroke review, and to ask them to complete the Hospital Anxiety and Depression Scale (HADS) (Snaith, 2003). The HADS was used to monitor service users' mood and to inform referrals to the team psychologists. The checklist was easily incorporated with this as an additional form to complete.

Preparing service users for their assessment was an initiative that both services were keen to implement and they established new, or incorporated its administration with existing processes. The use of the checklist was not specifically explored further in this study. However, observations revealed that it was rarely used during the assessment process. The Coordinators discussed numerous barriers to its use in practice e.g. service users' cognitive capabilities, poor literary skills, and confusion over its purpose. The Coordinators also reported that they often forgot to prompt its use during the assessment. Fieldwork supported these explanations. The majority of service users did not recall the checklist when prompted by the Coordinator. On the rare occasions when the checklist had been completed, the Coordinator did not use it to facilitate problem identification e.g. to target the individual's problem areas. Therefore it was not observed to enhance the assessment process. At the service level the teams' implemented the checklist as intended by the LoTS care team. However at the practitioner and patient level contextual barriers limited its ability to enhance the assessment process. This finding demonstrates the considerable task undertaken by some complex interventions, as their ideas and opportunities have to cascade through different levels before any benefits are realised in practice (Brady et al., 2011).

5.6   Dissemination of the LoTS care manual

The LoTS care manual was designed to inform the Coordinator's assessment and care planning processes. It facilitated access to educational materials that linked directly to the domains in the LoTS care assessment structure. Copies were disseminated to each service (seven to service one and five to service two) and in most circumstances Coordinators were provided with a personal copy. However, implementation of the manual's recommendations was left to the discretion of each

service, and reference to the manual was left to the discretion of each Coordinator, the manager at service one (S1SM) noted:

S1SM: I suspect there would be individuals who use it more, but I suspect it would be certain areas of where your expertise is not as strong, as a guide or just prompting a reminder, right we've got something that looks like a mood, mental health problem, right what do we do, but then it links into local, as what staff are wanting to know out of that is who do they go to. So the tool is useful in itself as it's best practice but the tool is most useful in its local form.

The manager supports the assumptions of the LoTS care team, providing insight of where the manual might be used i.e. in areas that lay outside the Coordinators expertise. However, they discuss that the information valued most by the Coordinators are the contact details of local services. The LoTS care team were aware that service availability varied between localities, and allocated space in the manual to document details of local services. At service one a Coordinator (S1OT1) expanded upon this section in the manual by developing a local information file. The Coordinator explained the purpose of the file:

S1OT1: To give people who weren't confident asking questions that weren't necessarily their remit, so for example, S1SN had come from hospital environment and hadn't worked in the community for a long time and sometimes it's a bit scary coming from the community, a bit like a fish out of water. It's not so much the questions you ask it's the answers that you're given. So collating the local information, I was aware that I was going on maternity leave; S1OT2 was only with us one day a week at the time, so to look after her as well. Mental health things all used to come through me, to make sure that people could appropriately deal with any mental issues, so it was making sure that all that information that was held in my head was there for everybody in a box.

Professionals who were new to community working might be unaware of the services available in the local area i.e. feel like a '*fish out of water*' when performing the Coordinator role. Colleagues with experience of working in the community were able to provide guidance, as the Coordinator (S1OT1) noted, '*mental health issues all used to come through me*'. However they wanted to facilitate access to this information when they were absent from the team office. The local file was stored in the service office and its content was reviewed during fieldwork. It was found to contain information about local services and copies of their referral forms (where available) that were categorised according to the LoTS care assessment domains. The Coordinators comments highlighted that there were an additional two sources that could be used to inform the Coordinators practice in the context of service one, 1) team colleagues and 2) the local information file. Further to this, they indicate that the information provided might be particularly useful for professionals new to community working.

In comparison to service one, in the context of service two the information in the manual was not adjusted to reflect local service availability. In reference to the manual the service manager (S2SM) commented: '*I thought that was quite useful actually […] particularly if you're not familiar, if you're not, you know, some people aren't that brilliant at completing documents, it does help to improve the quality of the information and it helps with the signposting and stuff as well.*' The manager felt that its content might improve the information elicited during the assessment, as it provided clarification for the professional if referred to. Use of the manual was left to the Coordinators discretion. However, during fieldwork it was noted that Coordinators, across both services, did not refer to the manual or the local information file (at service one). The copies of the manual were not visible in the service offices, which was also an indication of their absence from daily practice.

Copies of the manual were available as a reference at both services. Coordinators at service one had an additional source of support in the form of a local information file. This finding reflects the wider literature, as nationally developed guidelines are often adapted to local circumstances (Feder et al., 1999, Graham and Harrison, 2005, Fervers et al., 2006), and this is thought to promote their implementation in practice (Fervers et al., 2006). Further to this, other sources (team colleagues) were

also available to inform the Coordinators practice. These findings suggested that the necessity to use the manual might be negated by other sources, and this is explored further in chapter seven. Implementation of the LoTS care assessment booklet was made mandatory as part of the intervention group in the LoTS care trial. The next section clarifies how this booklet was integrated with the services existing documentation.

5.7   Integrating the LoTS care assessment booklet

The LoTS care assessment booklet contained a sixteen domain assessment structure and a care plan (see appendix iii). This documentation was repeated five times within one assessment booklet as separate 'contacts' to record every review (repeated assessments) completed. To amalgamate the LoTS care assessment booklet at service one, the manager reviewed its content to identify any overlap with the teams existing documentation. Prior to the LoTS care assessment the service used Easy-Care and had supplemented this with a Speech and Language (SALT) screen. The SALT screen was used to define changes in service users' speech, swallowing and language capabilities. This screen was considered a necessary addition, as the questions in Easy-Care were not deemed sufficient to prompt referrals to the team therapists. The Barthel Index (BI) and the modified Rankin Score (mRS) were also used to provide a recovery trajectory whilst in the care of the team. An information form was used to record demographic details of the individual, such as next of kin, ethnicity, age and the monitoring tool scores. On introducing the LoTS care assessment booklet some sections were removed from the service's information form (to save duplication), the Easy-Care assessment was replaced entirely with the LoTS care structure, but the SALT screen continued to be used. Table 10 below provides a summary of the 'assessment pack' used by the service pre and post LoTS care.

Table 10: Assessment tools used at service one

	Pre LoTS care	Post LoTS care
Assessment tools	Easy-Care (generic elderly assessment tool)	LoTS care assessment booklet (stroke specific assessment tool)
	Community stroke team information form	Refined community stroke team information form
	Speech and language screen	Speech and language screen
Monitoring tools	Barthel Index	Barthel Index
	Modified Rankin Score	Modified Rankin Score
Supporting tools	---	Client Checklist
	---	LoTS care manual
		Local information file

Service two used an Overview assessment, a Contact form that captured demographic details, and a Specialist Nursing Assessment to document the stroke reviews. The Barthel Index and the CROWN (locally developed disability score) were used to monitor changes in activities of daily living, and the Hospital Anxiety and Depression score (HADS) was used to measure mood and inform referrals to the team psychologists. For the purposes of the trial the LoTS Care assessment booklet replaced the Contact, Overview and the Specialist Nursing Assessments. Table 11 below provides a summary of the assessment tools used pre and post LoTS care at service two.

Table 11: Assessment tools used at service two

	Pre LoTS care (and non trial patients)	Post LoTS care (for trial patients only)
Assessment tools	Contact and Overview assessment Specialist Nursing assessment	LoTS care assessment booklet (stroke specific assessment tool)
Monitoring tools	Barthel Index	Barthel Index
	CROWN	CROWN
	Hospital Anxiety and Depression Scale	Hospital Anxiety and Depression Scale
Supporting tools	------------------------------------	Client checklist
	------------------------------------	Manual

Observations of service practice revealed that the Coordinators did not always use the monitoring tools, e.g. the HADS score was not always recorded (at service two) if the individual had not completed the tool and they did not report mood problems during their assessment. Further to this, the checklist was rarely used during the assessment and any the Coordinators did not refer to the manual during observations. The LoTS care assessment booklet was the only tool routinely used during the assessment process at the time of fieldwork. It is apparent from table 10 and table 11 that the changes introduced to the assessment documentation were the addition of supporting tools (the checklist and LoTS care manual), and the provision of a stroke specific assessment structure (LoTS care). However, the two tables demonstrate that the assessment process did not change from assessment structure 'a' to assessment structure 'b', but from a combination of assessments where the holistic, albeit generic elderly tool was replaced with one tailored to stroke. To provide further insight into what this change meant, the next section compares the content of the assessment tools used pre and post LoTS care.

5.7.1   Scope of the assessment structures

The three assessment tools (LoTS care, Easy-Care and the Overview) sub-divided groups of potential problems into domains with prompt questions to indicate what should be discussed. The LoTS care assessment consisted of sixteen domains,

compared to seven in the Easy-Care, and ten in the Overview. However, many problems included as part of the LoTS care assessment were also addressed in the service tools, but were amalgamated into fewer domains. To illustrate this point, table 12 below depicts the LoTS care assessment domains in the left hand column (numbered 1-16). The middle and right hand column indicate whether similar problems were addressed within a domain in the Easy-Care and/or the Overview, or if they were absent from these tools.

Table 12: Assessment domains

	LoTS care assessment domain	Addressed in Easy-Care	Addressed in Overview
1	Transfer of care	Absent	Absent
2	Communication and information	Absent	Absent
3	Medicine and general health	Looking after yourself / looking after your health	General Health /Medication issues
4	Pain	Your well being	General Health
5	Mobility and Falls	Looking after yourself	Mobility issues
6	Personal Hygiene & Dressing	Looking after yourself	Personal care and domestic needs
7	Shopping & Meal Preparation	Looking after yourself	Personal care and domestic needs
8	House & Home	Looking after yourself	Personal care and domestic needs
9	Cognition	Your Memory	Emotional well being
10	Driving and general transport	Absent	Environmental needs and resources
11	Finance & Benefits	Your accommodation and finance	Financial advice
12	Continence	Looking after yourself	General Health
13	Sexual Functioning	Absent	Absent
14	Patient Mood	Your well being	Emotional well being
15	Patient Social Needs	Your well being	Emotional well being
16	Other	Other	Additional information

It is apparent from the table that the domains addressed were broadly similar across the three tools. For example, 13 of the 16 assessment sections contained within

LoTS care are also addressed in the Overview, and 12 are addressed in Easy-care. The novel sections introduced at both services were 'transfer of care', 'communication and information', and 'sexual function'. 'Driving and General Transport' was also absent from Easy-Care. The main difference between the three tools is in the way they have categorised the problems, for example, 5 sections in Easy-Care include questions that addressed the 12 overlapping LoTS care domains. Table 13 below, provides the questions contained in the Easy-Care domain 'Looking After Yourself', and show how these questions have been categorised differently in the LoTS care assessment.

Table 13: Categorisation of the Easy-Care questions in LoTS care

Easy-Care section: Looking After Yourself Questions provided	LoTS-Care assessment domain
Can you do your housework?	House and Home
Can you take your own medicine?	Medicines and general health
Do you have accidents with your bladder? Do you have accidents with your bowels? Can you use the toilet?	Continence
Do you have any problems with your feet? Can you wash your hands and face? Can you use the bath or shower? Do you have any problems with your mouth or teeth? Can you keep up your personal appearance? Can you dress yourself?	Personal Hygiene and dressing
Can you walk outside? Can you get around indoors? Can you manage stairs? Have you had any falls in the last six months? Can you move yourself from bed to chair, if next to each other?	Mobility and Falls
Can you go shopping? Can you prepare your own meals? Can you feed yourself?	Shopping and meal preparation
Do you have any difficulties getting public services? Have you had any problems with your skin?	Not addressed

Table 13 demonstrates that questions addressing a wide range of problems are grouped together under the broad and vague heading, 'Looking After Yourself' in Easy-Care. In the LoTS care assessment, the same questions have been divided into six domains with headings that provide clarity on what will be addressed. For example, the section 'Mobility and Falls' contains questions that focus on these areas only. In comparison to Easy-care, the Overview assessment contains ten assessment domains and incorporates the thirteen overlapping LoTS care domains in seven. Table 14 below depicts how the questions presented in the Overview domain 'Personal Care and Domestic Needs' have been categorised in the LoTS care assessment.

Table 14: Categorisation of SAP Overview questions in LoTS care

SAP Overview section: Personal Care and Domestic Needs	
Do you have difficulty with any of the following and have you got any equipment that supports you?	**LoTS-Care Section**
Doing housework? Doing laundry?	House and Home
Washing and bathing? Using toilet/commode?	Personal Hygiene and dressing
Preparing food and drinks? Doing shopping? Do you need a special diet	Shopping and meal preparation
Keeping warm / cool?	Not addressed

Table 14 demonstrates that the questions provided in 'Personal care and domestic needs' were separated into four domains in the LoTS care assessment. Signifying that the LoTS care assessment structure provides more clarity than both service tools. However, despite differences in the categorisation of the problems there is much overlap between all three tools. This overlap can be explained as the Easy-Care and the Overview assessments were developed as holistic tools for use in elderly care. The needs and problems experienced by the elderly population overlap with that of stroke e.g. problems with mobility, continence, and cognition can link to ageing, but can manifest as a result of stroke regardless of the age of the individual. However, one theory underpinning the system of care was that the stroke specific

structure would provide a superior guide for problem identification. The extent to which this was realised in practice is explored further in chapter 8. However at the service level, adaptations to the LoTS care structure were noted, this is explored further in the following section.

5.8   Adapting the LoTS care assessment structure

One aim of the MDT (LoTS care) assessment performed at service one was to link stroke survivors to appropriate health, social and voluntary services in the community. The assessment tool facilitated this process, as it supported the identification of post-stroke problems, highlighting what services the individual required. Professionals in the multidisciplinary team could provide intervention to address many problems identified. For this reason, an important function of the assessment tool used was its ability to trigger appropriate referrals to the team professionals. The Coordinators at service one discussed that the absence of a domain that specifically addressed speech, language and swallowing was a weakness of the tool in the context of their service, as the service manager (S1SM) noted:

S1SM: One thing that for us as a team that was quite disappointing about LoTS was that swallow, speech was put under 'Other' [the final LoTS care assessment section] *and for a team that has a speech and language therapist on it that went down like a lead balloon, but we had our own speech and swallow screen that attached to it, so it didn't really matter, but that was something that wasn't as ideal for us.*

Swallowing is included as a prompt in the assessment domain, 'medicines and general health' to the question 'Do you have problems taking your medication'. It is also listed in domain 16 'Other'. Domain 16 provides a standard opportunity for service users to discuss problems that have not been addressed during the assessment. Specifically swallowing, speech, language, sleeping, vision, numbness, and oral health are all listed as possibilities for discussion (see appendix iii).

Unfortunately these prompts did not establish in enough detail whether the service user required intervention from the speech and language therapists on the team. The LoTS care assessment structure was designed to reflect the expressed needs of stroke survivors providing a patient, as opposed to professionally centred assessment. For this reason the domains focus on practical problems that may result from impairment e.g. shopping and meal preparation, rather than the physical impact on body function. However, a speech and language therapist (S1SALT1) explained why they felt further prompting was necessary:

S1SALT1: *It's* [speech, language and swallow] *a big proportion of the problems, it's only listed under 'other' at the end [...], the physical questions aren't really my expertise so it's good to have a few more specific questions to ask, and I think if people aren't aware of communication, and swallow problems, and the risks of aspiration, that they probably could do with guidance as well about what types of question to ask, so that people who are experiencing a bit of aspiration aren't getting missed, and people with reading and writing problems after a stroke aren't getting missed as well, as that tends to be the things that people forget about as well, you know. They might notice that someone has problems with their speech, but they might not think about asking about reading and writing you know.*

Some problems that the professional addressed as a speech and language therapist were not always physically apparent, such as aspiration, reading, and writing. These types of problems are not specifically prompted in the LoTS care assessment tool, apart from the reference to speech and language difficulties in the domain 'Other'. The implication was that without prompting these types of problems might not be discussed routinely during the assessment process, particularly if the Coordinator was less experienced or had limited knowledge of these areas. If the Coordinator did not routinely discuss these areas then problems pertinent to the service user might go unidentified. The absence of a speech and language section was also noted at service two, as one Coordinator (S2SN) described:

S2SN: *The communication of information, I always think is that supposed to be in speech there, is that about where we're supposed to put the speech difficulties and things, 'cos of being communication, and then does that go into the shopping and meal preparation one 'cos I'm always talking about swallowing and them problems there, so directing you to that speech and language therapy, which the communication is speech and language therapy so I think that's where I'm never quite sure where that fits into.*

The Coordinator was aware that problems with speech and language needed to be addressed, but could not see where they 'fit' within the LoTS care structure. For this reason the Coordinator advocated the addition of a 'sensory' section, they commented: '*I think it definitely needs a sensory section, definitely, 'cos not only just speech, it's eyesight's a big issue as well to people if they're having Hemianopia and things and that's not addressed anywhere really through it.*' The Coordinator noted that Hemianopia was also absent from the LoTS care assessment. Hemianopia refers to loss of vision in either the right or left side of both eyes (Intercollegiate Stroke Working Party, 2012a). In the LoTS care assessment vision is listed under 'Other'. However, the Coordinator did not consider this sufficient as a prompt to discuss the area. In the context of service two, the Overview assessment continued to be used alongside the LoTS care structure and this included a 'sensory' domain that prompted for sight, hearing, speech and communication. Therefore the Coordinator was advocating the use of a domain from the generic 'Overview' tool to improve the stroke specific assessment. Coordinators at service one also commented upon this, for example:

S1PT2: '*If we were to improve the LoTS it would be useful to have a section of speech, well communication, swallow, vision and sleeping even it was less comprehensive because you use the LoTS as a prompt really to make sure you cover things*'

The Coordinator described that they used the domains to prompt discussion of each problem area. For this reason, additional domains that highlighted the problem types listed in 'Other' were required to ensure that these were addressed routinely. It was felt that significant areas had been omitted, or as one Coordinator (S1OT2) described had been 'bunched' together at the end of the assessment. A Coordinator (S1PT1) described why this was problematic:

S1PT1: It's an open question at the end, 'is there anything else that you need help with, or that you think is important that we've not covered?' and you're hoping then that that person is going to remember it, and usually it's right at the end, it's a long assessment maybe they just want to get rid of you and they've had enough, so I do think that it needs more prompting.

The Coordinator suggests that problems pertinent to the service user might be missed using the domain 'Other', as it relies on the stroke survivor to report specific problems to the Coordinator. This problem could be solved with the introduction of additional prompts. The care plans reviewed supported the need for an additional domain; they revealed that 24 problems were categorised as 'Other' (domain 16), which accounted for a large proportion of all problems identified. Fourteen of the twenty-four problems documented in this domain (58 per cent) related to speech, language, swallowing or communication. The frequency with which these types of problems were identified suggests that an additional domain would be beneficial. A new domain would enable the Coordinators to accurately document the problems identified and incorporate the prompts required by the team therapists, negating the use of an additional screening tool. However, not all Coordinators found the absence of a speech and language section a problem. The remaining Coordinators at service two, for example, explained that they were able to integrate discussion of these problems in the relevant domains:

S2GW: Well, I don't think it's an issue [absence of speech, language and swallowing], *personally, because again, I'll bring that up into the*

*eating and the drinking part of it and always ask if there's any
swallowing problems there and, again, where there's any other
information, swallowing is actually addressed in there as well. So,
again, I suppose, it's depending on how you use the book… you
know, how we use the booklet, personally, but I always think that
you can introduce the speech and language into either the eating
and drinking or the other really. So we don't… well, I don't feel that
we need it* [a separate section]*, but, I don't know, I suppose it
depends on each service.'*

This Coordinator discussed speech, language and swallowing in assessment
domains that were associated with these types of problem, such as eating and
drinking. Observations supported this, as problems with swallowing were often
discussed in regards to taking medication, for example, one assessment booklet
noted that the individual was 'OK swallowing tablets with thickened fluids'. 'Eating
and drinking' are actually provided as prompts in the Overview section 'General
health' and not in the LoTS care assessment structure (see appendix iv). However,
the Coordinators comments emphasise that discussion of these areas relies on the
professional and how they choose to use the assessment structure. The remaining
Coordinator at service two (S2LN) supported this view:

S2LN: *I've never found that a problem me* [absence of speech, language
and swallowing] *because I think S2SN puts it in communication, I've
always put it in 'other' simply because it says speech and language
difficulties, so from the beginning I've always used this box for
speech and language, I don't think that… for me it's never been a
problem and it's never not prompted me to refer someone. So no, for
me personally it's never been an issue.*

The Coordinator explains that they had always used the domain 'Other' to discuss
and document problems in these areas, commenting '*it's never not prompted me to
refer someone*'. It is possible that the continued use of the Overview assessment

combined with the Coordinators knowledge and experience at service two supported their coverage of these areas, which is why they did not feel an additional section was necessary. However during the group discussion, which took place as part of respondent validation, the Coordinators at service two clarified that a sensory section was desirable as part of a post-stroke assessment, see Box 1 below.

Box 1: Service two: Speech, Language and Swallowing

S2SN: Yeah, I think it [speech, language and swallowing] *needs its own section, because at the moment we're putting it in 'other'.*

S2GW: In 'other', yeah.

S2SN: In 'other', so it's like an add-on, and speech and language can be a whole range between speech difficulties, reading and language comprehension, so it should have its own section. And I always felt uncomfortable; because it says 'communication and information', and I'd think 'Well should I put communication now', because it's talking about how people are communicating, whether vision deficits and different things. Reading the prompts its very much about communication and information upon discharge from hospital, and I don't think that needs to be replicated through the whole assessment, because if you've addressed it on the first time, why do you want to address it in six months, why do you want to address it in 12 months […] So I felt that difficult, for the communication and information. I've always wanted to write about how people communicated in that section because there isn't anywhere else really for it. So I do think it needs… not a speech and language section, but the communication section or something, some section which…

S2GW: Can cover overall.

S2SN…could cover a wider area, rather than in 'other', and if you haven't got an experienced clinician doing it then that's when I think speech and language problems…

S2GW: Could be missed.

S2SN: Yeah, could be missed.

The discussion reiterates the concerns originally expressed by the Coordinator (S2SN); that it was not clear which section should be used to document problems related to speech, language, swallowing and communication. The Coordinators agreed together that an additional section would be useful, as this would standardise the routine discussion of these areas, particularly when professionals with less experience were performing the assessment. The Coordinators at service

one also confirmed that additions were necessary for the purposes of their team, see Box 2 below.

Box 2: Service one: Speech, Language and Swallowing

S1PT2: I think for us having the MDT assessment, which is what LoTS care is, and having speech and language as part of our team then the assessment really needed to cover what these guys needed to know, to be able to know when they needed to see someone

S1SLT2: and also the last question is trying to fit in loads

S1PT1: Yeah they're too many things

S1SLT2: they were quite big things like speech, swallowing, sleep

S1OT1: and because it's the 'Other' you don't get the prompts that you'd devised for us to ask

S1SLT1: for example if you say 'have you got any swallowing problems?' They might say 'no', but if you say 'do you cough when you drink, or have you had any current chest infections? 'Oh yeah', so it sometimes highlighted problems that wouldn't otherwise be highlighted

S1PT2: The other thing that would go with sleep that is missing is fatigue

S1SLT2: and they're quiet common things post-stroke, they're not rare

S1OT1: Yeah and it's from the LoTS booklet that says how common it is and it's the biggest problem and its six years post stroke and it's not got its own little box.... or sometimes it's have you got enough to do during the day? 'Well no because I keep falling asleep and can't do anything.' So there are places where it could come up but you're not prompted to ask are you.

S1PT2: but everything else is spelled out, so why shouldn't they be spelled out too?

The team clarified that, in the context of their service, the LoTS care assessment (the MDT assessment) needed to establish whether the team's professionals were required to provide intervention for the service user. The speech and language screen was designed with this purpose and provided questions to trigger problem identification. These were considered appropriate and necessary in the context of service one to reflect the skill mix of the team. Further to this, the final section 'Other' was thought to contain a diverse set of problems, which needed separation into appropriate domains. The Coordinators explained that the domains provided in the LoTS care assessment might draw out other problems, fatigue is provided as an example, however the team felt that these areas should be 'spelled out' to the

Coordinator as other problems were. This clarification would help standardise the domains covered as part of the MDT assessment.

The discussion on speech language and swallowing demonstrate that the stroke specific assessment structure was adapted at the service level with the inclusion of the speech and language screen at service one. The Coordinators were required to complete this screen as part of each MDT assessment to prompt accurate problem identification. At service two these areas were addressed as a rule of thumb and the continued use of the Overview assessment might have supported their coverage. The addition of the SALT screen demonstrates how the LoTS care assessment was adapted to meet the needs of the service. Further adaptation was also identified in the context of service one where, on receiving the LoTS care assessment structure, the team clarified the information that should be elicited during the assessment.

5.8.1 Clarifying the information required from the assessment (service one)

At service one all professionals in the team were expected to perform the role of Coordinator. Some of the LoTS care assessment domains overlapped with areas that these professionals addressed as a therapist or nurse. For this reason, the Coordinators asked additional questions in the domains that fell within their specialist remit. As a result, the details collected during the assessment depended on which professional had performed the LoTS care assessment, as one Coordinator (S1OT2) noted:

S1OT2: We realised there were some discrepancies in things, like when we were asking about continence that would lead me on to asking about function or managing clothing and cleansing, whereas other people weren't necessarily asking that level of detail. So it [a team meeting] *helped us making a standardised set of questions.*

Aware of these '*discrepancies'* the service manager (S1SM) organised a team meeting, to which the therapist refers, to clarify the information required from the assessment process. A service checklist was established as a result of this meeting. Table 15 below provides an example of how this checklist supplemented the domains of 'Mobility and falls', 'Continence' and 'Finance and Benefits'.

Table 15: Example of service checklist

Section	LoTS care prompts	Service checklist prompts
Mobility and Falls	Can you get around indoors? Can you get out of your house? How confident are you carrying out daily activities without falling? How do you feel about your recovery so far? Discuss patterns of physical and emotional recovery	Can they walk around the house – how? – stick/frame/wchair – observe are they mobilising as they report. Any equipment Do they walk outside? If no do they have a w/ch Prompt to order w/chr Are access issues preventing outdoor mobility How are they transferring – chair/toilet/bed Have they fallen – what were they doing at the time – frequency of falls Do they feel they are making progress so far
Continence	Do you ever have accidents with your bladder/bowels? How is this being managed?	Any problems with waterworks/bowels Catheterised Using Pads Accidents – awareness Bowel routines – especially important with dependent patients in nursing homes Consider referral to continence nurse Is it physical problem affecting toileting- are they able to clean self Any menstrual issues – managing sanitary products
Finance and benefits	Do you have any difficulty managing your money? Are you able to pay your bills? Are you receiving all the benefits you are entitled to? Use benefits checklist.	Who is dealing with the finances/ bills – any problems with this? Prompt re. benefits agency/CAB/People First Benefits entitlement checklist Consider the cognitive and organisational side of finances

It is apparent from the table that the checklist expands upon the questions provided in the assessment domains, particularly in the domains of 'Continence' and 'Mobility

and falls'. The additional prompts encourage discussion of details that clarify the service users' capabilities and their coping strategies in the problem areas. The development of this tool indicates that there is likely to be variation in the details elicited during the assessment process across the LoTS care trial intervention sites. Variation was also found in the implementation of the Single Assessment Process, which aimed to standardise the assessments performed by front line staff in the care of the elderly (Abendstern et al., 2008). The Coordinators at service one identified this variation and attempted to regulate the information elicited by their team through developing the service checklist. The service manager also provided further insight into the purpose of the checklist:

S1SM: *I was discussing my expectations of what I would categorise into these things, to give all staff a wider view really [...] It's because our LoTS information is available as a whole team so you're actually building up a full picture within that assessment, you're not just doing a yes/no, you're doing a yes/no and this is what you're doing.*

The information collected during the assessment was accessible to the professionals who provided intervention for the problems identified. For this reason, certain details beyond the scope of the questions were desirable to elicit during the assessment. The manager stated that these details might reduce repetition in the assessment process, as the therapists would have knowledge of the service user's capabilities prior to their specialist assessment. The service checklist was not used to facilitate the assessment process during fieldwork. However, observations of the assessment process indicated that the Coordinators probed for further details in the domains that fell within their speciality, for example, one physiotherapist asked to observe an individual transferring from the bed to chair and from the chair to standing to ascertain their functional capabilities. This Coordinator later provided intervention to the service user as a physiotherapist. However, it demonstrates how the service made further adaptations to the LoTS care documentation in order to improve the assessments performed. A similar process was not undertaken at service two; this might be because there was less variation in the Coordinator's background i.e. two Nurses and a Generic Worker (who had been in post for six years) performed the role.

5.9   Implications for the theory of change

The LoTS care system of care was introduced to service one and two at a timely point in their history. The two teams recognised that their documentation was not fulfilling the needs of a service dedicated to stroke. For this reason, they displayed a 'readiness for change' (Weiner, 2009, Greenhalgh et al., 2004) and, in particular, were happy to introduce a stroke specific assessment tool. The two services provided a coordinating role prior to the system of care and this facilitated the integration of its components i.e. the intervention was a good 'system fit', as the components matched existing norms, goals and working ways (Greenhalgh et al., 2004). The checklist was administered to service users prior to their assessment, the LoTS care manual was available as a reference for the Coordinators if needed and the assessment booklet replaced the generic elderly tools previously used. The components were also adapted, most notably at service one with the addition of a complementary local information file and the continued use of the supplementary SALT screen. These adaptations reflect the course of many complex interventions as they unfold in practice (Pawson, 2006, Hasson et al., 2012, Greenhalgh et al., 2009). Flexibility in the system has been described as 'fuzzy boundaries' and is another facilitator of change, enabling local nuances to be added in order for the main ideas of the intervention to be implemented (Plsek and Greenhalgh, 2001, Greenhalgh et al., 2004).

The checklist, manual and assessment booklet were embedded within each service, however the only component routinely used in practice was the assessment booklet. An interesting finding was that the assessment tools used prior to the system of care addressed many overlapping domains. For this reason, the LoTS care assessment structure introduced 3 novel domains at service two and 4 at service one. Whilst this finding was not entirely unprecedented, as the Single Assessment Process tools informed the development of the LoTS care structure, it demonstrates that the two services used a structured and holistic approach to identify post-stroke problems prior to the system of care i.e. they considered problem areas that extended beyond the skill mix of the multidisciplinary team. Further to this, the adaptations described indicated that the new structure was not extensive enough for the purposes of each service. These findings might have repercussions for the theories of change

explored further in the following chapters, which consider enhancements in service practice.

5.10 Summary

This chapter has described some of the service characteristics and how they differed in each locality. It has also established how the system components (the checklist, the manual and the assessment booklet) were embedded within each service. The process of embedding the intervention components was facilitated as, 1) the services provided a coordinating role as part of their team structure, 2) the services were keen to improve the assessment performed in the coordinating role and 3) the system of care was flexible and allowed adaptations at the local level. At the service level the components appeared to be embedded successfully. However, the assessment booklet (the mandatory component) was the only component routinely used by the Coordinators, as it replaced the documentation they previously used for the same purpose. However, there was also an expectation that certain activities would be performed in the implementation of the assessment booklet. The following chapter explores the extent to which the implementation activities expected were realised in routine practice.

Chapter 6: Implementing the system of care

6.1   Introduction

The client checklist, the LoTS care manual and the LoTS care assessment booklet were embedded within each service, but the only component routinely used in practice was the assessment booklet. The assessment booklet was the only mandatory component of the intervention and there were certain activities expected its implementation. This chapter examines the extent to which the implementation activities performed adhered to or deviated from the theory of change and the reasons why. The Implementation principles advocated by the LoTS care team (see appendix v) were formalised in 12 points that were considered the 'take home' message from the LoTS care training days. The diffusion of a number of these principles, namely the use of problem solving and collaborative goal setting, and the processes of monitoring and review are the focus of this chapter. These activities were prioritised for investigation in chapter five, as they were considered important attributes of the system that would contribute to its aim i.e. to address the longer-term needs of stroke survivors.

6.2   The implementation principles prioritised for investigation

Two training days were delivered as part of the intervention (described further in chapter four), which provided an opportunity for the LoTS care team to impart to the Coordinators how they believed the components should be implemented as part of a system of care. There was an expectation that the system of care would include 1) the use of problem solving techniques and goal setting to promote patient centred care, and 2) an iterative process of assessment, care planning, monitoring and review to promote continuity of care. The use of problem solving techniques was encouraged in two sessions delivered at the training days and the LoTS care manual provided a description of the principles of goal planning (see appendix vii). However, there was no strategy employed to facilitate the iterative process of monitoring or review that was anticipated. To explore the implementation of the system of care, this chapter examines the extent to which the problem solving sessions delivered at the training resonated with the Coordinators, before describing the formal review processes that they performed. These factors were found to

influence the care plans developed and consequently the monitoring processes completed by the Coordinator.

6.3   Problem solving techniques

Chapter four established that formal problem solving skills were not taught as part of the LoTS care training. However two sessions were delivered that demonstrated problem solving techniques that could be applied when implementing the system of care. The aim was to shift the emphasis of the assessment to reflect a more collaborative approach, encouraging service users to take responsibility for their own problems where possible. Two Coordinators from service one, and one Coordinator from service two had attended the training. However, when asked most could not recall the problem solving sessions, for example one Coordinator (S1SN) commented:

S1SN: *I can't to be honest with you* [remember the problem solving sessions]. *It's too far back in my memory. I remember being quite daunted by it* [the system of care] *initially and thinking oh my god how are we ever going to do this? How are we ever going to make the time for this as this is a lot more thorough and I think that was my main drive in the beginning, as I just looked at all that paper work and I remember that sense of doom in a way* [laughs] *how we gonna do this?*

This Coordinator had worked in a hospital setting prior to joining the community stroke team. Their overriding concern was implementing the new system, which they initially found '*daunting*' being a) new to the community, and b) new to the role of Coordinator. The Coordinator at service two recalled discussing how their practice differed from professionals in other localities, but not the specific problem solving sessions.   Having no memory of these sessions suggests that the techniques advocated did not resonate with these Coordinators and therefore did not influence their practice. This finding is, perhaps, unsurprising considering the training sessions

were not intended to teach formal problem solving skills. One Coordinator (S1OT1), however, did remember the training sessions and commented:

S1OT1: The most useful part of the training session was the woman from the benefits office. She put it all in such an easy way to understand and I'm really confident about benefits now. Yeah it was good [problem solving session] *and I think if you were a Stroke Care Coordinator and you'd come from being a ward manager then it's very much out your remit to do that, but when you're involved with rehab and you're a therapist sometimes you've written the problem list and the action plan before you've gone out the door of the patient's house really cause it's what you're trained to see [...] it was a good training session but it felt a bit like teaching your granny to suck eggs.*

The benefits session, to which the Coordinator refers, was one of two lectures provided at the training days (the other was post-stroke pain). The Coordinator described that this lecture was '*the most useful part of the training*', and provided them with confidence to discuss the assessment domain 'finance and benefits'. In comparison to the lectures, the problem solving session was like '*teaching your granny to suck eggs.*' Evidence of problem solving was observed during fieldwork e.g. during one assessment observed the Coordinator discussed causes of shortened concentration (a problem identified), and how the service user might address this themselves without further intervention. However, the Coordinators remarks suggested that their approach to the assessment was a continuation of their previous practice, as opposed to the implementation principles advocated by the system of care. Professionals who joined the team after the system of care was embedded in practice supported this view, for example, one Coordinator (S1OT2) described:

S1OT2: I kind of worked it out for myself [how to use the LoTS care assessment booklet]. *It's difficult because when the LoTS was*

brought in, is when I started working for this team and I was only working one day a week with this team, so by the time I came full time the LoTS had been in process for quite some time and it was just a case of trial and error really for me. I wasn't given a huge amount of training.

The Coordinator established how to implement the assessment booklet '*through trial and error*' i.e. through practical experience. This remark highlights that the implementation principles did not form part of a formal induction process for new staff. Another Coordinator at service one (S1PT2) reiterated this: '*Basically I sat in on a LoTS with S1SN and saw her deliver the assessment. I was also shown the LoTS handbook, but to be honest I didn't read it all. I just read through the actual assessment itself and went from there.*' The Coordinator describes observing (shadowing) a more experienced member of staff as part of their induction. They were also provided with a copy of the LoTS care manual (the LoTS handbook); however they revealed that they had not read this. Therefore implementation of the system of care was dependent on their experience as a health care professional and their observations of more experienced colleagues. A similar induction process unfolded at service two; when asked how they were introduced to the system of care one Coordinator (S2SN) described:

S2SN: *Here's the LoTS document. That's what we're using for the trial. But main, really, it's quite self-explanatory really if I interpret it right on how I've been using it. I mean you don't, I don't think you need a lot of guidance to it […] after six months after I'd started working here I think a DVD, not DVD... CD Rom or something turned up, but if I'm quite truthful I've never had like looked at it 'cos you just don't have time, you've been using it for six months and you think...*

The Coordinator reported that the use of the assessment structure was '*self explanatory*'. The assessment structure indicated what areas needed to be addressed as part of the intervention group, but it does not reveal the type of

interaction expected between the Coordinator and service user. The DVD, to which the Coordinator referred, was a recording of the training days and included the problem solving sessions. However, the Coordinator explained that when the DVD had arrived they felt confident in their ability to implement the assessment and had not watched it. Further to this, the Coordinator reported that they had not received a copy of the LoTS care manual and had not read its content. Therefore, their approach to the assessment process reflected their experiences as a health care professional. This discussion indicates that the implementation principles were not formally disseminated amongst the Coordinators. Implementation of the system of care was shaped by the Coordinators experience and the expectations of the service within which they worked i.e. the service was not enhanced by the problem solving techniques provided as part of the LoTS care training. The next point of inquiry was the formal review process i.e. repeated assessments performed by the Coordinators in the context of each service.

6.4   Reviewing the needs of service users

The implementation principles stated that the duration of the intervention should reflect national recommendations. At the start of the trial, the most recent guidelines published on longer-term stroke care were those in the National Stroke Strategy. These proposed that stroke survivors be reviewed at six weeks, six months and annually thereafter (Department of Health, 2007). Therefore, there were two drivers (national recommendations and participation in the LoTS care trial) that encouraged a review of stroke survivors needs over the course of a year. However, fieldwork revealed that local policy dictated the number of reviews performed at each service. For example, at service one observations of the interaction between the Coordinator and the service user was limited to the initial visit, where the LoTS care assessment was performed. No stroke reviews or monitoring processes were performed using the LoTS care documentation. However, it would have been interesting to observe the therapist and nurse visits to their service users to establish if any coordinating activities were performed in these roles. The manager of service one (S1SM) explained that they had made their review processes explicit to the trial team at the time of recruitment:

S1SM: The thing with us and this is what I said to the trial manager when we came on board, was that really the LoTS would form our initial assessment, and then subsequent reviews, but it wouldn't form each assessment of the patient because of the nature of the team that we were. So that's how we probably used that differently to some of the other people, and we were told that was absolutely fine to do at the time. So in terms of standardising it into practice, our LoTS became the initial assessment and follow-up if people came back through the process.

The service manager clarified that after discharge from their service, individuals could refer back to the team if their needs or circumstances changed. These individuals would receive a 'review' of their needs using the LoTS care assessment structure i.e. would go '*back through the process*'. However, these were not performed at the intervals recommended in the National Stroke Strategy, and were not applicable to every service user. Providing stroke reviews in the community was under consideration by the service commissioners, but at the time of fieldwork the decision to implement stroke reviews had not been made, as one Coordinator (S1OT1) explained:

S1OT1: No [they would not review the service user] *we'd review the goals they were working towards* [as therapists or nurses] *but we wouldn't go through the whole system again. The idea is that we'd do six month or twelve month review clinics and you'd do it at that, but six months there are a lot of people still involved with the team and working on goals. Well, not a lot more like 30%. We're going to do a piece of work on 6 month reviews by the end of June, but it's looking at what would the impact be, how could it be delivered. So not necessarily that the stroke team would do all of them. It might be that GP's do them and use LoTS care. So it's looking at who could do it and how, and where and when, and cost implications is what they're interested in as it's the commissioners who are interested, but it's certainly something that needs looking at and that, it* [LoTS care] *would be perfect for that.*

The Coordinator states that the LoTS care assessment would be '*perfect'* as a review tool and also indicated that their team would be facilitating further research '*work'* in this area. However, stroke review tools were emerging to address the quality markers in the National Stroke Strategy (Rothwell et al., 2013, The Stroke Improvement Programme, 2008). One such tool had been developed in the local area and this was used in the '*work'* to which the Coordinator referred, as the service manager (S1SM) clarified: '*we would use a standard tool for that* (the six-month review) *and it's not the LoTS that we've specifically looked at. There is a local tool around here that we're looking at, but that is geared up to the key core questions that we would ask*'.

The system of care was developed in the years preceding the National Stroke Strategy. Both the system of care and the National Stroke Strategy advocated a review of stroke survivors' needs and the LoTS care assessment booklet provided a structure with which these might be achieved. However, a locally developed tool was selected to implement these reviews instead of the LoTS care assessment. This finding highlights how community services are in a constant state of change, influenced by numerous national initiatives, as discussed in chapter two. These initiatives tend to collide and compete at the local level, demonstrated in the context of service one, where a tool from the Single Assessment Process was replaced by the LoTS care system of care, which was disregarded for use as a stroke review tool in favour of those associated with the quality markers in the National Stroke Strategy. For this reason the LoTS care assessment booklet was implemented as an initial MDT assessment only. Figure 3 below, depicts part of the patient pathway through service one as illustrated in their service specification.

Figure 13: Patient pathway through service one

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┌─────────────────────────────────────────────────────────────┐
│           1. Initial holistic assessment from team           │
├─────────────────────────────────────────────────────────────┤
│   Identify key disciplines required and relevant referrals    │
│                      on as required                           │
└─────────────────────────────────────────────────────────────┘
                              ▼
┌─────────────────────────────────────────────────────────────┐
│          2. Specialist assessments (Relevant disciplines)     │
├─────────────────────────────────────────────────────────────┤
│  Consider.... Risk assessments, Outcome measures / Subjective │
│                      objective markers                        │
└─────────────────────────────────────────────────────────────┘
                              ▼
┌─────────────────────────────────────────────────────────────┐
│                 3. Plan treatment intervention                │
├─────────────────────────────────────────────────────────────┤
│  Develop problems lists, patient orientated SMART goals /     │
│                      treatment plans                          │
└─────────────────────────────────────────────────────────────┘
                              ▼
┌─────────────────────────────────────────────────────────────┐
│   4. Review progress at regular intervals including MDT       │
│                         meetings                              │
├─────────────────────────────────────────────────────────────┤
│     Review reassess achievement of goals and plans as         │
│                         relevant                              │
└─────────────────────────────────────────────────────────────┘
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The patient pathway was developed prior to the system of care and essentially remained the same on its implementation. When the team accepted a referral a copy of the checklist was administered to the service user, as described in chapter five. Following this, the MDT assessment (as depicted in figure 4, step 1) was performed using the LoTS care assessment structure in replacement of Easy-Care. The Coordinator would not revisit the individual, as indicated in the pathway, but would refer on to appropriate services (within and outside the team). If referred to, professionals within the team were expected to make Specific, Measurable, Attainable, Realistic and Timely (SMART) goals with the service user (figure 4, step 3) (Wade, 2009). The professionals were expected to review SMART goals with the service user at appropriate intervals, and intermittently with their team colleagues at weekly multidisciplinary team meetings. These SMART goals were differentiated from the 'actions' recorded by the Coordinators in the LoTS care, care plan; this point is illustrated in section 6.5 using data from the care plans reviewed. The SMART goals dictated the duration of the service's intervention with the individual.

Service users remained in the care of the team until they had achieved their rehabilitation goals and no further goals were identified, or if a plateau had been observed in their progress. The service user was then discharged to the care of their GP.

6.4.1 The review process at service two

In comparison to service one, at service two the review team visited stroke survivors at six weeks, six months and annually for three years and observations were performed of each type of review. The review process performed at service two was in line with the recommendations of the National Stroke Strategy to a greater extent than at service one. However, stroke reviews had been provided in the local area for more than ten years, as the service funded three practitioners specifically for this purpose. Administrative support was also provided to help manage their large caseload e.g. to correspond with service users and organise their case notes. The provision of reviews for up to three years post-stroke was in line with, but also extended beyond the recommendations of the National Stroke Strategy, as the service manager (S2SM) commented.

S2SM: 'We're doing over and above that actually [recommendations in the National Stroke Strategy], but just due to resource issues and that we've made sure that we do that as a minimum and if we can, if somebody needs a three month review, if, you know, if someone who's perhaps more complex we've left that for the nurses to make professional judgement as to whether they feel that review or not and they make a decision. Some people can't wait. In fact, what we'd like to do is keep that as a permanent but we've had to respond to sort of pool our resources in another area, so, but yeah we do the minimum that is outlined in the Stroke Strategy, but we'd like to do more than that 'cos I presume they've told you that we review up to three years....so that's over and above but we're gonna have a look at that again and maybe think well rather than review it at year three, maybe stop at year two or something and then concentrate more on the first twelve months, so bring back in the three month review but

take off the three year review. We haven't made any final decisions on that.'

The three-month review, to which the manager refers, was previously provided as standard practice in the context of service two. Due to restraints on local resources and the publication of the Stroke Strategy (which recommended less frequent reviews) the three-month review was removed. However, the team were keen to re-introduce this and occasionally still provided it to individuals that had complex needs. The service manager's remarks indicate how the provision of stroke reviews was also subject to change in the context of service two and the system of care was implemented in line with the decisions of local stakeholders.

The patient pathway at service two was slightly different to the one followed by individuals at service one. The Stroke Liaison Nurse (S2LN) identified stroke survivors prior to their hospital discharge through attendance at MDT meetings held on the acute stroke unit. These meetings were observed during fieldwork and revealed that the Coordinator had knowledge of all individuals admitted to the stroke unit, their progress during their period of inpatient rehabilitation and their discharge destination, as these were the areas discussed during the meeting.   Stroke survivors were discharged to either the Intermediate Care Team (ICT) where intensive rehabilitation in an inpatient setting was provided, Early Supportive Discharge (ESD) where intensive ongoing rehabilitation in a community setting was provided, or directly home and to the care of the community stroke team. The Liaison Nurse contacted individuals discharged to the community within two weeks to ensure that they were coping in their home environment, and to inform them of their six-week review. A service letter including the HADS and the checklist was then administered. At the six week visit the Liaison Nurse completed the LoTS care assessment and provided specialist-nursing input (as described in chapter five). A copy of the care plan documented was sent to the individual with a letter providing contact details for the service. The Specialist Nurse repeated this process at six months, and the Generic Worker annually for three years. Service users were discharged from the team's active caseload at their three-year review.

The intervals in which the stroke reviews took place indicate when service users had contact with a Coordinator, and consequently the system of care. The number of reviews performed in the context of service two was markedly different to that at service one. These differences are depicted in table 15 below for clarity.

Table 16: Coordinators contact with service users

Service one	Service two
Referral accepted - checklist administered to service user	2 week phone call to service user
LoTS care assessment within 8 weeks of receiving referral, care plan developed	Checklist and HADS administered to service users (administered before each review)
Service user reviewed if re-referred to the service, or their needs substantially change	6 weeks post-discharge: LoTS care assessment and care plan developed
	6 months review: LoTS care assessment, new care plan documented
	12mth review: LoTS care assessment, new care plan documented
	Reviews continue annually for three years

Although not stipulated, a review of service users' needs was expected as part of the system of care. A stroke review would enable the Coordinator to identify and address new problems as they emerged over time. Pilot work had suggested that this was a necessary process (Murray et al., 2006, Dowswell et al., 2000). However,

the review process employed at each service was shaped by local policy, which resulted in two distinct applications of the system of care. In the context of service one the Coordinators performed one LoTS care assessment when stroke survivors entered their service. Stroke reviews were being piloted in the local area, but locally developed tools were used for this purpose. At service two individuals were assessed three times within the space of a year (the duration of the trial) using the LoTS care structure i.e. stroke survivors had three opportunities to discuss emerging and ongoing problems with a Coordinator. These review processes adhered to the implementation principles to a greater extent than at service one, but this reflected a continuation of previous practice rather than an enhancement through the system of care.

The next point of inquiry became the monitoring processes performed i.e. what was the role of the Coordinator in ensuring the care plan was implemented after the initial assessment at service one, and between stroke reviews at service two.

6.5   Monitoring the implementation of the care plan

Monitoring the implementation of the care plan was another activity expected from the Coordinator as part of the system of care. Monitoring would ensure that the service user had received the interventions they required and were progressing towards achieving their rehabilitation goals. This intention was reflected in the implementation principles, which stated that Coordinators should 'follow up' on actions and review the goals documented in the care plan (see appendix v). However, observations of service practice and the care plans documented by the Coordinators quickly revealed that these processes were not performed as intended.

In the context of service one, stroke survivors were not provided with a copy of their care plan and it was not reviewed with them after their initial assessment. For this reason, the Coordinators referred to the care plan as the 'action plan'. The Coordinators separated the actions they performed as a Coordinator from the SMART goals they developed as therapists. Actions were usually tasks that could

be completed by the Coordinator; the care plans documented can help to clarify this point. Table 17 below depicts some of the service responses employed by the Coordinators at service one during fieldwork.

Table 17: Example of care plans documented at service one

SCC		Problem	GOAL/ACTION	Outcome
S1OT2	1	Limited info on CVA	Refer to POPPS	---
	2	No benefits advice	Provide number for benefits advice	-----
S1PT1	3	New memory and concentration changes	Refer to OT	Goal achieved
	4	Difficulty with long distance sight since stroke	Refer to vision call	Goal achieved
S1SLT 2	5	PT unsure RE risk factors for stroke and preventing further events	Refer to SSN for health promotion and BP check Post 'What is stroke leaflet'	Referral complete
	6	PT reports some coughing on eating	Refer to SALT for swallow AX	Referral complete
S1SN	7	Falls x 2 since discharge home, client reported changes to balance	Referral to physiotherapy for AX	Referral accepted 040711
	8	Facial drop, expressive dysphasia, word finding difficulties, stutter	Referral to SALT for AX	Declined intervention 040711

POPPS: Partnership for Older People Projects, AX: Assessment

Eight problems are depicted in table 17. In total there were nine service responses, as problem five required two. The service responses included referring to a team colleague, referring to an outside agency and information provision. It was the Coordinators' responsibility to 'action' all service responses. The actions were documented as completed when the paperwork for the referral had been sent to the appropriate service, or when the information required by the individual had been provided to them. The monitoring processes advocated as part of the system of care were redundant when the care plan was used in this way. Once the actions were completed, the Coordinator did not use the care plan to monitor the progress of the

service user. The Coordinators at service one explained why they used the care plan in this way:

S1OT1: *It's difficult because depending on what the problem is, is what you would do about it, and that might involve lots of different professionals, which is where it doesn't fit well with our service. It does for patients, but for the system of care it becomes a bit duplicatey, and it's something that happens anyway.* [...] *Once it's refer to OT it's what you would do anyway, and then your review of that is that it's been completed, and that you've given them information on transport and you sign It off that way. To use it as a separate piece, it doesn't really guide my thinking, but it might if I was in a satellite office and away from the team'*

The therapist describes that the system of care would be '*duplicatey'* if used as a goal planner and monitored as intended, as goals are developed by the professionals who provide intervention, '*once its refer to OT it's what you would do anyway'*. This finding is one example of how the multidisciplinary team structure impacted on the implementation of the system of care, shaping how service responses were documented in the care plan. However, the Coordinator indicated that professionals who worked separately from a team might document goals and use the care plan to monitor progress, as there would be less duplication with the work of others. The team structure provides one explanation for why goals were not documented in the Coordinator role at service one. However, some Coordinators also discussed that they did not consider goal planning appropriate, for example, one Coordinator (S1PT2) explained:

S1PT2: *'If someone's got a continence issue and you're referring to the continence team, I don't feel I'm equipped to make a goal around that, as I don't know what's a realistic outcome for them, cause it's not my area of speciality, and the same with meal preparation in the kitchen or safety making a hot drink. I'm happy to refer to the OT for*

assessment, but the goal would be refer to OT for assessment, and
then the OT would make their own goals, so some, and then I feel
like to have a bit of consistency, then all the physio goals I'm going
to put in to have a physio assessment, even though I do that myself,
and I know in my head what the goals are

The Coordinator clarifies that some problems identified during the LoTS care assessment were outside their expertise as a physiotherapist. For this reason, they were unable to suggest a realistic outcome (goal) to document in the care plan. This point was also emphasised by another Coordinator (S1OT2), who stated: '*I think it's knowing where your limitations as a therapist are, knowing that we have got that ability to refer on, because we don't want to take it too far out our skill area, so like I say for continence, I'd refer on to a district nurse or the continence team rather than try to address it myself.*' The formulation of a goal was associated with the provision of a direct intervention, which was not something that the professional could provide for all problems identified. Therefore the role of Coordinator was to refer on to an appropriate service that would develop a realistic goal for the service user if required. This finding highlighted that the assumption made by the LoTS care team i.e. that goal planning would be easily incorporated by the Coordinators was not accurate in the context of service one.

6.5.1   Monitoring the care plan at service two

In comparison to service one, stroke survivors at service two were provided with a copy of their care plan. The care plan was also reviewed with the service user at their following stroke review. However, the Coordinators did not monitor the implementation of the care plan between the designated review dates. For this reason, there were similarities in the documentation of the care plans documented at service one and service two.   For example, many of the service responses employed at service two could also be described as 'actions', table 18 below provides examples of this.

Table 18 Care plans documented at service two

SCC	Problem		GOAL/ACTION	Outcome
S2LN	1	Some forgetfulness on occasion. Occasional anxiety and worry	To monitor psychological well-being. Advised to write reminders down to aid memory and break down tasks into small steps	Not creating concerns now
	2	PT worries as dinner lady and still on sick leave	To maintain well being remain on sick leave for present time. Obtain sick note from GP. Reconsider return to work, Sept 2011	Unsure if wishes to return to work. To discuss at occupational health meeting next week.
S2SN	3	Some apprehension about travel abroad	Reassurance and signposted to SA website info on holidays	Has not yet booked any holidays
	4	Unaware of stroke support for young survivors	Info sent re HUGS support group	Has information
S2GW	5	Problems getting up when lying down in bed	Refer to OT for AX	Seen by OT
	6	Complaining of pain in left leg	Advised to discuss with GP, causing low mood at times	July12

Table 18 demonstrates the similarities between the care plans documented at service one and service two e.g. signposted to SA (Stroke Association) website against problem three, and refer to OT (occupational therapy) for AX (assessment) against problem five could both be described as actions. The difference between the two services was that most actions documented at service two were considered the responsibility of the service user. This difference reflects the perspective of the Coordinator and the context within which they worked, one Coordinator (S2SN) commented; '*it's* [the care plan] *the patient's document, the patient wants to improve then it's got to be tailored to them I think'*. The care plan was seen as the 'patient's document'; therefore they were expected to act upon the information and advice provided to them in order to resolve their problems. Whether the service user had acted upon the information could be established at their following review, as indicted in the examples provided in table 18. Another Coordinator (S2GW) explained why they documented service responses in this way:

S2GW: *It's all to do with Expert Patient, isn't it, really, in* [service two] *anyway. And it's... I mean, again, it's knowing your patient. Obviously you can't say to, I don't know, an eighty-eight year old lady who's quite infirm and can't get out the house, oh, go and talk to your GP and different things like that. So again, it's knowing the individual, knowing what their capabilities are, knowing whether they've got the mental capacity to be able to follow through what you're talking to them about. And, you know, taking it really from that. But yeah, we do like our patients to take the onus upon their selves.*

The 'expert patient programme', to which the Coordinator refers, is a national initiative that aims to educate and empower service users to self manage their health conditions (Challis et al., 2010b). The programme forms part of a wider government strategy to address the needs of people with long-term conditions, (Department of Health, 2005b), which was discussed briefly in chapter two. Ideas from this programme influenced the Coordinator when implementing the system of care. However, as the needs of their service users varied, the level of support they provided was adjusted accordingly. Another Coordinator in the review team (S2LN) also noted that this approach reflected a shift in the wider NHS ethos, for example:

S2LN: *In the past few years, a lot of ownership has been put on patients to look after aspects of their own care so, you know, in terms of like say I don't know, smoking, they've got to take some ownership of that and that's why you set that as a goal for them really don't you, for them to do it, so that yeah. I suppose policy and practice comes into it as well doesn't it, like I say, and the expert patients programme and all that.*

In recent years the emphasis in government policy has been for service users to take 'ownership' of their condition (where possible), and this shift influenced the Coordinator's practice. Smoking cessation was provided as an example; this

requires the active engagement of the service user for success. For this reason, the Coordinators at service two documented that they had advised the service user to reduce their habit, but it was the stroke survivor's responsibility to act upon this advice to address the issue. Reference to the Expert Patient Programme is further demonstration of how national policy initiatives collided with the system of care at a local level, shaping its implementation. In the context of service two this was reflected in the documentation of the care plans.

The monitoring processes performed by the Coordinators were not those anticipated as part of the system of care. In the context of service one the care plan recorded actions that were completed by the Coordinators. For this reason, confirming the care plan had been implemented was a relatively short process. In the context of service two the care plans were also used to record actions, but the problem documented was reviewed with the service user at their following stroke review. The LoTS care assessment booklet was not used to document all monitoring activities performed by the multidisciplinary teams, therefore, these activities needed further clarification.

6.6   Clarification of the coordinating role

The Coordinators adapted their use of the care plan to reflect the role they performed. In the context of service one this meant that the care plan provided a list of actions, which were agreed with the service user, but usually completed by the Coordinator. The monitoring and review processes performed by the Coordinators at service one were clarified with the team during respondent validation. The team were asked whether it would have been feasible for them to perform stroke reviews, if this had been a requirement for participation in the LoTS care trial, see Box 3 below for discussion.

Box 3: Service one: Reviews and Care Planning

> **OT1:** *It would have been a big impact on us* [complete reviews], *the amount of time we had to it, no we wouldn't have been able to do that*
>
> **Researcher:** *Because the idea was, maybe not even for formal reviews but to take it back as needed. Was that something that was never going to happen?*
>
> **OT1:** *But if you go through*
>
> **SN:** *But you would redo a LoTS if somebody changed hugely. So for example if we were working with someone who was unwell and went into hospital, pneumonia, whatever, and they came out and they initially seemed to be very different from the handover from the hospital, then we would do a new LoTS then. So if it was clinically indicated then we would, but if things were staying on a par then we wouldn't*
>
> **PT2:** *But I think it's the way we use it as well, as we use it as an action planner, so you'd be going back and saying we identified this problem we referred to an occupational therapist, do you agree that we did that? Tick. You're not actually addressing the specific goals with them that's for each of the disciplines to review themselves, because of the way we use it.*

The Coordinators confirmed that, a) reviews would only take place if the individual's needs substantially changed, and b) the way the team used the care plan meant that monitoring or reviewing its content with the service user was not necessary. The implementation of formal reviews (repeated assessments) was also described as unfeasible because of time limitations. This remark was interesting considering the service was participating in a different study that was investigating the implementation of stroke reviews in the local area and signified that other drivers of change might be necessary to prompt the review process desired. The monitoring processes performed by the Coordinator in the context of service one were limited. However, the service user was often in the care of the team over a prolonged period of time. The care plans reviewed revealed that all service users were referred to at least one professional in the team. The intervention provided by these professionals meant that their progress was monitored over an extended period of time, as one Coordinator explained:

S1OT1: *I think this is where because we're a stroke team every professionals' notes all live together in one place all that information*

on that patient is in one area. If you didn't have a community stroke team and you were a Stroke Coordinator it would be very different as the OT notes would be in the OT department. Everything would be somewhere different and different community services, so I can see the sense in it, but it doesn't, we use it as an initial assessment document rather than as a system of care I would say. Once they've done that it's on the go with what we've been doing in the past I would say.

This remark emphasises that the intervention components were used to enhance the initial assessment performed at service one rather than the processes of care. They also indicate that monitoring activities were recorded in the professionals' notes, rather than the LoTS care assessment booklet. The team organised their case notes by service user, as opposed to professional discipline. Therefore details of their service users' progress were stored together. The case notes were reviewed during fieldwork and revealed that the service documentation included the LoTS care assessment booklet, a 'MDT summary form', 'progress review notes' and correspondence with other services e.g. referral forms. The MDT summary form was used at the team meetings, which took place once a week, to provide a brief overview of the individual's progress with the team therapists and/or the nurse. Progress review notes provided a summary of any contact e.g. visit or telephone call made to or about the individual whilst they were in the care of the team and were quite extensive. These documents were used to record the care inputs provided by the team.   The teams continued intervention also enabled new problems to be identified over time, as one Coordinator (S1PT1) commented:

S1PT1: I guess because we work as an MDT, and because we have MDT meetings along the way and discuss patients at regular intervals, say if there was just the OT or Physio involved and other issues we're coming up, we'd discuss them as a team and then it might be, even if the nurse hadn't been involved at the start, then you might bring in another profession further down the line. So I do think because we work as a team there is a holistic eye all the time.

The Coordinator indicated how new problems could be identified after the initial assessment, despite the fact that there was no formal review process. Evidence to support this was found in the service's progress review notes. For example, the notes of one service user revealed that they had required intervention from the occupational therapist to improve their handwriting skills. The service user received intervention and was discharged from the care of the therapist when their rehabilitation goals had been achieved. However, they continued to receive intervention from a social worker who had been referred to as a result of the LoTS care assessment. The social worker contacted the occupational therapist, as the service user reported that they had not received intervention from the stroke team. The occupational therapist contacted the service user to discuss the issue and identified a potential problem with their memory. For this reason, the service user received a second assessment from the occupational therapist to address the new problem identified. These events were recorded in the progress review notes and revealed how problems were identified and addressed after the initial LoTS care assessment had been performed. The Coordinators also reflected upon these eventualities during respondent evaluation, see Box 4 below.

Box 4: Service one: Problem identification over time

S1SALT2: Sometimes its only after you've met someone a few times, for example memory problems don't come up, its only when you see them for a second visit and they can't remember what you've said the first time

S1PT2: Yeah it's their interpretation initially of what they feel they're problems are, but a lot of stuff is covered by what you observe but they don't necessarily have the insight into it initially

S1PT1: I think sometimes as well people aren't sure what to expect from us when we first turn up, so they don't know to tell us certain problems and its only then after a few visits it's that you might pick them up, as it's not just that were here to do X, Y and Z we seem to be doing a bit more, so maybe I'll tell them this and they might be able to help

S1SALT2: Sometimes problems emerge like you've got someone who is not going out to the shop and then they have physio and they can get out to the shop and suddenly more cognitive problems might arise, as they might be in a situation where it's not been a problem before

The Coordinators discussed that the initial assessment might not be an accurate reflection of the service user's problems, it was '*their interpretation initially of what*

they feel they're problems are'. However, Coordinators reported that they identified some problems through observation and some problems as they arose during progress in the rehabilitation process. These eventualities highlight that problems are not always easily identified through the formal assessment process. The LoTS care team identified these types of situations during the development of the system of care and as a result they were directly addressed by the implementation principles advocated. However, service one accounted for these eventualities using processes established as part of the multidisciplinary team structure.

In comparison to service one, clarification of the review processes performed at service two involved establishing what happened between the designated stroke reviews. Coordinators were only expected to visit service users at their specific interval, which meant that in most circumstances there were at least five months and at most one year between an assessment and a subsequent review. One Coordinator (S2LN) explained that the size of their caseload prevented them from visiting service users as needed:

S2LN: *'If we had a set caseload, that would be feasible what you're saying about the monthly reviews or sporadic, you know, if I had 100 patients and that was my filing cabinet with that 100 patients in it that'd be manageable because it'd be by my desk, so if I needed to check in two weeks' time if he had his rails done, I'd go into my drawer, I'd get his notes, I'd do the thing, when you've got two file… it's this volume isn't it that's the thing, so like a Community Matron has a caseload of about 80 patients, she can work that way. She can see them all, lead them all in, you know what I mean, that it's volume isn't it really. I think in an ideal world yes of course you'd like to see these people more often and there are some instances where I actually think that's necessary sometimes, I don't… I can't 'cause I haven't got the remit to do it but there are patients where I could really do to come back here in a few weeks' time and just check how things are but I can't.'*

The Coordinator described that, in some situations, more frequent visits may be warranted, but that they were unable to provide this level of contact. The community matron role, to which the Coordinator refers, was initiated to provide intensive case management for those with long-term conditions and who were at highest risk from readmission to hospital (Drennan et al., 2011, Hudson, 2005). This role is discussed in chapter two as part of the government initiative to manage long-term conditions (Department of Health, 2005b). The caseload of the community matron was purposefully kept small, at around 50-80 patients, to enable them to monitor service users as needed. At service two, the Coordinators were expected to review every individual discharged with stroke in their locality i.e. they did not target subgroups of stroke survivors, which would limit their caseload. This further demonstrates how community roles established in response to national initiatives can overlap at the local level i.e. it is possible that a stroke survivor could be in the care of a Coordinator as well as a community matron if their needs put them at high risk from readmission to hospital. This eventuality might involve duplication in the care provided.

At the time of fieldwork service two were identifying, on average, 107 referrals each month. For this reason the Coordinators' time was dedicated to performing their designated stroke review and they were unable to monitor services users as needed. Observations of practice supported this assertion, the Coordinators could perform up to four assessments per day with each lasting approximately one hour or more, every assessment required paperwork to be completed (e.g. sending a copy of the care plan to the service user), and the Coordinators also had to complete the actions documented in the care plan (e.g. onward referrals). Further to this, the Coordinators had the additional duties, such as attending the MDT meetings and attending a day centre for stroke survivors, which their service helped to manage. However, the weekly multidisciplinary team meetings held at service two were used to monitor the service user's progress towards their rehabilitation goals set with the team therapists. This meeting provided an opportunity for the Coordinators to establish whether the service user had received the interventions they required. However, these meetings prioritised the intervention provided by the team therapists, as opposed to outside agencies and one Coordinator (S2SN) acknowledged this as a potential gap in service delivery:

S2SN: *The benefits and welfare rights and different things like that we refer out but we never get to know if they've been or anything like that, so you send the referral out and expect it to be done, it's only when you next see the patient that you actually know if it's been followed up or not. So, within the medical model it's quite easy to keep a track on how the patient's going, but it's the wider, wider community, housing services and different things often left in the dark about what's happening with those.*

The Coordinator describes that within the '*medical model*' i.e. the provision of health care services provided by the team, the Coordinator could '*keep track*' of their service users progress through the team meetings. However, for all other referrals, such as those to social and voluntary services, monitoring was not maintained between review dates. For example, in one care plan reviewed a problem with continence had been identified and a referral had been made to the continence team. However, at the next stroke review the Coordinator noted '*chase up continence assessment*' indicating that the individual had not yet received the service they required. As part of respondent validation the review team described the main benefit introduced to their care planning process through the system of care, see Box 5 below.

Box 5: Service 2: Reviews and Care Planning

S2SN: And the benefit of the LoTS document over the old Contacts and Overview in the Management Planning is that the Specialist Nursing document in SAP, its set up as identifying the problem, then the intervention, so what you do about it; then it's about patient and carer, then it's about evaluation. Now a lot of our work is signposting, so we wouldn't go in and evaluate in two weeks to see the outcome like a District Nurse would do with leg ulcers. So we were struggling with the Care Plan because we could have 10-12 problems, but all we do is write out the problems, then say 'Refer to so-and-so'. So the SAP documentation, Single Assessment Process, the nursing documentation, doesn't support the signposting kind of a role which we do, it's more about that 'you reassess in two weeks if the leg ulcer's got bigger or smaller', and so it supports District Nursing per se, but it doesn't really support stroke services. We could have 10 problems, identify them, and then have to write individual… and trying to do evaluations, well, you can't evaluate something if you're not seeing them again for six months, you've got to be able to signpost on and other services pick up. Smoking cessation, we wouldn't evaluate…

S2GW: Whether they'd stopped or not, would we.

S2SN: Yeah, until the next time.

S2GW: Until the next time we see them.

S2SN: Whereas that document should be about that they've been issued with nicotine patches and different things, so you can re-evaluate the effectiveness of the treatments you're giving. We're not giving treatments, we're about educating and signposting on and things, so that document didn't lend itself to it, where the LoTS does because it's got more action. You know, you're not saying that you've got to re-evaluate two weeks with blood pressure, it's about identifying, that you've identified with the problem, the blood pressure, and you've then done something about it, who can monitor them on a regular basis, which we can't do, but it's about identifying that initial problem.

Box 5 highlights that the interpretation of the Coordinator role at service two was similar to that at service one. Although reviews were performed, the Coordinator's responsibility was to identify a problem and either signpost or refer the stroke survivor to an appropriate service i.e. it was not to monitor their progress regularly, as a district nurse might do when healing a leg ulcer. For this reason the Coordinators found that the LoTS care assessment booklet was more appropriate than the Single Assessment Process tools used in their area. Although the system of care was intended to be malleable to the context in which it was applied, its implementation at both services conflicted with some of the implementation principles advocated, the implications of this are discussed below.

6.7   Implications for the theory of change

The system of care intended to promote patient centred care through the use of problem solving techniques and goal planning. The system of care also advocated an iterative process of assessment, care planning, monitoring and review to promote continuity of care. The purpose of these attributes was to ensure that the problems identified were addressed collaboratively with the service user, and to establish that the individual had received the services they required. A review of post-stroke needs at timely intervals would also enable new problems to be identified and addressed as they emerged over time. This chapter has established that the implementation of the system of care was shaped by the Coordinators experience as health care professionals and by local policy, as opposed to the principles advocated by the LoTS care team. Therefore, the system of care did not enhance service practice in regards to the amount or type of contact provided by the Coordinators' to their service users. The significance of this finding to the theory of change was perhaps best demonstrated through examination of the care plans.

The care plans reviewed revealed the extent to which the Coordinator was involved in resolving the problems identified i.e. achieving the aim of the system of care. The Coordinators performed actions to address post-stroke problems e.g. referring onto an appropriate service, and providing information or advice. These actions formed the boundaries of their role i.e. they were not expected to monitor progress towards problem resolution once the action had been completed. In the context of service one there was no formal review using the LoTS care assessment structure. At service two Coordinator visits were performed at specific intervals only. The team structure enabled the Coordinators to establish whether their colleagues had provided the interventions required. However, this structure prioritised the interventions provided by professionals within the team, over those provided by outside agencies. Therefore, gaps in service provision, that the system of care intended to address, persisted.

6.8   Summary

This chapter considered whether the implementation principles advocated by the LoTS care team were translated into activities performed in routine practice. The problem solving approach and the processes of monitoring and review were used as exemplars. The physical components of the intervention (the checklist, the manual and assessment booklet) were embedded relatively easily within the two services, as described in chapter five. However, initiating changes to the implementation processes employed proved a more exacting challenge. The assessment booklet was implemented according to local policies, which resulted in two distinct applications of the system that deviated from the theory of change. This finding highlighted that the 'series of circles' described as necessary, by one member of the LoTS care team, to successfully resolve the problems identified were not performed as part of the Coordinator role.

The implementation activities described provide insight of the influence exerted by the system of care on the two services. Looking only at these activities suggests that changes were minimal, as the role of Coordinator appeared similar to that previously performed as part of the MDT assessment at service one, and as part of the review team at service two. Therefore the system of care did not enhance the Coordinator role through increasing their contact with service users, or through encouraging a more collaborative approach than what was already provided. However, at the individual level the educational materials and treatment algorithms provided in the manual were available to inform the Coordinators practice. The next chapter will explore the extent to which the manual influenced the Coordinators practice within the boundaries of the role established in this chapter.

Chapter 7: Promoting an evidence based service

7.1   Introduction

This chapter draws upon the principles of realist evaluation to explain how, why and in what circumstances the system of care promoted the use of evidence based service responses. The proposition prioritised for investigation in chapter four is presented as a tentative Context (C), Mechanism (M), Outcome (O) proposition at the start of the chapter. To refine this proposition the chapter begins by recapitulating the boundaries of the Coordinator role and the types of service responses they employed. The Coordinators' experience of addressing the assessment domains will then be elucidated to provide insight into the scope of their knowledge. These characteristics (boundaries of the role and the Coordinators' knowledge) signify the context in which the LoTS care manual was expected to enhance service delivery. However, the Coordinators did not work in isolation, they formed part of a multidisciplinary team and this structure was found to affect how new information was absorbed and exchanged between professionals. The findings are summarised in diagrammatic form at the end of the chapter and signify the refined CMO proposition.

7.2   Informing the care planning process

The component of the system of care offered to inform the Coordinators' practice was the LoTS care manual. Coordinators who attended the LoTS care training days had participated in a workshop that demonstrated the manual's utility i.e. they were aware of its content and how the recommendations could be applied in practice. The LoTS care manual contained educational texts for each assessment domain and treatment algorithms that led, where possible, to either evidence based recommendations or expert opinion (see appendix viii for examples). Dissemination of the LoTS care manual facilitated access to information intended to inform the care planning process, see figure 14 below for CMO proposition.

Figure 14: CMO proposition: Informing the coordinators' practice

Resource: Manual facilitates access to educational information	**M:** Coordinators informed of evidence based/ expert opinion	**O:** Service responses in line with evidence / expert opinion
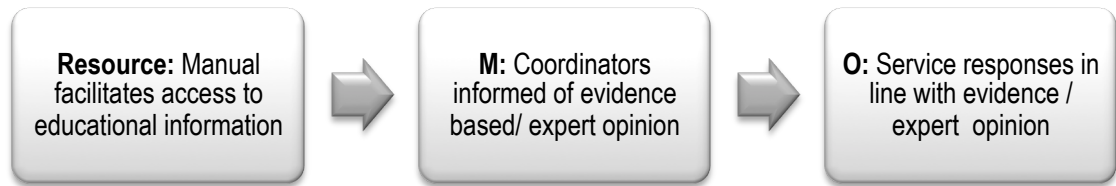
Exploring the Contexts (C) in which the LoTS care manual was expected to 'work' i.e. inform the care planning process was based on the expectations of the LoTS care team elicited in chapter four, and were supported by the comments of the service managers described in chapter five. The expectation was that the LoTS care manual would be used as a source of support by professionals new to the Coordinator role, and for assessment domains outside their professional expertise i.e. it would be used to address knowledge gaps, as an accessible source of information. The Coordinators at service one and service two came from varied backgrounds. Some were new to the role on joining the team and some had limited experience of assessing areas outside their professional expertise. These variations provided an opportunity to explore the proposition.

7.3   Observations of routine practice

At the time of fieldwork the Coordinators had implemented the system of care for at least one year. As an observer it was possible to gain insight into the activities they performed in real time including the care planning process. Solutions to the problems identified were discussed with the service user as they arose during the assessment and were recapitulated at the end i.e. this is when decisions regarding problem resolution were made and confirmed with the service user. The LoTS care manual was not referred to during the care planning processes performed at either service. The copies disseminated were not visible in the service offices and their location was clarified during respondent validation, which is an indication of their absence from daily practice. Fieldwork revealed that in the context of service one and two a number of factors converged to limit the use and impact of the LoTS care manual, one of which was the boundaries of the Coordinator role.

7.4   The boundaries of the Coordinator role

Chapter five described that the Coordinators were expected to complete a holistic assessment (the LoTS care assessment), and respond appropriately to the problems identified within the boundaries of their role. The 'boundaries' refer to the observation that the number of visits performed by the Coordinator was limited at each service. The care plan was not reviewed with the service user after their initial assessment at service one, and at service two reviews were performed at specific intervals only. Therefore the Coordinators did not monitor progress with their service users using the care plan provided in the LoTS care assessment booklet. For this reason, service responses were recorded as actions that could be completed by the Coordinator (usually) i.e. a referral to an appropriate service, providing information or advice, as illustrated using the care plan data in chapter six.

The boundaries of the Coordinator role conflicted with some of the recommendations in the LoTS care manual. For example, the algorithm for the domain 'Driving and General Transport' and 'Mood' both recommend that the Coordinator review the service user intermittently over several weeks, and suggest alternate strategies to manage the problem during this period if required (see appendix viii). To implement these recommendations required changes to the monitoring processes performed by the Coordinator. However these changes were not prompted through participation in the LoTS care trial at either service. The Coordinators responsibility was to refer or signpost the individual to an appropriate service. These services could then provide more frequent monitoring to resolve the problem if necessary. This finding emphasises a point made by the service manager (S1SM) in chapter five - that the information valued most by their Coordinators was local service availability.

The aim of the system of care was to enhance service responses ensuring they were in line with the evidence base or expert opinion where possible. However, adaptation of nationally based guidelines to local circumstances is common (Silagy et al., 2002, Capdenat Saint-Martin et al., 1998, Graham et al., 2002), and there was flexibility in the system that allowed for this. Therefore, in the context of service one and two enhancing service responses focused on the actions they performed, as

opposed to the ongoing management of the problem. At service one an information file was developed to complement the manual, which contained details of local service availability to inform onward referral. At service two the information in the manual was not tailored to the local area. However, the need to access any information was dependent on the knowledge and experience of each Coordinator, and this varied substantially. The Coordinator's professional experience is clarified in the following section.

7.5   Professional experience

During fieldwork the Coordinators revealed that many of the assessment domains included in the LoTS care structure overlapped with areas that they routinely addressed as a therapist or nurse. To clarify which areas this included, the Coordinators were asked to indicate which domains fell within their specialist remit. Table 19 below provides a summary of their responses, and also reiterates the areas addressed in the Single Assessment Process tools used by the service prior to the system of care.

Table 19: Overlap with professionals specialist assessments

	LoTS care assessment section	Specialist Assessment		Previous assessment
		Service one	Service two	
1	Transfer of care	-------------	SN, LN, GW	--------------
2	Communication and information	-------------	SN, LN, GW	--------------
3	Medicine and general health	SN	SN, LN, GW	EC/O
4	Pain	SN, PT	SN, LN, GW	EC/O
5	Mobility and Falls	OT, PT	SN, LN, GW	EC/O
6	Personal Hygiene & Dressing	SN, OT	SN, LN, GW	EC/O
7	Shopping & Meal Preparation	OT	SN, LN, GW	EC/O
8	House & Home	OT	SN, LN, GW	EC/O
9	Cognition	OT	SN, LN, GW	EC/O
10	Driving and general transport	--------------	SN, LN, GW	O
11	Finance & Benefits	--------------	SN, LN, GW	EC/O
12	Continence	OT	SN, LN, GW	EC/O
13	Sexual Functioning	--------------	SN, LN, GW	--------------
14	Patient Mood	OT	SN, LN, GW	EC/O
15	Patient Social Needs	OT, PT	SN, LN, GW	EC/O
16	Other	OT, SALT	SN, LN, GW	EC/O

EC: Easy-Care (service one), O: Overview (service two)

It is apparent from table 19 that 11 domains were familiar to one or more of the professionals at service one. The domains marked indicate the areas in which they provided intervention as a therapist or nurse. The largest overlap was with the occupational therapists who addressed problems with 'Mobility and Falls', 'Personal Hygiene and Dressing', 'House and Home', 'Shopping and Meal Preparation', 'Cognition', 'Continence', 'Mood', 'Social needs' and sleep (Other). The smallest overlap was with the speech and language therapists who addressed certain problems listed in the domain 'Other'. The overlap depicted in the table indicates

that, as a multidisciplinary team, the services were able to address many problems identified i.e. many service responses might involve a referral to a team colleague.

The nurses at service two explained that they were already trained to consider all domains included in the LoTS care assessment structure, as their nurse training was based on the Roper, Tierney and Logan model (Roper et al., 2004), see Box 6 below. Further to this, they had experience of assessing these areas in practice using the Overview assessment tool, which they have also referred to in Box 6. In comparison to service two, the nurse at service one had joined the community stroke team from a hospital environment where they had not performed this type of assessment i.e. their background might explain the difference in their response.

Box 6: Service two: nurse training

S2LN: *It follows more or less different sections in the* Roper, Logan, Tierney *model of activities a day, which we all get drummed into us, don't we?*

S2SN: *Yeah, from the training.*

S2LN: *From training.*

S2SN: *We don't forget it, do we.*

S2LS: *There's no new domains in there.*

S2SN*: No.*

S2LN: *It was only a merging of what's already in the Overview, but just in a different layout, so different format, different sequence, that's probably the only differences. There's nothing new.*

S2SN*: Domain wise, was there?*

S2LN: *No.*

Researcher: Was sexual function in there?

S2SN*: Yeah.*

S2LN*: Yeah, there was.*

Establishing what domains the Coordinators were familiar with addressing provided insight into which areas might be most supportive in the LoTS care manual. However, some Coordinators had experience of performing holistic assessments either as part of the community stroke team, or in a previous role. This meant that they had knowledge (gained through experience) of how to address a diverse set of problems, which was then applied in practice. For example, a Coordinator at service two was new to the stroke team on implementing the system of care. In this context the LoTS care manual had the potential to act as a useful source of information when addressing stroke related problems. However, the Coordinator reported that they had not received a copy of the LoTS care manual and had not read its content. During one assessment observed the Coordinator identified nine problems (see section 7.10, table 20 for this care plan). These problems were diverse including high blood pressure, loss of confidence in driving and fatigue. The Coordinator discussed the problem and potential solutions with the service user during the assessment process, and these were then documented in the care plan i.e. the Coordinator developed the care plan without support from the manual or any other sources. On responding to the problems they identified the Coordinator commented:

S2SN: *I've worked in* [service two] *community services a long time so I know what services are available. I know that if it was a grab rail, if it's equipment then it's Social Services OT. Now if it's not equipment, if it's about therapy then it's stroke services OT, so it's depending on which one. So how do you know about it? You, uh, working in the system for years, really knowing where to go to signpost people.*

The Coordinator was aware of what services were available through their professional experience in their local area. They were also aware of what was expected of them in their role of Coordinator on the stroke review team. For this reason, they felt confident in their ability to address the problems they identified without reference to supportive guidelines. Therefore the manual did not inform the care planning process in this context i.e. where the Coordinator was experienced and confident in their role, consequently the Coordinators practice was not enhanced by the intervention. The Coordinator valued their knowledge, as it was context specific and could be applied in practice. Knowledge established by this

method is often referred to as 'tacit' defined as, '*knowledge in practice developed from direct experience and action, highly pragmatic and situation specific, subconsciously understood and applied; difficult to articulate; usually shared through interactive conversations and shared experiences*' (Kothari et al., 2011).

Tacit and explicit knowledge are often described as two poles on a continuum (Kothari et al., 2011). Explicit knowledge is distinct from tacit knowledge as it is codified i.e. presented in written form e.g. the National Service Frameworks, the National Clinical Guidelines and the LoTS care manual. However, the influence of tacit knowledge on the use of explicit forms is emerging as a significant theme in the literature (Gabbay and May, 2004, Greenhalgh et al., 2008, Kothari et al., 2011). Tacit knowledge certainly appeared to play a large role in the implementation of the system of care. In the context of service one and two the LoTS care manual provided one source amongst many that were used, when necessary, to inform the Coordinators practice. These sources are discussed further in the following section.

7.6   Sources used to inform the Coordinators practice

In the context of service two, the Coordinators reported that they were familiar and had experience of addressing all assessment domains included in the LoTS care structure. One Coordinator (S2GW) had worked as part of the review team for six years. They had attended the LoTS care training and reported reading the manual, on which they commented: '*well, there was elements of it* [the manual] *what was useful, I wouldn't say it was all useful because, obviously, there is a lot of it that I was already au fait to.*' The Coordinator's experience as part of the stroke review team meant that they felt 'au fait' with much of the educational material provided within the LoTS care manual i.e. it did not significantly add to their knowledge base. When asked what reference guides had been particularly useful the Coordinator commented:

S2GW: *'well, it was to do with psychological problems and things, I think, I used it for. I can't think of any other specific really, no, I can't recall any other specifics, um no, I can't.'*

This Coordinator recalled referring to one reference guide from the sixteen included in the LoTS care manual. This remark indicated that although read, the manual's recommendations did not change how problems were managed. To clarify, the reference guide for the domain 'Mood' (which addressed psychological problems) recommended monitoring the service user intermittently over a number of weeks. If adhered to, this guidance could introduce change to the Coordinator's established practice. However, as the previous chapters have clarified, implementing the system of care did not extend the boundaries of the Coordinator role. The care plans reviewed at service two revealed that problems with mood were sometimes addressed by advising the service user to monitor their mood i.e. whether it was improving or deteriorating over time (see section 7.10, care plan 20 for example). However, the Coordinators responsibility was to re-assess the problem at the next designated stroke review not according to the recommendations in the LoTS care manual. Further to this, the service now employed two psychologists as part of the stroke team and the Coordinator reported that they would liaise with these professionals if they had concerns in this area. Therefore the Coordinator prioritised the information held by their team colleagues over the information contained in the LoTS care manual.

The sources used to inform the Coordinators' practice at service two were diverse, for example, the remaining Coordinator (S2LN) commented: '*That's* [knowledge] *just knowing the services out there really, so when I started in post here I would have identified what services were out there, either by being told or by looking or finding or googling or whatever really, so that's just experience*.' The Coordinator had received a copy of the LoTS care manual, but used other sources e.g. the Internet (googling), and asking others (being told) to establish what services were available in the local area, and this was part of a learning process performed when new to the role. The findings demonstrate that the LoTS care manual competed with other sources that were available to inform the Coordinator's practice and that context specific information was usually prioritised over the nationally based information in

the manual. Liaison with team colleagues was a particularly valued source of information. Liaison with colleagues was facilitated as the team shared an office, as one Coordinator (S2LN) described: '*obviously we're based altogether; physio referrals, OT referrals, speech and psychology referrals tend to get discussion through anyway… so if you refer in the morning we'll talk around it and say, "Is it appropriate?" that sort of thing*.' Referrals to team colleagues were discussed directly with the relevant professional; therefore the Coordinator could clarify that their service response was appropriate. Another Coordinator (S2GW) noted that discussion would also take place as needed:

S2GW: *Obviously, if we do come against a complex patient, a patient who has either deteriorated quite rapidly or something that we're unsure about, we don't specifically need to wait till the referral meeting, because, again, the team is on standby, if you like, all the time. So, again, we can liaise quite openly and quite quickly with each other*

Sharing the office with a number of different professionals enabled the Coordinator to liaise '*openly*' and '*quickly*' with their colleagues if they were '*unsure*' how to address a problem. There were no rapid deteriorations of service users during fieldwork, however liaison between colleagues was observed e.g. therapists would often report patient progress on returning to the office after a therapy session and the Coordinators would discuss the service user they were about to review with their colleagues to identify if there were details they should be aware of prior to the assessment. These brief interactions demonstrated that the Coordinators could easily access support from their colleagues if this was necessary. In the context of service two i.e. where Coordinators were experienced in performing the role and accessed support from local sources, the information in the manual did not enhance their service responses. As part of respondent validation the review team at service two clarified the sources that had contributed to their knowledge base, see Box 7 below for discussion.

Box 7: Service two: Establishing Knowledge

Researcher: And what training is that that you do every year?

S2LN: *Erm, its mandatory stuff like health and safety, there's the stroke for new staff, they do a stroke…*

S2GW: *Yeah, a stroke induction programme for new staff, and that's going through all the basics really, like what positioning is best.*

S2LN: *Yeah, consultant actually does a talk doesn't he and the specialist nurses do, and you've got the TIA Nurse who does the talk, Manor staff.*

S2GW: Manor staff, and then of course Tracey from the rehab side. I don't know if Hazel does a talk, and of course S2SN or S2LN as well.

S2SN: *So it's an integrated training for all new starters into the stroke, the acute or the community, training we all do.*

Researcher: Right, okay. So that's how you address what you identified, that's where the knowledge comes from?

S2LN: *Yeah, I think its experience. I think you'd need to have the experience of the community and what services are available out there.*

S2GW: *I think as a team as well, because we work quite well together, that if you have got any concerns obviously you're quite open, you can discuss it, and that gives you confidence to going out and sort of carrying on sort of thing if you like. So the more you do the job and everything else, you grown more confident with it, don't you?*

S2LN: *Yeah.*

Researcher: And just on the flip side of that then, has there been an occasion where you feel that the LoTS Care Manual has helped you to make a decision about what you're going to with a problem?

S2GW: It hasn't me, personally, because I feel, me personally, you know, I already covered most of the things if not all of them before the LoTS document came along, but every day is new and sometimes you never know what challenge you're going to come up with. So again it's just being confident in your role, because you don't know the answers to everything anyway. Some issues may come up again, like if you come up against abuse or something like that, obviously that's something that you don't deal with every day but you have to be aware of how to deal with that situation, and sometimes, even if you feel comfortable yourself from a professional point of view, you have to stay calm and try and comfort whoever you're with and that aspect of it. So again I think a lot of it comes with experience, and it's like anything really, the more you do something the more confident you become.

The Coordinators at service two clarified that the combination of their compulsory training, their practical experience of performing the role, and the support they

received from their team colleagues provided them with the knowledge and confidence needed to perform their role, even when addressing sensitive areas such as abuse. In contrast to service two, the Coordinators at service one did not receive compulsory training on joining the team. However, some Coordinators supplemented their knowledge in similar ways to the Coordinators at service two. For example one Coordinator (S1OT2), an occupational therapist by background, identified three problems during an assessment. The problems concerned mobility, risk factor management and eating and swallowing, therefore two problems were outside their expertise. The Coordinator addressed these problems, without support, by referring to the team's physiotherapist, stroke nurse and the speech and language therapists. In reference to the LoTS care manual the Coordinator commented:

S1OT2: I think I used the continence one [reference guide] *for somebody but now we've got the continence team just down the corridor and we go and talk to them and it's, we tend to phone people and find out what the best route is from the professional that, or the person that is best placed to speak to. So for example benefits I'd speak to a social worker or [city] advice rather than refer to the algorithms.'*

This Coordinator described their occupational therapy role as 'generic' i.e. they were familiar with addressing a broad range of areas and named one reference guide from the LoTS care manual (continence) that they had referred to. However, as the team now shared a building with the continence nurses, the Coordinator sought advice directly from these professionals when needed. The Coordinator (S1OT2) stated: '*It's knowing what is there locally. I think if you didn't have the local knowledge if you were new to using the system it* [the manual] *would be more useful.*' This remark emphasises the value placed on local knowledge, which was not provided in the LoTS care manual but through experience and liaison with professionals who worked in the community. It was suggested that Coordinators new to the role might benefit more from the information contained in the LoTS care manual, and similar views have been reported in the wider literature (Rycroft-Malone et al., 2008, Kitchiner and Bundred, 1996). However, working as part of the multidisciplinary team was described to facilitate an informal learning process for

those new to the Coordinator role at service one, this is explored further in the following section.

7.7   Informal learning processes

At service one every professional was expected to act as a Coordinator, this meant that their backgrounds and experience were more varied than those performing the role at service two. For example, there were some professionals who had not performed a coordinating role prior to joining the stroke team. In these situations reference to the LoTS care manual was hypothesised, as it provided a source of information and support in their new role. However, fieldwork revealed that the multidisciplinary team structure facilitated an informal learning process for professionals new to the Coordinator role. Service users who had received their LoTS care assessment were presented at the next multidisciplinary team meetings as 'LoTS patients'. Observations of these meetings revealed that the Coordinator, who had performed the LoTS care assessment, summarised the problems identified and their intended service responses. This summary often led to discussion amongst the team about the care plan documented, which facilitated the exchange of knowledge between colleagues, as one Coordinator (S1OT1) commented:

S1OT1: *I think we've all got bits of each other's skills in that like, S1SN is a nurse. Before she worked in this team doing this general assessment* [LoTS care] *she would have never have referred anybody for a second stair rail, but now because she has worked with us and seen us, the first thing we would do for someone who was struggling on stairs, if there is only one stair rail, we would order another stair rail that can be in in two days, and that's there ready for the physio to do. So she fed back from one this morning 'and she's only got one stair rail, she's coming down the stairs on her bottom, so I've referred for a second stair rail and I've put her on the list for physio.'*

The professional (S1SN), to whom the Coordinator refers, had not performed this type of role before joining the team. However, their comment demonstrates that the professional was able to extend their knowledge through observing their colleagues practice. This knowledge was then applied in practice when addressing areas outside their expertise and evidence to support this was found in their care plans e.g. the Coordinator (S1SN) noted in the mobility section of one care plan that the service user already had two stair rails installed and that their problem was diminished confidence mobilising outdoors, therefore their response was to refer to the team physiotherapist. The Coordinator could then share this knowledge 'f*eed back*' at the team meeting, which provided an opportunity for those new to the team to learn from their experience. The multidisciplinary team meetings were acknowledged as a valuable source of information and support, as one Coordinator (S1PT1), explained:

S1PT1: *I think we use MDT's very well to do that* [develop a care plan]*. So every LoTS we'll do we discuss in MDT and I'll say some of my thoughts about what I would do and we just advice each other and say, 'well have you thought of this or that', and we're all experienced therapists, so we tend to be able to come up with the action plans between us. So I think that's how we do it, more through the MDT and I think that's why the manual doesn't get used as much.*

The care plans documented by the Coordinators were discussed with their team colleagues as part of routine practice. This discussion enabled different options to be explored and the care plan to be adjusted as needed For example, during fieldwork one 'LoTS patient' was described as 'needing to get out more than anything else', however they also had memory problems and Dysarthria. The Coordinator referred the individual to the physiotherapist, occupational therapist and the stroke nurse. During the discussion, a physiotherapist suggested that a health trainer (a local community service) might also be of use, but they clarified that this service did not take 'complex cases' and the individual might fall into this category having multiple problems. This example highlights how knowledge was exchanged in team meetings and the Coordinator could be confident that they had responded appropriately to the problem in the context of their service. Professionals new to the

Coordinator role supported this finding. One Coordinator (S1SLT2) had performed three LoTS care assessments at the time of their interview. During the assessment observed the Coordinator identified ten problems only two of which were within their expertise (the care plan is presented in section 7.10, table 19) and they addressed these without reference to the LoTS care manual. The Coordinator explained where they had learnt how to address the problems identified: '*At each MDT people go through the LoTS care that they've done and they say, 'and this was identified and I've done this, and this is identified so I've done this.' You pick up quite a lot about what you can do and similar*.' The Coordinator describes being informed through attendance at the team meetings and not through the LoTS care manual as anticipated in the CMO proposition, the Coordinator further explained:

S1SALT2: If there is ever a problem the rest of the team is always around, if it's outside you're area. The guy that I saw when I was deciding what to do with the bath board his sister gave him from a nursing home, I wasn't really sure what I should do with that piece of information and whether I should refer to OT or what I should do and I spoke to S1OT2 and she was able to say get in touch with social services and they would replace it if they thought it needed that.

The Coordinator clarified that outside the formal team meetings they spoke directly to colleagues if they did not have the knowledge to address a problem identified. This comment refutes the CMO proposition and emphasises that those with less experience in the role relied on their team colleagues, as opposed to the LoTS care manual, to address gaps in their knowledge when acting as a Coordinator. Another example from service one was a Coordinator (S1PT2) who had joined the team from a hospital background where they had performed a uni-disciplinary assessment (physiotherapy) only. They commented:

S1PT2: When someone else is presenting their LoTS you can see other things, like if there was something that was missed, when you're thinking about it in your head, you get other peoples feedback when

they're presenting a patient. It also makes you think about questions you would ask as well. So I never feel like I'm missing anything. Maybe I would be if I read the booklet properly and obviously I was meant to do that, but I feel like it's got enough points within the LoTS booklet that you can do your assessment without reading all the background.

The Coordinator described that they found the assessment structure sufficient as a guide, which is why they had not read '*all the background*' information contained in the LoTS care manual. The Coordinator was unaware that the LoTS care manual contained algorithms stating that reference to these '*didn't make sense*'. For this reason, they further commented that they '*had not given them* [the algorithms] *the opportunity to impact*' on their practice. This finding was interesting as it indicated that some Coordinators, who were provided with a personal copy of the LoTS care manual, did not consider that its content might be a useful source of support in their new role. The Coordinator compared their practice against their team colleagues, which provided them with confidence, never feeling like they were '*missing anything*' when implementing the system of care. They identified 6 problems during one assessment including loss of vision, problems performing domestic chores and lack of knowledge regarding the stroke incident i.e. areas that were outside their traditional role, and they addressed these without support. Similarly to the previous Coordinator they further explained:

S1PT2: *Especially around finances and benefits* [identify problems that they don't know how to respond to]. *If you don't know the answer when you're with the person, you just need to document what they've said and take it back to the team. If no one else knows the answer, they'll at least know where you should look for it, for example, social services or Disability Living Allowance, and then I just call the relevant organisation*

Finance and benefits was an assessment area outside the expertise of the Coordinator and was not addressed directly by the team. However, the Coordinator stated that their colleagues were able to signpost them to the relevant agency, who would then advise them on an appropriate course of action. The evidence suggests that professionals new to the Coordinator role relied on team meetings and liaison with colleagues to inform their practice, one Coordinator (S1SALT1) summarised nicely why they thought this was the case: *'It's quicker plus sometimes people know what's local, there can be local things that are helpful for people that might not be in a book that is national for people, so it's just a bit quicker and more local really.'*

It was hypothesised that the manual would be used in contexts where professionals were new or less experienced in the Coordinator role. However, in the context of service one the Coordinators worked as part of a multidisciplinary team and team colleagues were viewed as a quick and reliable source of context specific information i.e. they knew what was expected of the person acting as a Coordinator and what services were available in the local area (information that might not be provided in a manual designed for national use). Knowledge was shared at team meetings and in day-today practice. This interaction facilitated an informal learning process, which enabled the Coordinators to address the problems they identified. Informal and incidental learning are common themes in professional practice (Cheetham and Chivers, 2001, Marsick and Watkins, 2001, Eraut, 2000). Examples that overlap with the findings in this study include collaboration i.e. working as part of a multidisciplinary team and working alongside more experienced members of staff, observation of practice and learning from complex and multifaceted problems (Cheetham and Chivers, 2001). These processes appeared to play a large role in how both new and more experienced members of staff established tacit i.e. context specific knowledge to perform the Coordinator role. In the context of service one the manual was not used by all Coordinators who were new to the role, therefore it did not directly inform their service responses and consequently did not enhance their practice, as hypothesised in the starting CMO proposition. However, the LoTS manual was used as a source of reference by some Coordinators within the team at service one and this is discussed further in the following section.

7.8   Confirmation of existing practice

In the context of service one a Coordinator (S1PT1), who was also a senior member of the team, described that they used the LoTS care manual to confirm that their practice was in line with the recommended pathways: '*well it's almost just double-checking that I've gone down the right route, just checking that I haven't missed anything glaringly obvious.*' This Coordinator had previously worked in a community neuro-rehabilitation service, where they had performed a role similar to that of the Coordinator at service one. This role was known as a key worker and addressed all domains in the LoTS care assessment structure, although for a different population group. This finding did not support the initial CMO proposition, as the Coordinator was experienced in addressing the assessment domains. However, as a senior member of the team the Coordinator provided support for more junior staff. This position might have prompted them to clarify that the advice they provided was in line with the evidence base or recommended guidelines, particularly as they had joined the team from a non-stroke background. Therefore, an experienced member of the team, who came from a non-stroke background and supported junior members of the team, used the manual. However, in this context the manual fulfilled a different function to the one anticipated, it was used for confirmation of practice, which does not equate with an enhancement in the service responses they employed i.e. the output anticipated.

One coordinator (S1OT1) had attended the LoTS care training days where they had used the LoTS care manual in fictional scenarios. Further to this, they had taken responsibility for developing the local information file to complement the LoTS care manual. They had also been instrumental in establishing correspondence to service users to enable administration of the client checklist. For this reason, they could be described as a 'champion' of the system of care i.e. an enthusiastic promoter of its new ideas and a facilitator of its implementation in practice (Gosling et al., 2003, Greenhalgh et al., 2004). Most Coordinators had not referred to the local file as a supportive tool. It is possible that this is because of the support they received from their team colleagues, however, the Coordinator (S1OT1) also noted that the information file had been '*lost in the ether*' when the team moved offices (prior to the start of fieldwork). The fact that the Coordinator had developed the file meant that

they had absorbed the information that was applicable in the context of their service, in regards to the LoTS care manual they commented:

S1OT1: *The driving's good, depression's good, the sexual functioning bit. It's got really nice ways of being able to approach, I mean if you were starting off in a new area, and you were, not a huge amount of experience, it* [the manual] *would just be an absolute god. I wish I had it when I started working here… but I've had to muddle through on my own without it.*

The Coordinator noted that driving, mood, and sexual function were '*good*'. This comment indicates that specific areas in the LoTS care manual were considered supportive. However, the Coordinator also stated that they had had to '*muddle through without it* [the manual]' suggesting that they had addressed similar problems prior to its introduction, and they clarified: '*I suppose it* [the LoTS care manual] *sort of confirms it* [service response]*, but it's not hugely different, and there's certain things in it, like bits in the sexual functioning that are, um, it's not applicable because some of those services aren't available in our area.*' Therefore, the LoTS care manual was considered supportive, but its reference confirmed rather than changed their practice. This finding could be described as a 'ceiling effect', as the ability of the manual to enhance service delivery was limited, as the service was making appropriate referrals prior to the LoTS care manual. This type of effect has been found in previous research studies on the use of clinical guidelines (Mol et al., 2005, Ramsay et al., 2000). Respondent validation provided an opportunity to clarify the impact of the manual and this Coordinator noted on their feedback:

RS1OT '*info within* [the manual] *gives you more confidence in some of the advice and referrals that you discuss / suggest to the patient. This advice filters back to team members through those who have read the manual.*'

The LoTS care manual provided the Coordinator with confidence discussing some of the assessment domains. This information was then informally disseminated amongst their team colleagues through the channels described in the previous sections. This finding emphasises the dynamic way in which new knowledge was absorbed by the team. The professionals, who had read the manual and assimilated the information applicable in their local context and within the boundaries of the Coordinator role, disseminated this new knowledge amongst their colleagues using the multidisciplinary team structure. For this reason, the information in the LoTS care manual might have been more influential than originally thought, although most Coordinators would be unaware of this. Only one Coordinator reported that they had used both the LoTS care manual and the local information file to directly inform their practice, how and why is explored further below.

7.9 Informing the Coordinators' practice

A Coordinator at service one (S1SN), who had joined the team from a hospital environment, explained that performing the role had been '*a big change'* for them. At the start of the LoTS care trial the Coordinator had been in post one year, but had taken leave for eight months of these, they explained: '*I wasn't that long in the tooth really when LoTS started. I wasn't aware of what was out there in the community and where I could go to, I was still very much learning*'. The LoTS care manual was described to support the learning process for them, however, this was in reference to the identification of problems: '*Like cognition is a big thing for me as I'd not really been involved in it in the hospital, it was all really medical based, so memory and those kind of things and the LoTS kind of gave a bit more guidance into what I should have been asking.'* The information in the LoTS care manual guided them in the assessment of a new area. The assessment and identification of post-stroke problems are discussed further in chapter eight. In terms of the service responses employed, the Coordinator described that they had referred to the local information file developed by their team colleague:

S1SN: Again as I was fairly new to the role it was just knowing what was where. So stuff like how do you apply for blue badges, RADAR keys stuff I've not done before, but then once you've done it once you

don't need to go back into the box do you because you know how to do it. The disability stuff, yeah blue badges and RADAR keys, referral to benefits advice it was just stuff that I'd not done a lot of before

The information file addressed gaps in the Coordinator's knowledge base and its recommendations were applied in practice i.e. promoting the use of appropriate service responses. In comparison to other Coordinators who were also new to the role, this Coordinator used the supportive tools provided to inform their practice. An explanation to account for this difference might be that the Coordinator had attended the LoTS care training days. Therefore unlike their colleagues they were aware of the content of the LoTS care manual and its indented purpose. Further to this, they were also present when the local information file was developed and before it was lost to the '*ether*' i.e. the combination of their limited experience and their awareness of the content of the supportive tools prompted their use in practice. However, the Coordinator addressed the problems they identified without referring to the supportive tools during fieldwork, the Coordinator explained that nowadays: '*I would go and ask somebody first rather than root through the box file*', which indicted that their sources of support had changed over time. A reason for this might be that they had become accustomed to using the channels described in the previous sections to inform their practice, such as the multidisciplinary team meetings. The Coordinator explained that team working had been very different in the hospital environment and they had not liaised routinely with a variety of different professional disciplines, as they did in the community stroke team, they explained:

S1SN: *I wouldn't know how to split the LoTS from just the different way of working here and what helps with that [...] I do think the fact that we work differently has got a big part to play really, as like I say if I was in hospital I would go to another nurse or a manager above me, I wouldn't necessary have gone to a therapist. Whereas here as I'm the only nurse my only choice is to go to a therapist, but I'm not sure if that's directed by the LoTS it's more directed by the way we work.'*

The Coordinator described that it was difficult to differentiate between the role played by the system of care's components and the support they received from their team colleagues in adjusting to their new role. However, the discussion demonstrated that a combination of factors were influential. In this context i.e. where the Coordinator was new to the role, new to the community and were aware of the content and purpose of the manual and local information file, the tools were used to inform their practice as anticipated. This enabled the Coordinator to respond appropriately to the problems they identified in their new role. Respondent validation provided an opportunity to clarify how the manual had impacted on service one, see Box 8 below for group discussion.

Box 8: Service one: The LoTS care Manual

S1OT1: For things like, that we didn't address before like sex the LoTS care was really useful sort of gave you a step by step of what to do, so you'd use it for that, not that it was frequently an issue for people, was it? But otherwise it's just back to the professional and professional goal setting

Researcher: I've put that a lot of the assessment relate back to you as a team, so for most of these you would know what to do if you know what the skills of your colleagues are, is that right

S1OT1: Yeah

Researcher: So how the manual did help you was to verify your practice and as a training tool,

S1OT1: For students

S1SN: And driving and RADAR keys

S1PT2: I think driving is more common for us as after you've had a stroke you can't drive for a month and that automatically affects any driver that has a stroke

S1OT1: and we see those people quicker now whereas before it was sort of after the event

S1PT1: they'd started driving again, hadn't they

Researcher: So that might be something particular to stroke

S1PT1: Yeah definitely for stroke rather than other progressive disorders where it might pop up along the way, but it's not a blanket

The discussion reiterated that most domains could be addressed by liaising with a team colleague. However, the LoTS care manual had been useful for domains that were not targeted by the Easy-Care, in particular sexual function is noted. The reference guide on sexual function had been used by the occupational therapists to inform a training presentation delivered to colleagues in the area, which is why it is described as a training tool by the researcher. This discussion reaffirmed the point that Coordinators, who referred to the manual, could disseminate its information to team colleagues i.e. ensuring that problems not targeted by the Easy-Care were addressed appropriately if identified through LoTS care. However, the Coordinator also notes that problems with sexual function were not frequently identified.

In the context of service one, 'Driving and general transport' was another domain introduced to the assessment process via the system of care. The Coordinators discussed that problems with driving were identified more frequently at the time of respondent validation. The reason for this was that the waiting list for the service had been reduced. Therefore the Coordinators were visiting service users earlier and at a time when problems with driving were still apparent. For this reason, the reference guide for 'Driving and general transport' in the LoTS care manual was providing a useful source of information. The Coordinators suggested that problems with driving were more specific to stroke i.e. they might have had less experience of addressing these types of problems outside the context of the stroke team. This might explain why the manual was now being used. To examine the service responses employed by the Coordinators in comparison to the manual's recommendations, two care plans were examined in more detail.

7.10 Example of service responses employed

To illuminate how the services' responses compared to the LoTS care manual's recommendations, table 20 and 21 below provide an example of a care plan documented at each service. The speech and language therapist (S1OT2) at service one documented the care presented in table 20, and the specialist nurse at service two documented the care plan presented in table 21. These care plans were used as examples, as the Coordinators explicitly stated that they had not referred to

the LoTS care manual, although both were new to role on implementing the system of care.

Table 20: Care plan documented by S1SALT2

	Problem	Service response	Reference Guide
1	Carer stressed – tired from providing care	Refer to social services Refer to PoPPs (support group)	**Ref guide 16:** Provide Stroke Association leaflet: 'Stroke, a carers guide' Consider presence of depression / anxiety For complex problems refer to social worker for assessment
2	Poor hearing	Refer to audiology	**Not addressed by reference guides**
3	? Not using the correct bathing equipment	Refer to contact centre	**Ref guide 6:** Identify needs for aids/ adaptation. Refer to social services for assessment and advice
4	Limited info on CVA	Refer to PoPPS	**Ref guide 2:** Provide info on stroke and check understanding
5	No benefits advice	Provide no. for benefits advice	**Ref guide 11:** Algorithm addresses more specific problems. Numbers of relevant national services provided
6	Fear of falling. Slithering walking pattern. Would like to walk outside	Refer to Physio	**Ref guide 5:** For mobility problems refer to physiotherapist For falls – refer for full evaluation from falls specialist
7	Poor Car transfers	Refer to Physio	**Ref guide 10B:** offer referral to Physio /OT if appropriate
8	Poor swallow	Refer to SLT	**Ref guide 7B:** refer to speech and language therapist
9	Dysarthria	Refer to SLT	**Ref guide 15:** Discuss and consider speech and language barriers
10	House being demolished	Determine if any help available re housing	**Not addressed by reference guides**, however ref guide 8 contains contact details for elderly accommodation counsel

Table 21: Care plan documented by S2SN

	Problem	Service Response	Algorithm/reference guide
1	Been diagnosed with trapped nerve in elbow causing lack of sensation in two fingers	Still awaiting treatment. Advised to attend GP to chase up referral to neurologist	**Not addressed by reference guides**
2	BP higher than usual	To inform GP	**Ref guide 3:** Not addressed by algorithms Advice re: medication for blood pressure
3	No exercise. Used to swim. Discussed how to resume this activity	SA leaflet on stroke and exercise sent	**Ref guide 3:** Not addressed by algorithm Advice to take regular exercise
4	Feels unsteady on feet	Offered Physio but three times a week too much. Advised to contact to CST if reconsiders. No recent falls	**Ref guide 3:** For mobility problems refer to Physiotherapist For Falls refer to Falls team
5	Struggling to maintain garden	To send leaflet of handy men from age concern	**Ref guide 15:** Not addressed by algorithm Social activities pre stroke should be considered
6	Would like another step at front of property	A step has been fitted at rear of property, another will not be fitted	**Ref guide 8:** Discuss options to adapt current property AGE concern/ Local handy men schemes, Social services OT, Advise on availability of grants for home adaptations
7	Lost confidence driving	Info sent on regional driving assessment centre	**Ref guide 10a:** Algorithm relates to regaining driving licence Text refers to 'Mobility centres' that can assess fitness to drive.
8	Becoming short tempered easily	Declining psychology input at this moment. To monitor	**Ref guide 14:** Review within two weeks for post-stroke depression Irritation noted as a symptom of depression
9	Fatiguing easily	To send SA leaflet on tiring after stroke	**Not addressed by reference guides** Included in frequency table

The first two columns of table 20 and 21 present the problems identified by the Coordinator and the service response documented. The recommendations provided

in the reference guides (algorithms and educational text) in the LoTS care manual are summarised in the final column of each table. If the algorithms did not address the problem, the educational text was reviewed to establish the recommendation. The complete algorithms for reference guides 3, 5, 10a and 14 are provided in appendix viii as examples. In total nineteen problems were identified by the two Coordinators. The care plans reveal that the problems experienced by one person can be extremely diverse, and some were not related to the stroke incident.

7.10.1 Problems not related to the stroke event

The reference guides did not address four of the problems identified (2 at service one and 2 at service two). Three of these problems were not related to the individual's stroke, for example, house being demolished (problem ten in table 20) and a trapped nerve (problem one in table 21). The fact that these problems did not result from stroke explains why they were not directly addressed in the LoTS care manual, which targeted stroke related problems. However, this finding also demonstrates that an assessment, which aims to be holistic and patient-centred, is likely to identify problems that are not linked to the individual's condition. In response to the trapped nerve, the Coordinator at service two advised the individual to liaise with their GP to resolve the problem. In response to the individual's house being demolished, the Coordinator at service one attempted to investigate the situation further. Unfortunately the service user passed away, which ended the team's involvement in their care.

The identification of non-stroke related problems demonstrated the complexity involved in meeting service users' needs. All problems whether they have resulted from stroke or not, are likely to have some impact on the individuals health (in its broadest definition, see chapter one). However, one service might not be equipped to address every problem or need experienced by a service user, and this has been indicated in previous research findings (McKevitt and Wolfe., 2000).   The Coordinators who work at 'street level' have to manage these day-to-day eventualities and adapt their practice as necessary. This finding is common in policy research where national guidance cannot address the individual situations that are the policies endpoint (Bergen and While, 2005, Blackmore, 2001) Both services

limited the boundaries of the Coordinator role, which reflects an attempt to resolve this issue. However, these eventualities have the potential to impact on the outcomes measured in the LoTS care trial.

7.10.2 Service responses and the manual's recommendations

The majority of the service responses employed were in line with the recommendations in the LoTS care manual. For example, problem three in table 20 queried whether the individual was using the correct bathing equipment. The Coordinator documented the response as 'refer to contact centre' (social services). They were advised to do this by the team's occupational therapist (S1OT2), and this was in line with the recommendations in the manual. Problem seven in table 21 was diminished confidence in driving. The algorithm in reference guide 10 'Driving and general transport', focused on the steps necessary to restore the individuals driving license (see appendix viii). Observation of the assessment revealed that the service user had been given permission to drive post-stroke. The Coordinator addressed the problem by providing information about a regional driving centre that would assess the individual's capabilities, provide reassurance and hopefully restore their confidence. Although the LoTS care manual was not referred to, this action was supported by the educational text it provided. Problems six and seven in table 20 and problem four in table 21 related to mobility and falls. All problems were addressed with a referral to the team physiotherapists. This action was in line with the manual's recommendation; however the educational text further stated:

Reference Guide 5: Your role as Stroke Care Co-ordinator will be to encourage patients to practice tasks which they have been taught relating to moving, walking, transferring and using the stairs and to monitor their progress, liaising with and referring back to physiotherapy as required.

This extract emphasises that there was an expectation that the Coordinator would have more involvement with the service user in the resolution of their problems. However, this level of involvement was not provided in the context of service one or

service two due to the boundaries of the role described. Therefore, even if the Coordinator referred to the LoTS care manual they would not be able to implement all its recommendations. This point was also demonstrated in problem 8 in table 21, which related to mood. The algorithm for mood recommended reviewing the service user within two weeks of identification of the problem. The Coordinator noted that psychological input had been declined and this problem was to be monitored. In the context of service two, this meant that a Coordinator would review the problem at the individuals following review i.e. not within two weeks.

Further discrepancies between the Coordinators practice and the manual's recommendation concerned referring to a falls team or a falls specialist. This response might have been appropriate for problem 4 in table 21; however in the context of service two the Coordinators were unable to refer to the falls team (who shared the same building as the stroke team) until the individual was one year post-stroke i.e. the eligibility criteria of local services impacted on the implementation of the manual's recommendations. In this situation the individual declined the intervention, as they did not feel they could commit to three physiotherapists appointments per week. This example further emphasises the difficulties of addressing the problems of each service user i.e. the service user can refuse the intervention leaving the problem unresolved, despite being identified and addressed by the Coordinator.

The care plans selected as examples provided insight into how the service responses deviated or adhered to the manual's recommendations. Examining these particular care plans was of interest, as the manual had not directly informed their development. However, they revealed that most service responses were in line with the recommendations although to a limited extent e.g. the action was as expected but the longer-term management of the problem was not. This finding emphasises that those who had read the manual considered its content useful, but the ability to enhance service practice was limited by the boundaries of the role and local service availability.

7.11 Refined Context, Mechanism, Outcome proposition

The starting CMO proposition was that the LoTS care manual would inform the Coordinators practice leading to the use of evidence based or recommended service responses and that this would reflect an enhancement in service practice. This proposition was expected to hold true in contexts where Coordinators were new to the role and in areas outside their professional expertise. However, the majority of Coordinators reported that they did not refer to the manual as a source of support. The reasons for this varied, some Coordinators had established knowledge through experience, which enabled them to address the problems they identified. Working within a multidisciplinary team also played a large role; discussion with colleagues at team meetings and informally within their shared office was a simple and easy way to access context specific information i.e. information applicable within the boundaries of their role. Information shared through these channels facilitated an informal learning process enabling Coordinators to address areas outside their expertise. Context specific information provided by team colleagues was prioritised over the nationally applicable information contained within the LoTS care manual. Therefore its recommendations did not directly inform the majority of the Coordinators' practice and consequently did not directly enhance their service responses. However, in specific contexts the LoTS care manual was referred to, but this did not always result in the output anticipated. Figure 15 below depicts the CMO configurations identified during fieldwork that refined the starting proposition.

Figure 15: Refined CMOC: Informing the Coordinators' practice
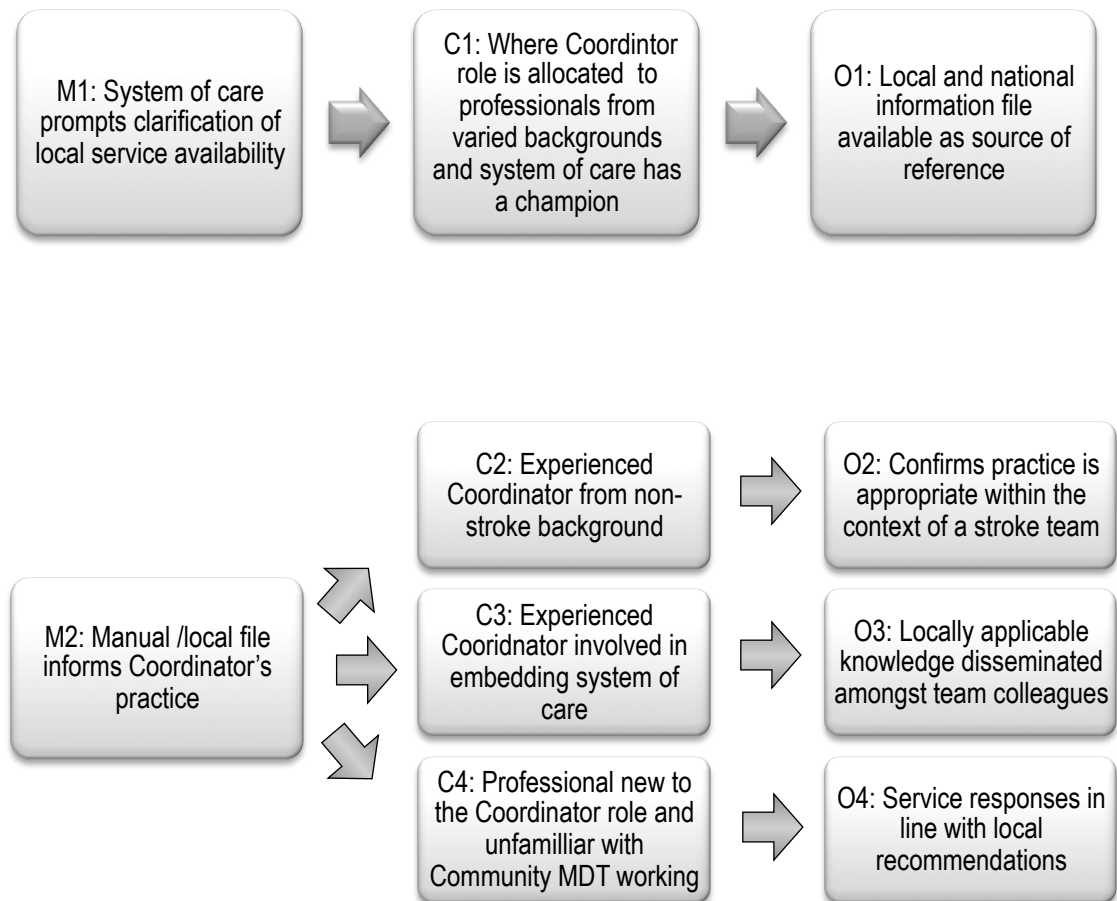
Figure 15 depicts how and why the LoTS care manual was used and the outputs that were realised in practice. At the service level, the initial response to the manual at service one was to develop a local information file as a complementary tool (discussed in chapter five). One Coordinator had taken responsibility for assimilating the information relevant in the context of their service to develop this tool. They explained that this was undertaken to support professionals from varied backgrounds who were allocated the Coordinator role of in the context of their team. Therefore there were two sources of support available to the Coordinators in the context of service one (although these were not routinely used).

At the individual level, an interesting finding was that experienced Coordinators had used the LoTS care manual to inform their practice. One reason postulated for this was that they had come from a non-stroke background and wanted to clarify that that their service responses were appropriate in stroke care. In this context the manual confirmed that their service responses were in line with recommended pathways, rather than changing or enhancing their practice. One Coordinator who was a) new to the Coordinator role, b) aware of the content and purpose of the manual and local file, and 3) adjusting to working in the community team, described that they had used the LoTS care manual to inform their practice (when new to the team) and that this information was applied in practice. In this context the manual worked as intended. However, the impact of this was mediated by the boundaries of the Coordinator role (established by their service) and local service availability. These factors meant that on the rare occasions when the LoTS care manual was referred to, most service responses were a continuation of previous practice rather than a change or enhancement.

7.12 Implications for theory of change

One purpose of the LoTS care manual was to bring service responses in line with the evidence base or expert opinion, as an enhancement in service practice. However, fieldwork revealed that most Coordinators were not informed directly by its content; therefore it did not have the opportunity to enhance their practice. Those who did refer to the manual stated it confirmed rather than changed their service responses. In the instance where the manual was used as intended, the Coordinator's service responses remained within the boundaries of the role and local service availability. The intermediate output realised in practice, therefore, was that the Coordinators documented a care plan that was appropriate in the context of their service and the teams had intended to provide this prior to the system of care. Further to this, the care plans reviewed revealed that addressing service user needs was a complex process e.g. problems were not always related to the stroke incident, and service users could refuse treatment. The Coordinators managed these eventualities in their day-to-day practice, but they signify the limitations of the LoTS care manual to address all problems experienced by the service users.

The findings presented in this chapter raise questions as to whether the outcomes measured (GHQ-12, FAI, BI) in the LoTS care trial would be sensitive to the changes (or lack of) introduced by the LoTS care manual. Multidisciplinary teams in the control group are likely to have similar processes for sharing knowledge and addressing multifaceted problems, therefore it is likely that their service responses would also be appropriate in the context of their service, as in the two research sites. Ellis (2008) suggested that service utilisation might be a better measure of the Stroke Liaison Worker, a role similar to that of the Stroke Care Coordinator. Looking at service utilisation might better capture the linking and signposting activities that the Coordinators described as the remit of their role.

7.13 Summary

This chapter examined whether the LoTS care manual promoted the use of evidence based service responses. The particular contexts in which this was expected to work were explored further. However, a number of factors appeared to limit its impact, a) the boundaries of the Coordinator role were to perform actions as opposed to providing ongoing monitoring activities, b) many Coordinators had knowledge developed through direct experience of how to address the problems they identified and, c) context specific knowledge was valued most by the Coordinators, and their preference was to liaise with a colleague or professional in the local area to obtain new knowledge i.e. the Coordinators did not perceive many benefits from referring to the LoTS care manual. The manual was used in some circumstances, but this did not necessarily reflect an enhancement in service practice. The implication was that the service responses employed by the Coordinator were usually a continuation of previous practice. It is possible that the LoTS care assessment structure had most impact on service delivery, as it was stipulated that this structure must be completed as part of the intervention group. The next chapter, therefore, explores the extent to which the assessment structure enhanced the Coordinators' practice.

Chapter 8: Completing a comprehensive assessment

8.1 Introduction

The LoTS care assessment booklet was the only mandatory component of the system of care. One purpose of the tool was to enable a comprehensive post-stroke assessment to be completed. However, the ability of the assessment structure to introduce this, as an improvement in service practice, was partly dependent on the scope of the areas and the adequacy of the questions provided in the tools that it replaced. The findings presented in Chapter five indicated that both services used a structured and holistic approach to identify post-stroke problems prior to the system of care. Considering the service context, this chapter examines the influence of the stroke specific structure on the assessments performed by the Coordinators. The CMO proposition prioritised for investigation in chapter four is clarified. The influence of the assessment structure is then explored in four stages, 1) identifying whether a comprehensive post-stroke assessment was documented as completed, 2) examining the type of problems identified at each service, and 3) unearthing how and to what extent the stroke specific structure enhanced the assessments performed. The data collected was used to refine the starting CMO proposition through a better understanding of what had worked, for whom, how and in what circumstances.

8.2 Enabling a comprehensive assessment

One intention of the system of care was to promote a comprehensive post-stroke assessment. If realised this output would enhance service delivery in sites randomised to the intervention arm of the LoTS care trial. The system of care offered a stroke specific assessment structure, which targeted problems across functional, emotional, social, psychological and clinical domains in order to achieve this aim. It was hypothesised that this structure would inform the Coordinators of the areas that needed addressing post-stroke extending the scope of their assessment (see figure 16 below).

Figure 16: CMO proposition: Enabling a comprehensive post-stroke assessment
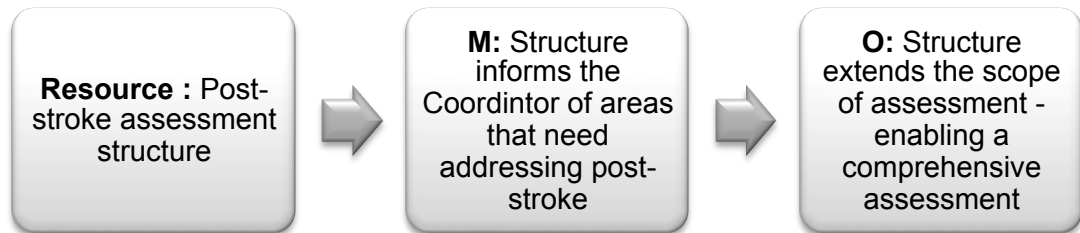
According to the LoTS care team this proposition would be realised in contexts where non-stroke specific or ad-hoc assessment tools were used, and where the professional acting as Coordinator was essentially 'rebadged' without receiving training or guidance to perform the role. The two research sites allowed exploration of these propositions, as both services had used generic elderly tools prior to implementing the system of care, and the professionals performing the role of Coordinator came from varied backgrounds.

Chapter five established that service one and service two used tools from the Single Assessment Process to identify post-stroke problems, and that there was much overlap in the scope of these tools with the LoTS care assessment structure. The novel domains introduced by the system of care were 'Transfer of care', 'Communication and information' and 'Sexual function'. 'Driving and general transport' was also introduced at service one (see chapter five for further details). Therefore, at the service level the system of care extended the scope of the assessment by up to four domains. This chapter focused on how the stroke specific structure enhanced the assessments performed at the individual level of Coordinator. Criteria had been established by the LoTS care team to assess the extent to which Coordinators adhered to the principle, 'ask all questions'. These criteria were applied to the assessment booklets reviewed in this study, and revealed whether a comprehensive assessment was documented as completed.

8.3   'Ask all questions': Documenting a comprehensive assessment

The domains in the LoTS care assessment booklet provided questions with tick boxes to indicate whether there was a) no need and no further action, b) a need to be addressed in the care plan, c) a need that had already been addressed, or d) other (see appendix iii for example). The LoTS care team considered a domain addressed if at least one box was ticked, or if the written notes demonstrated that the area had been discussed. The LoTS care team were satisfied that the intervention had been adhered to if 12 of the 16 domains were documented as addressed in the initial contact (the first assessment). Using these criteria the assessment booklets reviewed as part of the LoTS care trial revealed that 92.6% of the assessments performed by the Coordinators at service one, and 100% performed by the Coordinators at service two adhered to the study protocol. This adherence rate was reflected in the assessment booklets reviewed in this study, which revealed that there was 100% adherence at both sites.

Looking purely at this data suggested that a comprehensive post-stroke assessment was completed for the majority of service users i.e. the output anticipated was realised in practice. However, observations of the assessment process revealed the complex nature of problem identification. For example, Coordinators did not discuss sexual function consistently with all service users despite it being documented as addressed; this is discussed further in section 8.6. The assessment process was sometimes hindered by communication barriers e.g. an Asian lady assessed at service two had limited use of English. It was difficult to establish from the observation whether they had understood and reported all problems pertinent to them, although the Coordinator was confident that they had identified the relevant problems. Later the same day the patient's daughter (not present during the assessment) contacted the service to speak to the Coordinator and this provided an opportunity to confirm their findings from the assessment. This type of eventuality means that problem identification is reliant on more than discussing the relevant domains; other barriers to problem identification are discussed in section 8.11. The types of problems that were identified using the stroke specific structure during fieldwork are examined in more detail below.

8.4   Problems identified using the LoTS care structure

Twenty-six assessment booklets were reviewed in total across both services (fourteen from service one and twelve from service two). In total 107 problems were documented in the Coordinators' care plans. A problem could link to more than one domain, for example, a problem with pain (domain 4) might also impact on the individual's mood (domain 14). Therefore, the 107 problems linked to 217 domains. Figure 17 below depicts the frequency with which problems were categorised in each domain.

Figure 17: Types of problems identified

S1: Service one S2: Service two AX: Assessment	1: Transfer of care 2: Communication and information 3: Medicines and general health, 4: Pain, 5: Mobility and falls 6: Personal Hygiene and Dressing 7: Shopping and Meal preparation 8: House and home	9: Cognition 10: Driving and general transport 11: Finance and benefits 12: Continence 13: Sexual functioning 14: Patient Mood 15: Patient social needs 16: Other

Figure 17 demonstrates that problems were documented in all domains, with the exception of continence (domain 12) at service one, transfer of care (domain 1) at service two, and sexual function (domain 13) at both services. Therefore a range of

problems were identified that extend beyond the remit of the multidisciplinary team e.g. finance and benefits (domain 11), and in the novel domains introduced by the LoTS care structure (with the exception of sexual function). Figure 17 enabled some comparisons to be drawn between the two services in the types of problems frequently identified and addressed.

8.5   Problems frequently identified

The majority of problems identified (n=32) were categorised as 'Medicines and General Health' (domain 3). Twenty-eight problems were identified at service two; however, this data was taken from three reviews. Data from the initial assessment might be more comparable to that of service one where only one assessment was performed. Thirteen problems were identified in this domain at the initial assessment at service two compared to four at service one. This difference might be attributed to the type of role provided. At service two specialist nursing was provided at each review, as part of standard practice e.g. management of risk factors. These types of problems were documented in the care plan and usually categorised as domain 3, for example, high blood pressure was often noted as a problem. In comparison to service two, at service one the Coordinators did not routinely measure blood pressure during their assessment.   This finding indicates that the problems documented in the care plan reflected the context in which the Coordinator worked.

At service one, the majority of problems identified (n=14) related to Mobility and Falls (domain 5). Twelve problems were identified in this domain at service two, but only four were identified at the initial assessment. An explanation that might account for this finding is that at service two individuals who required ongoing rehabilitation on discharge from hospital were often linked directly to the community therapists by hospital staff. Therefore problems with mobility and falls (usually addressed by the physiotherapists and occupational therapists) were more likely to be addressed when the initial assessment was performed.   In comparison to service two, at service one stroke survivors received community rehabilitation after the stroke team had accepted their referral and the LoTS care assessment had been performed i.e. all referrals to the team therapists (including physiotherapist and occupational therapists) were documented in the care plan. This highlights how the development

of an integrated stroke care pathway at service two, might have impacted on the types of problems frequently identified and addressed by the Coordinators using the system of care.

8.6   Discussing sexual function

Sexual function (domain 13) was a novel area introduced to the Coordinators routine practice with the LoTS care assessment structure. However, it was also the only domain in which no problems were documented at either service. Observation of the assessment process indicated that this domain was not always discussed, but was usually documented as addressed by the Coordinator. For example, one assessment observed was of an elderly lady whose husband had died five years previously. She was currently single and residing in a residential home awaiting allocation of a warden controlled flat. The Coordinator did not discuss sexual function during the assessment, but documented the domain as addressed (no need) based on their conversation with the individual. Many Coordinators discussed using their judgment in this area e.g. S1SALT1 commented: '*if they look like they're elderly and they live on their own I probably wouldn't ask it*, and another (S1OT2) also explained:

S1OT2: One that I think, and the others have probably said that they struggle with, is the sexual function question and sometimes we think it's not appropriate to address with certain types of people, like [service user] *had said that his wife was in a nursing home so I don't think I dealt with that issue with him because it was just not appropriate really but all the others are basically consistent.*

Sexual function was the only domain that the Coordinator reported 'struggling' to address consistently. In the example provided its discussion was avoided as the individual's partner was in a nursing home. However the domain was documented as addressed i.e. that no problem was experienced. A Coordinator at service two (S2GW) often documented N/A (not applicable) in the domain. They explained that this meant that the area had been addressed at the previous assessment, therefore

did not need discussion at their review. Observations of this Coordinators assessments revealed that sexual function was not discussed with any of their service users. However, this does not account for the fact that some post-stroke problems emerge over time, therefore these areas need reviewing at appropriate intervals. Without discussion of this area the assessment could be reduced to an administrative task of ticking boxes, rather than a comprehensive process of problem identification.

Informal discussion with the Coordinators revealed that they considered sexual function an important area to address, however it was still avoided on occasions. This type of behaviour is not unusual e.g. the findings from a study of health care professionals who addressed the needs of women with gynaecological cancer, found that the professionals struggled to discuss sexual function as a potential problem of the condition (Stead et al., 2003). This finding was also apparent in studies involving Cardiologists and GPs caring for the elderly population (Nicolai et al., 2013, Gott et al., 2004). Reasons for avoidance included the fact that professionals did not feel they had the knowledge or skills to do address the area confidently, and that they made assumptions about the needs of the service user based on their age (Nicolai et al., 2013, Stead et al., 2003). Only one Coordinator in this study (S2SN) described that they routinely discussed sexual function with service users:

S2SN: I've learnt from experience that by just looking at someone you can't tell...and it's one of the things that they come out with so, yeah, you've got to get over your fear, because it is your fears and I'll always say 'if you don't, I'm going to ask you a question, if you don't feel comfortable to answer it you don't have to', so it gives them the option before I start.

The Coordinator explained that avoidance of sexual function stemmed from the professionals' fear, which they needed to overcome as part of their role as Coordinator – they had learnt to do this through experience and consequently addressed the area as part of the routine assessment process. Observations of this

Coordinators assessment supported this, as they discussed sexual function with all service users, however, no problems were reported. In the context of service one, some Coordinators reported that if avoided at the initial assessment, the area could be revisited at a later date, e.g. one Coordinator (S1PT1) explained:

S1SN: *If I'm going into someone's house and meeting them for the first time they don't know what I'm like, they don't know how I'm going to react to things and you need to build that confidence up before you get to the bottom of everything, but I do think it's very good and it guides you along that path, but like I say really people aren't always going to feel ready to give you all their information themselves on that first visit*

The structure can inform, remind or prompt the Coordinator to address the relevant domains, and this had promoted the consideration of a new and sensitive subject. However, establishing whether a problem was experienced was reliant on more than asking the appropriate question. The Coordinator felt that the service user might not want to reveal such a sensitive problem during the initial assessment, and this assumption prompted avoidance of the domain. However, it was believed that the information could be obtained and possibly more accurately, as the Coordinator continued to visit the service user over a prolonged period of time. Another Coordinator (S1PT1) at service one reiterated this point:

S1PT1: *I think there's an issue with sexual function question whether that's appropriate on your first visit with people. It's clearly quite a sensitive topic and there you are a person that they don't know, delving into things that are quite personal for them. I think some people do feel embarrassed and to be honest I gage the situation as to whether I'm going to ask it the first time, or whether I'm going to get to know them and their personal situation a bit better*

The Coordinator indicates that the development of a relationship over time can provide a more appropriate context to discuss sexual function. In the context of service one this was achieved as a therapist or nurse. Therefore if sexual function was avoided at the initial assessment, the professional had to remember to address the area when visiting as a specialist, or ask a team colleague if they did not provide further intervention. Ascertaining whether this took place during fieldwork was problematic, as observations of specialist visits were not performed and in most assessments performed the domain was addressed as 'no problem' i.e. that no further action was required.

The system of care extended the scope of the assessment tool used to guide problem identification. However, the addition of the domain 'Sexual function' highlights the limitations of the structure. Identification of sensitive problems requires the Coordinator to confidently address the area, and the service user to reveal their problem (if one exists) to the professional. The Coordinators reported that there are potential barriers from both parties in achieving this. This finding suggested that the Coordinators might benefit from further training in problem identification in this sensitive domain that was outside the remit of the team specialists. A need for further training of health care professionals was also identified in the previous studies in this area (Gott et al., 2004, Berman et al., 2003, Nicolai et al., 2013).

Examination of the care plans revealed that a comprehensive assessment was documented as completed in the majority of cases. Further to this, the Coordinators identified problems in a range of assessment domains. However, although documented as complete, the structure also prompted avoidance of 'Sexual function' in certain circumstances. Therefore documenting a comprehensive assessment does not necessarily mean that all areas were discussed with the service user. This finding highlighted some of the limits of the structure in enhancing service practice. The next point of inquiry focused on the improvements reported by the Coordinators when implementing a stroke specific assessment.

8.7   Streamlining the assessment process

Chapter five established that the Easy-Care and the Overview assessment were used by service one and service two respectively to perform a holistic assessment. For this reason, it was assumed that Coordinators, who had assessed individuals using these tools, were aware of the majority of assessment domains included in the new structure. However, these professionals were able to reflect upon the changes that they felt had been introduced. At service one a Coordinator (S1OT1) commented:

S1OT1: *It's* [LoTS care] *a better structure and I don't think it's that we necessarily missed it* [post-stroke problems], *but it didn't all used to come out at the same time as you get everything together, and you would get everything together with Easy-Care, but with Easy-Care you get a lot of things that weren't relevant. 'Are you happy with your house?' I mean what sort of a question was that? And the other thing is if, 'well no, I really don't like my wallpaper,' as a Stroke Care Coordinator what am I going to do about that? You need to ring a painter decorator, you don't need someone who's a healthcare worker to come and tell you that, do you? So I think it asks questions that you can do something about and that was the thing that was frustrating about Easy-Care you still had to ask.*

The Coordinator explained that post-stroke problems were not necessarily missed using the Easy-Care assessment tool, but that some questions included in its structure were not applicable as part of a post-stroke assessment (e.g. are you happy with your house?). Table 22 below depicts the section in which the question 'are you happy with your house' is categorised in Easy-Care (Accommodation and Finance), and compares this with how the LoTS care assessment prompts discussion of the same area.

Table 22: Comparison with Easy-Care: Accommodation and Finance

Tool	Section	Questions and prompts
Easy-Care	Your accommodation and finance	In general, are you happy with your accommodation? In the last year have you had difficulty keeping your house warm? Do you have concerns about the size and space of your home? Do you have concerns about the condition of your accommodation? Do you have concerns about the location of your home? Do you have concerns about the cost of your home? Are you able to manage your money and financial affairs? Would you like advice about financial allowances or benefits?
LoTS Care	House and Home	Can you do your housework? Does anyone help you with your housework? Do you have any problems with accommodation?

The domain in Easy-Care contains more questions, but most do not prompt the discussion of problems that manifest as a result of stroke. For example, Easy-Care asks about the size, condition and location of the individual's home. In comparison the LoTS care assessment focuses on how the individual is managing household tasks. These questions were considered more appropriate as they discuss problems that are known to result from stroke. However, it is important to note that Easy-Care also prompts discussion of household tasks in the domain 'Looking After Yourself' (see appendix ix). The questions listed above were additional, and the Coordinator commented that the '*frustrating thing*' about the Easy-Care was that '*you still had to ask*'. In this context, therefore, the stroke specific structure worked to streamline the assessment process and another Coordinator (S1SALT1) also commented upon this, for example:

S1SALT1: *Well they* [Easy-Care] *had a question that was like, 'have you been screened for cancer?' Which I don't know how relevant that was, and certainly if they have or haven't been screened for it, it doesn't really contribute to our care really. And there was another question about, 'are you happy with your accommodation?' I think it was, but the way it was worded, it wasn't really promoting, you know, I've got difficulty going up the stairs and things like that, or I've got*

difficulty with the shower and need adaptations. It was more like well
I could do with a bigger house. It was kind of leading into something
that you couldn't do anything about.

Screening for cancer forms part of a generic elderly care assessment, however it is not a problem that results from stroke. Therefore the Easy-Care structure did not '*promote*' discussion of problems that the Coordinator, as a stroke specialist, was there to address. One Coordinator (S1OT1) estimated that 40% of their service users were under 65 years old (the age range targeted by Easy-Care), therefore a large proportion of people might be asked questions that are not applicable to their condition or their age. The LoTS care assessment was designed to focus on the '*problems of central importance*' to stroke survivors. Therefore in the context of service one, the stroke specific structure might have introduced more domains, but also streamlined the assessment by removing areas not related to the stroke experience.

This finding was of interest as it further indicates the complex environment into which the system of care was embedded. The Single Assessment Process had been developed to address gaps in the care management approach (see chapter two) and provide a more holistic and standardised assessment for those aged 65 and older, including individuals with stroke (Department of Health, 2001b). For this reason, the assessment tools developed as part of this process intended to be comprehensive of the problems experienced in the elderly population, and therefore should be addressed with them. Use of the Single Assessment Process was also advocated in the National Stroke Strategy (Department of Health, 2007). For service one, the LoTS care assessment streamlined the assessment process, but this raises questions about whether all problems pertinent to their elderly service users were adequately addressed, and if so did this indicate repetition with a previously performed assessment from another professional group? These questions are beyond the remit of this thesis; however they highlight the complex issues experienced at 'street level' when attempting to address the needs of individuals, who can cross traditional user groups.

At service two the Overview assessment was used by the Coordinators to perform the initial assessment. The Overview had been through an iterative process of review an amendment for use by all health and social care professionals in the local area. The similarity between the Overview and the LoTS care assessment was established in chapter five; one Coordinator (S2GW) further commented: *'I would say 90% of it* [LoTS care and SAP tools] *is sort of crossing over, because there's a lot of duplication in it, because, again, SAP has been tweaked over a fair few years and there's been bits put in and bits taken out. So, again, I think that that's got a lot of information in.'* The Overview was, perhaps, more appropriate than the Easy-Care for the purposes of a post-stroke assessment, however it also included questions that were not directly linked to stroke e.g. the domain of personal safety (see appendix x), when comparing the two tools one Coordinator commented:

S2SN: *The Contact and Overview asks the same questions… But isn't, uh, how can I explain it? The, it's very long-winded the contact and overview, not stroke specific, so the contact and overview is a snapshot only at that specific time. So for the very first assessment the contact and overview is good, but then when you do subsequent visits, so you've got your six month visit, your twelve month visit, your two year visit, three year visit, you've got no structure to your paperwork then because you don't do the contact and overview then.*

The Overview assessment was described as '*long winded*' and '*not stroke specific*', which suggests that some questions were considered superfluous for the purposes of a post-stroke assessment. However, the Coordinator also commented that it '*asked the same questions*' and was '*good'* for the initial assessment. The problem indicated with the assessment documentation used at service two was that the Specialist Nursing assessment was used for every subsequent review.

8.8   Structuring the stroke nurse reviews

The review team described that the Specialist Nursing documentation was more appropriate for use by the district nurses in the local area, as it reflected problems that they managed over a prolonged period of time, such as pressure ulcers. Table 23 below depicts the sections provided in the Specialist Nursing Assessment.

Table 23: Sections of the specialist nursing assessment

SAP Specialist Nursing Assessment
1. Activities of Daily Living
2. Baseline Observations: Pulse, Blood Pressure, Blood Glucose, Respirations, Temperature, Weight
3. Previous Medical History / Current Symptoms
4. Pressure Ulcer Risk Calculator
5. Medication – Current & Changes

It is apparent from this table that the Specialist Nursing assessment does not provide an extensive set of domains to guide a post-stroke assessment e.g. it does not prompt discussion of a number of relevant areas, such as, finance and benefits, mobility, falls and mood. During fieldwork the Coordinators discussed that other specialist nurses in the local area (e.g. who specialise in Chronic Obstructive Pulmonary Disease and Diabetes) had been able to tailor their documentation to the condition they addressed. The community stroke team had not received permission from their service commissioners to do the same with their paperwork at the time of fieldwork, although this was being sought. Participation in the LoTS care trial provided an opportunity to use a tool that targeted stroke problems in advance (see chapter five). The improvements introduced as a result were in the reviews performed using the Specialist Nursing assessment, as one Coordinator commented:

S2LN: *There's not a lot of prompts on the specialist assessment* [specialist nursing assessment] *really so it does mean that if they don't volunteer that information and perhaps you miss it for whatever reason, especially perhaps not on the first visit, on the first visit I have to do Overview but on the second visit, or perhaps when S2GW visits at 12 months you don't have to do the Overview again. So without the Overview, if you weren't to look at the Overview and you just did the specialist, you perhaps wouldn't pick up the same problems because it's not prompting you to ask the questions.*

The Coordinator described that identifying problems after the Overview assessment had been performed relied on service users volunteering information, the Coordinator's knowledge, or their reference to the Overview performed at the initial assessment. The LoTS care assessment booklet provided five 'contacts', each included a new assessment structure and a care plan i.e. provided an appropriate structure to document each stroke review. However, it was suggested that this improvement was beneficial for professionals with less experience than the current review team, as one Coordinator (S2GW) explained:

S2GW: *You've got all the prompt questions there, whether you need them or not, so from a new member of staff's point of view I think the LoTS is an ideal booklet, because I suppose you could say it's idiot-proof really, because all the prompts are there if you need to use them. So you could give someone that booklet and send them out and all the questions what are specific, what we need to know, are there anyway, so it's just a matter of reading through.*

This Coordinator had been in post for six years, therefore, they were experienced in performing the stroke reviews. The stroke specific assessment structure was described as an '*idiot-proof*' guide to the assessment. This remark indicated that the structure would enable professionals with less experience to obtain a similar level of detail as the current review team. For this reason, the improvement introduced through the system of care, in the context of service two, appeared to be the

provision of a structure that adequately documented the areas addressed and this was supported by the Coordinator (S2SN) who was also the team lead:

S2SN: *Before I came in post eighteen months ago this special, the nursing specialist documentation basically wasn't filled in because it didn't address the problems we have with stroke patients, it was just left blank, and basically there'd be a two line assessment, two line evaluation of what the patient's needs are, what, and when I first started I shadowed other staff and I knew they were asking all the pertinent questions but they didn't, there wasn't anywhere to demonstrate they were addressing those issues. So I like the document that it's structured that, we did devise a stroke management plan to use with the nursing specialist document, but basically, this fits all our needs.*

The Coordinator explained that the areas '*pertinent*' to their service users were discussed, but were not documented as such using the Single Assessment Process tools. Whilst awaiting permission from the service commissioners to develop a stroke specific assessment, the Coordinator supplemented the Specialist Nursing documentation with the 'stroke management plan', to which they refer, for use with stroke survivors not participating in the LoTS care trial. The stroke management plan was informed by the LoTS care assessment structure and the recommendations in the National Stroke Strategy. The document provided simple prompts to guide the Coordinators when performing their stroke review. Table 24 below provides an example of the questions used in the stroke management plan.

Table 24: Comparison of the LoTS care, Overview and SMP

Domain	LoTS care	Overview	SMP
Mobility and Falls	Can you get around indoors? Can you get out of your house? How confident are you about carrying out various activities without falling? How do you feel about your recovery so far? Discuss patterns of Physical and emotional recovery	Do you have any difficulty with: Getting around the house? Transferring in / out of bed? Transferring in / out of chair? Getting in / out of property? Getting up / down stairs? Do you use anything to help your mobility inside? Do you use anything to help your mobility outside? Have you had 2 or more falls in the last 6 months?	What difficulties is the patient experiencing with mobility and falls? Is a mobility aid used? Does the patient require assessment for aids? Consider referral to physiotherapy.
Finance and benefits	Do you have difficulty managing your money? Are you able to pay your bills? Are you receiving all the benefits you are entitled to?	Do you currently receive any of the following? Disability living allowance/ Mobility- attendance allowance, if so what level? Do you have difficulty managing finances? Are you dependent on others to manage your finances? Would you like a benefits review?	Has the patient received a financial assessment? Consider a referral to welfare rights
Mood	Have you recently felt very sad or fed up? Have you felt anxious frightened or worried? Do you find it difficult to control your emotions? Discuss as appropriate frustration and irritability Have you been offered or are you have any treatment? Do you have a partner, relative or friend you feel close to? Do you get on well? Can you talk to them about your worries or problems? Discuss feelings of burden.	Do you have difficulty with? Disorientation, feel confused or have any problems with co-ordination? Concentrating or remembering? Anxiety/ distress/ mood changes? Depression/low in mood/sad? Do you rely on others for all your care? Do you rely on others for part of your care? Do you feel socially isolated? Have you experienced a loss or bereavement recently?	Identify patients anxiety and depression levels using HADS tool Consider referral to psychology if indicated

Table 24 demonstrates that the difference between the three tools are the prompts they provide to guide the discussion. For example, the Overview and the LoTS care assessment provide questions to prompt discussion of depression, anxiety and other changes in mood, whilst the stroke management plan refers to the use of the

HADS. As described in chapter five, the HADS was used to monitor changes in service users' mood (anxiety and depression), and to inform referrals to the team psychologists. There are fewer prompts in the stroke management plan, however, the review team clarified that they did not rely on these prompts to identify a problem. Their decision to refer to the team psychologist was based on their discussion with the individual, as well as what was indicated by their HADS score. Observations of the assessment process supported this e.g. one patient discussed that they had problems with their mood post stroke. The Coordinator asked them to complete the HADS, as this helped to inform their referral to the team psychologists. The HADS score did not indicate that a referral was warranted, but the Coordinator reassured the individual that they would refer them based on their discussion. Therefore the assessment structure provided a conversation guide, but problem identification was driven by the Coordinators experience. This finding indicated that the system of care had limited impact on problem identification for professionals experienced in performing the Coordinator role; and this is clarified in the following section.

8.9   Experienced Coordinators

The Coordinators at service two reported that they addressed all of the LoTS care assessment domains as part of their nursing role (see chapter seven). One of their main roles on the review team was to provide the holistic post-stroke assessments and they performed these on a daily basis. In regards to the stroke specific structure one Coordinator (S2SN) commented: '*I think it* [LoTS care] *forms the basis of a holistic assessment, and a holistic assessment covers all those things really, social services and different things, so yeah. I think the document acts as a framework*.' The content of the LoTS care assessment was seen as typical of any holistic assessment, however presented in a stroke specific 'framework'. When asked whether the specific prompts had been supportive, the Coordinator explained:

S2SN: I think it's been so used to using the nursing process for so long, so a lot of the things are similar to what's already in the contact. Now if you were just, it's just a nicer structure towards a stroke patient and the prompts… Yeah, are good. I think if you're experienced a lot of

it's there but it doesn't hurt to have a prompt because you don't know who's going to fill in this document in, whether it's the most junior nurse or someone who was very experienced so you need to have that document what fits all really.

The Coordinator indicates that, as a holistic assessment, the LoTS care structure was similar to the 'contact assessment' (initial Overview assessment), which they had used in the local area for a long time. They confirmed that: '*those are things that we were discussing anyway*' when clarifying if the LoTS care structure had introduced any new areas to their assessment. In terms of supporting problem identification in areas outside their professional remit, another Coordinator (S2LN) noted:

S2LN: *I suppose I've got a lot of experience so it wouldn't really faze me asking any of the questions. That a lot of them are covered in the past by SAP, in the past before that by other things, by the fact that a lot of them are general… well what I would call basic nursing questions really, nursing stuff like personal care and, you know, social things. I suppose intermediate care has given me a good background to look at social things, rather than just focusing on health.*

The Coordinator explained that they were experienced in addressing a range of problem areas, as part of their role in an intermediate care before joining the stroke team. For this reason they were not fazed by the stroke specific structure, as these are the areas they had addressed using the Overview assessment and in previous roles. The Coordinators comments reiterated that the improvements introduced to their assessment was in the accurate documentation of the stroke review. In reality it is hard to discern how problem identification differed for the Coordinators when using different assessment tools. It would have been interesting to observe assessments in which the Coordinators used the Overview or the Nursing assessment to identify problems, in order to make some comparisons. However, this study focused on the implementation of the system of care, therefore patients assessed from hospitals not recruiting to the LoTS care trial i.e. those assessed

using the Overview assessment were not observed. What was noted during the assessments was that the Coordinators did not rely of the specific questions provided in the LoTS care assessment to discuss the problem areas. They appeared comfortable discussing the areas in conversation and, like the Coordinator indicated (S2SN), used the assessment structure as a framework to guide the conversation. This impact of the assessment structure was clarified during respondent validation; see Box 9 below for discussion.

Box 9: Service two: Using a stroke specific assessment structure

Researcher: Do you think that you personally, when using the LoTS Care, that you've identified more problems compared to if you're using the single assessment process tool?

S2SN: I think I've documented more problems because the paperwork made it easy to do that. I think when we were using the contacts and overview we discussed and identified problems but the documentation… so if we said to someone 'Oh, I think you should go and see a chiropodist', well you've said it but we wouldn't have documented it because it would have meant writing reams to say 'Go and see a chiropodist', whereas now we can say that they've got problems with their feet and we've put 'advised to see a chiropodist', it's simple to do. So yes, we do do more problems because it's easier to do so. Not easy, it's easy to document it. So the problems aren't new problems, but you document it better.

S2GW: I wouldn't like to think, me personally, that the LoTS document has made me do my job any different than I would have done previously. I wouldn't hope that it has, but like S2SN said, quite rightly, it gives you the opportunity to just make a quick reference to it instead of writing reams and reams on something else.

Researcher: It's just interesting because that's one of the things I was trying to look at really, because obviously in terms of introducing something that's an improvement in terms of patient outcomes, it can only be an improvement if what you were doing before didn't capture those things.

S2GW: Yeah.

Researcher: Whereas, from what we've discussed, it's just the way you document it.

S2GW: That's right, yeah, and I think that's what it's all about, documentation, because I think the documentation, especially in our team, has got far better. When you think of documentation a couple of years ago it was quite basic and there wasn't a lot of information there, whereas now you've got what you need.

S2SN: Yeah, I think the documentation, because I've been in the post two and a half years, and when I came into the post I was appalled by the documentation, it was appalling. If we'd have had to go to court we would have been torn to shreds. Now I can go with the documentation and know that our documents stand up to it.

The discussion highlights that the Coordinators recognised that there were deficiencies in their documentation. Steps had been taken to improve the service and the LoTS care assessment structure marked another step in this journey. The improvement described was that the content of the stroke review was now accurately recorded, providing evidence of their role. It was suggested that this was useful in the 'court of law' i.e. the record provided protection from litigation if needed. The use of the assessment structure in this way is similar to findings from a study on protocol-base care, which found that nurses with extended roles followed protocols for this purpose (Malone et al., 2003). However, this reflects an enhancement for the professional rather than the service user assuming that the same problem areas were discussed previously.

It was anticipated that the stroke specific structure would inform the assessment process, extending the scope of the Coordinators' assessment. In the context of service two the system of care introduced three novel domains to the assessment. However, the Coordinators' continued to use the Single Assessment Process alongside the system of care, and reported that there was little difference between the two in terms of problem identification. In reality this would be hard to discern, as both tools would exert influence over their practice. However the point made by one Coordinator: '*I wouldn't like to think, me personally, that the LoTS document has made me do my job any different than I would have done previously*' is revealing. It highlights that a new structure does not necessarily change the professionals approach to the assessment, and this was further emphasised as sexual function (a novel domain introduced) was avoided at the practitioner level. In the opinion of the review team the stroke specific structure provided a better guide to document the stroke reviews, but they did not feel that this enhanced problem identification for the service user. The context of service one allowed the impact of the assessment structure to be explored further with Coordinators from a more varied background.

8.10 Addressing gaps in knowledge

Table 19 in chapter seven indicated the domains that the Coordinators addressed as a therapist or nurse. In the context of service one this varied substantially. The largest overlap was with the occupational therapists who addressed nine domains

and the least was with the speech and language therapists who addressed problems in one domain. It was anticipated that the stroke specific assessment structure would inform the Coordinators' practice enabling them to complete a comprehensive post-stroke assessment. However some Coordinators had addressed areas outside their expertise whilst performing the MDT assessment on the stroke team, or in their previous role. This affected the impact of the stroke specific structure e.g. one Coordinator (S1PT1) had joined the service from a community neuro-rehabilitation team where they had undertaken a 'key worker' role. Observations of the LoTS care assessment performed by this Coordinator revealed that they discussed all areas with the service user with the exception of 'transfer of care', as the individual had been residing in the community for many months. The Coordinator identified 4 problems, 3 of which were outside their specialist remit (increased weight, low mood and problems with their wheel chair). In regards to problem identification they commented:

S1PT1: *I think LoTS care has helped me* [identify problems outside physiotherapy] *do that in this area, in terms of stroke care, because I am fairly new to the team so yeah it's given me some structure to hang things on if you like, and the prompts certainly do help to do some probing but I don't know. I feel that some of that coordinating role I've used in previous jobs as one of the things I did in my last job was that we did a key worker role and it was very much like a care coordinator.*

The Coordinator explained that as a key worker the assessment areas they considered overlapped with those addressed as a Coordinator. Their previous assessment had considered barriers to 'social participation' and they noted: '*that is what you're looking at in the LoTS care; looking at the medical areas, looking at mobility, looking at activities of daily living, looking at mood, looking at social aspects you know and other parts of function, you know those areas make up a person's ability to participate socially*'. As part of respondent validation the Coordinator clarified that their knowledge of problem areas had been established in their previous role, but noted on their feedback form that: '*The LoTS provided a good structure/basis to follow in conducting an initial interview and then the subsequent flow charts in the manual are a good cross reference tool, especially if you are less*

experienced and if you do not have access to an MDT' i.e. the assessment domains did not inform them of new areas, but ensured that the relevant domains were addressed in their new role on the stroke team. They also indicated that the manual was useful as a cross-reference tool particularly for professionals with less experience or who worked alone. One Coordinator (S1SN) who had used Easy-Care to perform the assessment, but still felt new to the community role when initially implementing the system of care noted:

S1SN *It [the LoTS care assessment structure] has tended to highlight the areas that you do take for granted so I think continence is one of the really good ones, as you tend to assume if someone's physically quite well after the stroke they won't be incontinent and that question can easily get missed, and I think the good thing about LoTS care is that it kind of draws you and makes you ask those things. You can't assume then which is quite good and I'm probably guilty of that a little bit. When you see someone's physically quite well and independently mobile you kind of assume that they haven't got a problem but that's not always the case*

The Coordinator was aware that problems with continence could result from stroke, but did not address this area consistently using the Easy-Care assessment. The Coordinator described that in comparison to Easy-Care the stroke specific structure '*draws*' the assessor to discuss each domain, regardless of the service user's physical capabilities. Evidence to support this comment was found in the assessment booklets documented by this Coordinator e.g. one service user had no problems documented with continence in their care plan. However, the Coordinator had noted in the assessment section that there was occasional faecal incontinence, which was a side effect of the service user's medication and that the service user was managing this problem themselves i.e. the area had been thoroughly addressed. The Coordinator stated that they no longer paid '*lip service*' to any of the areas and commented: '*I think it* [LoTS care structure] *gave you the ability to focus on each single thing rather than just covering everything broadly and kind of the questions that I should have been asking but I wasn't before if I'm honest'*. Chapter seven also revealed that the manual had informed this Coordinator when assessing

areas not routinely addressed in the hospital environment, such as cognition. In this context i.e. where the Coordinator avoided domains using a generic elderly tool, and were new to the role on implementing the system of care, the stroke specific structure prompted a more consistent discussion of each domain. Other Coordinators also described that the structure informed their assessment, e.g. one (S1OT2) explained:

S1OT2: *The OT role covers the majority of aspects within our individual assessments, but yeah it* [LoTS care] *does help to think about slightly other things. Like I wouldn't necessarily think about particular medications, I'd think about how it was taken, but not about particular medications, and taking blood pressure and that side of things. So it does help to be kind of more of a Coordinator.*

The Coordinator commented that their specialist role was '*generic'* and '*holistic'*. For this reason they were familiar with many of the assessment domains (see table 19 for specific areas addressed by the occupational therapists). However, the structure prompted them to consider problem areas not usually addressed as an Occupational therapist. They provide medication as an example; the therapist would discuss how medication was taken, but not which medications or why (which falls within the remit of nurses). Therefore the prompts in the assessment domain extended the scope of their assessment and supported them to act as '*more of a Coordinator'*. Another Coordinator (S1PT2) at service one also reported this finding:

S1PT2: '*Definitely initially* [informs the assessment] *because when you come into this service, well for me coming into a community team, I'd worked on multidisciplinary teams before but when someone's in in-patient rehab or hospital you don't go in and do such a holistic assessment because everyone tends to do their own assessments and then you discuss them in a meeting […] Whereas when you go out and do that MDT assessment* [LoTS care assessment] *you are the first port of call and you have to find out if they are having issues in that area. So it's good to be able to see the patient in a more*

*holistic way, especially that's important in the community as you
don't have the other services in the next office'*

This Coordinator came from a hospital background where they were required to perform a uni-disciplinary assessment only. For this reason, the LoTS care structure prompted them to consider areas that they had not previously addressed. Cognition was provided as an example during an informal discussion; the structure prompted them to discuss this area and to discern whether it affected the individual's memory or concentration i.e. it enabled them to accurately identify problems outside their professional remit. Whilst this demonstrates that the structure addressed their gaps in knowledge as intended, the Coordinator explained that they would be expected to perform a holistic assessment as part of their new role, regardless of what structure was used. Further to this, they did not feel that the LoTS care structure alone was sufficient as a guide. As part of respondent validation they noted that: '*There were gaps in the LoTS assessment, so the LoTS alone did not provide enough information to inform and prompt me for the full holistic perspective*.' The gaps, to which the Coordinator refers, were discussed in chapter five and relate to the absence of speech, language and swallowing. This discussion reiterated the point that capturing the information required by the team was a priority in the context of service one and was also emphasised by another Coordinator (S1SLT1) who noted:

S1SLT1: *Really in my mind it's* [aim of the assessment] *who to refer to really, but when you've referred to them, the people on the team generally want to know more information than what is asked by these prompts. So predominantly these questions would help me with who to refer to, but because they often ask me more specific questions, which probably they would have asked doing the LoTS themselves in the first place, as it's more their area, then I try and remember to get some of that information next time, but I don't always remember to, but that's what I try and do.*

This Coordinator explained that the assessment structure prompted referrals to relevant professionals. However their team colleagues also influenced the details

obtained during the assessment. During respondent validation the Coordinators at service one discussed how, as a team, they informed one another of the details that were useful to elicit during the assessment process, see Box 10 below.

Box 10: service one: Discussing the assessment domains

S1PT1: I think if you're comparing someone who is newly qualified doing the LoTS care with your level of experience the questions and the advice would be quite different, and so I do think it is dependent on experience as to what advice is given and how detailed that advice might be

S1SN: I mean I would still now come back to anyone else in the team if I was out my depth

S1PT1: Of course we all do (agreement amongst group)

S1PT2: Just to get more information

S1SN: I think over the years I've just got better at tweaking out the information that that professional might need. When I come back and say Joe Bloggs has got this problem, and you would want answers wouldn't you – 'Well how long's it been?' And I think I've just got better at triggering the background questions really so when I come back and ask for support with something I've got a good picture to tell somebody

S1PT1: I would also imagine that we're better at doing this than the Coordinators because we're a multidisciplinary team. So you gain that experience when we all bring the LoTS back in the MDT assessment and discuss it, and then you've said as the assessor, I think this, and that person who is actually the professional in that area will say 'oh yeah I agree with that', so then you're gaining knowledge, so you know if you come up with a patient like that again you will give that advice because it'd been verified by the individual professional

S1SN: or quite often just a different perspective, yes but have you thought of this

S1OT1: And extra questions and other things

S1SN: Yeah if that doesn't work try this, and sometimes when you do bring it back to an MDT you get a wider view of things and much more alternatives than you could manage on your own

S1PT1: And that's when we had that meeting when we sat down and talked about some of the prompts we were all giving in the different areas and we padded that out a little bit more to help people home in on questions that would help them probe a bit better

The discussion emphasised that the detail captured during the assessment and the advice provided was enhanced by the informal learning mechanisms described in chapter seven. The LoTS care structure provided the overarching framework for the assessment, however the professionals who addressed the domains, as a therapist or nurse, clarified what details were useful to obtain during the assessment. This

information was then applied in practice and formed part of the Coordinators tacit knowledge, although they were also formalised in the service checklist described in chapter five. Interestingly one Coordinator commented that they felt that, as a multidisciplinary team, they were perhaps better at performing the Coordinator assessment because of the support received from colleagues. Respondent validation also provided an opportunity to clarify what improvements had been introduced to the assessment process through the new structure; the discussion is presented in Box 11 below.

Box 11: Service one: Influence of a stroke specific assessment structure

> *S1PT2:* it sounds like it has streamlined the assessment though made it easier for new staff, probably easier for speech and language therapist as well who, like you said, probably work more separately from the Physios and the OTs, whereas we often work together
>
> *S1OT1:* and I think another thing as well it identifies it from the beginning, if there's outstanding equipment issues or if a wheelchair was ordered from hospital and never turned up, those soughts of things used to wait till either the OT or the Physio went in, and that might have been at three of four months time at some points, whereas now it's done in that initial screen
>
> *S1SN:* yeah
>
> *S1OT1:* that phone call can be made in the beginning, so by the time the OT is in that equipment is there. So it's made it quicker for patients because it's more streamlined really, from the beginning everyone picks up the same things rather than everyone doing their own bits
>
> *S1SN:* I don't think that's necessarily because of the LoTS though
>
> *S1OT1:* it makes you ask them questions though, before with Easy-care not everything was asked
>
> *S1SN:* I think it's easy to avoid sensitive questions with the Easy-Care
>
> *S1OT1:* and the equipment things was forgot, and just waited

The Coordinators' discussed that the LoTS care assessment structure provided a better guide than the Easy-Care for new staff and those with specific roles when assessing areas outside their professional remit. They also described that the structure had introduced more consistency at the initial assessment, as '*with Easy-Care not everything was asked*' and it was '*easy to avoid sensitive questions*'. As a result, one Coordinator (S1OT1) felt that more problems were addressed earlier in

the rehabilitation process, which indicates an enhancement in service delivery for stroke survivors, assuming they received more timely services.

The influence that the LoTS care assessment structure exerted varied depending on the background and experience of the professionals who performed the Coordinator role. The Coordinators at service two were experienced in performing holistic assessments and this was also one of the main functions or their role. In this context the stroke specific structure was described to evidence, rather than extend the scope of, their assessment. In comparison to service two, at service one the Coordinators came from more varied backgrounds and the LoTS care assessment was not the main focus of their role. In this context the stroke specific structure addressed gaps in professional knowledge and appeared to promote a more consistent coverage of each domain. However, this was mediated by the fact that the professionals were expected to perform a holistic assessment that extended beyond their professional remit regardless of what tool was used and their team colleagues supported them to do this.

8.11 Accurately identifying the pertinent problems

The Coordinators described that on most occasions they discussed each assessment domain with the service user. However, the discussion on sexual function highlighted some limits of the structure. Further to this, the Coordinators also described that there were certain circumstances that complicated the accurate identification of problems. For example, individuals would not always engage in the assessment process (personality linked barriers), or they could not always engage effectively in the assessment process (impairment linked barriers). The patient level was beyond the remit of this thesis; however, the Coordinators discussed many examples of how the assessment was influenced by their interaction with the service user. One Coordinator (S1PT2) described that individuals who were '*high level*' i.e. had recovered quite well might feel that the assessment questions were '*prying'* which meant that they could '*shut down'* and were unwilling to engage in the assessment process. The Coordinator described that in these circumstances they encouraged discussion by explaining to the individual that the assessment domains might not relate to them, but need to be completed as part of a standard post-stroke

assessment. Adapting the approach to the assessment was described as a key attribute in the accurate identification of problems.

A Coordinator at service two (S2SN) noted similar issues, for example, they explained that the assessment could become more '*stilted*' if individuals did not engage in discussion, they commented: '*It can be more, yes, no, but then it's about getting questions, get questions, get patients to open up, so it's a way of questioning then isn't it?*' These examples highlight that the use of a structure needs to be tailored to the person assessed in order to identify and consequently address their problems. In the stroke population this is particularly pertinent, as cognitive and communication problems can result from stroke and manifest as barriers to a successful assessment. One Coordinator (S1PT1) commented that in these situations: '*it is the experience of the interviewer that is able to guide the patient and ask questions in a very directive way rather than very open questions which some people with cognitive difficulties have problems with*.' Another Coordinator (S1OT1) described an interesting example of how they had managed one particularly difficult assessment:

S1OT1: *I went to see a guy who was a new stroke and has quite a lot of speech problems, but he's not been diagnosed with learning difficulties but he has obviously got some learning difficulties, and he was in a warden controlled flat, and when we sent the letter out the warden offered to come with me which was fantastic, as if I'd have said to him, 'are you able to get washed and dressed?' Yeah. Can you cut your nails? Yeah. Do you cut your nails? No,' and he couldn't necessarily follow the questions so it was very much, 'you have carers that come in the morning, tell me what they do for you,' and then he could say, 'help me get dressed, have a bit of a wash,' and she'd fill in the other bits, as if you did it like that you would have just got yes/no answers, and you could ask him, 'have you got any pain anywhere?' and he might have been doubled up in pain and he would have said no as his understanding was so poor. So I suppose for people like that it's really difficult to fill it in, as the warden doesn't know all his history and he can't accurately tell you. So when I came*

back I rang the social worker and went through the referral form
again, the referrer from the hospital and rang his GP to fill in the
other bits.

In this situation insight issues were confounded by possible learning disabilities and the absence of a carer who could provide details about the individual's condition. The Coordinator explained that they adapted their questioning to establish what the individual's capabilities were and used other sources e.g. the individual's warden, their social worker, their referral form and their GP. This enabled the Coordinator to complete the assessment domains as comprehensively and as accurately as possible. These examples have been provided to demonstrate an appropriate structure is only one component of a successful assessment. The data collected was used to refine the initial CMO proposition identified in section 8.2.

8.12 Refined Context, Mechanism, Outcome proposition

The stroke specific assessment structure was developed to extend the scope of the Coordinators assessment to be comprehensive of post-stroke needs. The overall aim was to identify the problems pertinent to each service user in order for them to be addressed. Use of the assessment booklet was mandatory and it was quickly established that the Coordinators used it in routine practice. However, both services had attempted to identify post-stroke problems using a holistic and structured approach prior to the system of care. At the service level, the LoTS care structure extended the scope of the assessment tool by up to four domains. The Coordinators reported that the new structure streamlined the assessment process, removing non-stroke related domains, and that it evidenced the Coordinator role in the context of service two. The structure was also adapted with the addition of a Speech and Language screen at service one, which suggested that the structure was not extensive enough for the purposes of their team. Figure 18 and figure 19 below depict the CMO configurations identified during fieldwork that refined the starting the proposition.

Figure 18: Refined CMOC: Service level
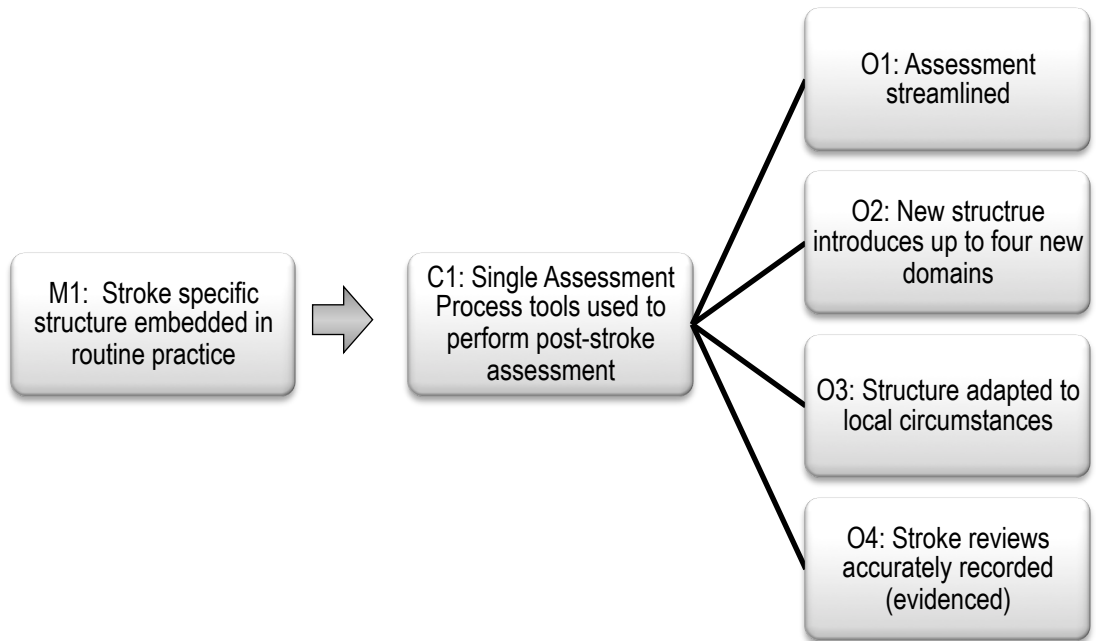
Figure 19: Refined CMOC: Coordinator level
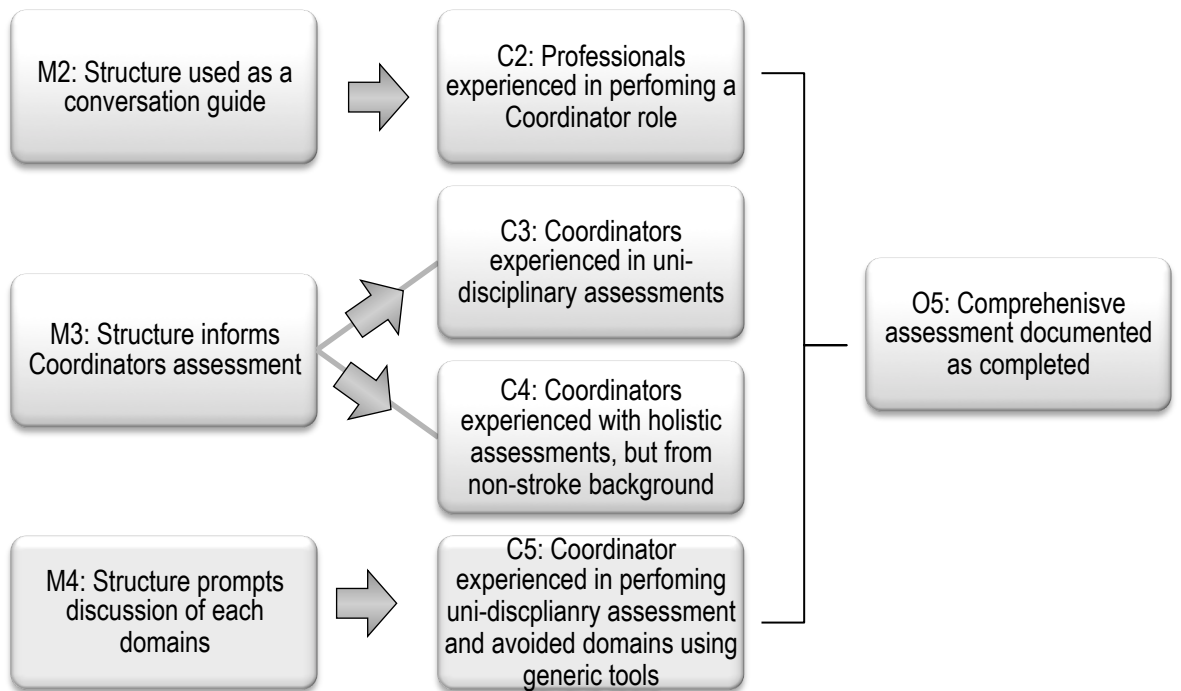
The stroke specific structure was used with all service users taking part in the LoTS care trial and according to the criteria developed by the LoTS care team, both services adhered to the intervention principle, 'ask all questions'. Therefore in most circumstances a comprehensive post-stroke assessment was documented as completed. This finding was some indication that the output anticipated was realised in practice. However, the extent to which the assessment structure informed and consequently extended the scope of the assessments performed varied depending on the background of the Coordinator. Coordinators, who were experienced in the role and performed the assessments on a daily basis, described that the structure provided a stroke specific framework to discuss areas that they already addressed. Professionals familiar with holistic assessments, although for a different population group, described that the structure ensured that the appropriate domains were addressed with stroke survivors. Professionals who were familiar with performing uni-disciplinary assessments described that the structure addressed their knowledge gaps, enabling them to address domains outside their expertise as intended. One Coordinator reported that they had not addressed domains consistently using the Single Assessment Process tools. In this context the structure promoted a more consistent discussion of each domain, as it emphasised that the problem area needed to be addressed with each service user. Therefore the assessment structure promoted the documentation of a comprehensive assessment, but the extent to which the domains informed the Coordinators of areas outside their professional remit depended on the context in which it was used.

8.13 Implications for the theory of change

Despite being mapped against the 'expressed needs' of stroke survivors, the LoTS care assessment domains overlapped with many areas included in the assessment tools used prior to the system of care. This finding undermined one of the underlying assumptions on which the system of care was based; that community stroke services were not adequately addressing the range of problems experienced and that a stroke specific structure would address this problem. Whilst the structure addressed knowledge gaps, in certain contexts as intended, its impact was mediated by the fact that the service already provided a holistic assessment and that the Coordinator was supported in problem identification by the multidisciplinary team. Further to this, documenting a comprehensive assessment did not necessarily

mean that all areas had been discussed e.g. the Coordinators avoided the discussion of sexual function (in certain circumstances); this was one of the novel areas introduced to the assessment process. Successful problem identification was also described as a combination of an appropriate structure, and the communication skills of both the Coordinator and the service user. Therefore, documenting a comprehensive assessment did not necessarily represent an enhancement in the assessments performed. The relevant domains might have been discussed more consistently using the LoTS care assessment structure, but it is unclear how this links to the outcomes measured as part of the LoTS care trial (GHQ-12, FAI, BI, LUNS).

8.14 Summary

The intention of the LoTS care system of care was to inform professionals of the range of problems experienced post-stroke in order to complete a comprehensive post-stroke assessment. The evidence suggests that in most circumstances this output was documented as achieved. The CMO proposition examined hypothesised that the structure would inform the Coordinators practice extending the scope of their assessment. Whilst this proposition was supported by empirical work (in some circumstances), the Coordinators suggested that the improvements that this introduced were not necessarily linked to problem identification. The stroke specific structure formed only one part of a successful assessment, as it was subject to the same facilitators and barriers as any other assessment tool e.g. professional and patient interaction. Sexual function was also avoided on occasions, which further emphasised the limitations of the structure in extending the scope of the assessment. The findings highlighted that one of the main assumptions underpinning the system of care was not completely accurate in the context of two multidisciplinary teams that used tools adapted from the Single Assessment Process to perform a holistic assessment.

Chapter 9: Discussion

9.1   Introduction

Problems that result from stroke are multifaceted; they affect individuals in different ways and can endure over the months and years following the incident. This is detrimental to survivors who wish to return to their pre-stroke life, it places a large burden on the economy and presents a challenging problem for community services. In response the Academic Unit of Elderly Care and Rehabilitation developed the LoTS care system of care to address the needs of community dwelling stroke survivors. To achieve its aim the system of care employed numerous strategies to enhance the role of health care professionals termed 'Stroke Care Coordinators'. These strategies included training, disseminating educational materials and introducing a stroke specific assessment structure. The outputs (service enhancements) anticipated were properties of a system that would work together to address post-stroke problems. However, as with most nationally based initiatives, the system of care was introduced with enough flexibility for services to adapt their implementation to local circumstances (Bergen and While, 2005).

To establish whether the system of care was superior to usual care it was evaluated in a Randomised Controlled Trial, which measured patient and carer outcomes including the GHQ-12, the FAI, the BI and the LUNS. However, the trial design does not account for the processes of change that are necessary for the intervention to impact on the outcomes of interest. The main efforts to generate change were not targeted at the patient level, but at the community stroke services that coordinated care inputs on their behalf. For this reason, this study aimed to complement the LoTS care trial using a theory-driven approach to examine the implementation and impact of the system of care i.e. examine the extent to which it enhanced service practice. To reflect on the study findings, the following section provides a brief overview of the chapters in this thesis.

9.2   Thesis Overview

Chapter one provided an introduction to the thesis describing the causes of stroke, the prevalence and mortality rates in he UK, and its longer-term consequences. Whilst a firm evidence base is available to inform the development of inpatient care, less progress has been made in developing a comprehensive community stroke service. The LoTS care system of care was described as a recent attempt to add to the evidence base in this area through evaluation in an RCT. The system of care aimed to meet the 'longer-term needs' of stroke survivors, however the chapter highlighted that this term is not easily defined or measured. The LoTS care trial used standardised measures of psychological and functional recovery to establish the system's superiority over usual care. The system of care differed from previous interventions, as it was informed by reviews of the literature that reported the longer-term problems experienced by stroke survivors and their carers. However, it also shared characteristics with policy initiatives that have influenced the development of community services and these needed further clarification.

Chapter two provided some insight into the context in which the system of care was implemented, by describing policy initiatives that have attempted to coordinate care inputs for service users (Department of Health, 1989, Department of Health, 2000b, Department of Health, 2004). The chapter highlighted that these initiatives have focused on providing 'needs led' services through assessment, care planning and the use of follow up objectives i.e. principles similar to the system of care. However, these policies have been adapted at the local level and have not adequately targeted the needs of stroke survivors (Allen et al., 2004, Bergen and While, 2005). The chapter described how stroke was prioritised on the policy agenda with the publication of the National Stroke Strategy(Department of Health, 2007). More recently objectives in longer-term stroke care were subject to an accelerated improvement programme (The Stroke Improvement Programme, 2008). The chapter conceptualised the LoTS care trial as a complex intervention inserted into a complex social system and argued that methods other than the trial design were required to understand how the intervention had worked, or not, to produce which outcomes. This provided the rationale for the theory-driven approach documented in this thesis, which drew upon the principles of realist evaluation.

Chapter three defined the study objectives and the research questions addressed in the thesis. A theory-driven approach was described as an appropriate strategy to explore the linkages between inputs and outcomes. The use of theory in the investigation and the concepts of mechanism, context and outcome (the explanatory tools used in realist evaluation) were clarified. This study prioritised the outputs anticipated from the system of care i.e. the changes in service practice (enhancements) that were the focus of the change efforts. The decision was made to perform a small and focused inquiry using two community stroke services as case studies. The case studies enabled the complex processes involved in implementing the system of care to be examined in context and real-time. Multiple methods were employed to enable a detailed exploration of the theories of change. The framework approach was described as the method of choice to reduce and organise the data. This approach facilitated the analysis process, which aimed to refine the theories of change.

Chapter four described the processes through which the theory of change was elicited. The problem perceived was conceptualised at the practitioner level i.e. that health care professionals (Stroke Care Coordinators) were not adequately identifying the range of problems experienced post-stroke. The solution came in the form of the system of care that offered a stroke specific assessment structure, a supporting manual and training to enhance the role of Coordinator. The mechanisms of change identified were educational and structural in nature; their intention was to address gaps in professional knowledge. However, the strategies employed to enhance practice also promoted the acquisition of new skills (problem solving techniques) and advocated an iterative process of care planning, monitoring and review. The anticipated outputs were attributes of a new system that would work together to address post-stroke problems. This study considered the implementation activities expected in the delivery of the system of care. It also focused on whether the system promoted the use of evidence based service responses and a comprehensive post-stroke assessment. These ideas were explored in the context of two multidisciplinary teams.

Chapter five described the contextual characteristics of each research site and distinguished the two by their eligibility criteria, their size and the allocation of the

Coordinator role. The chapter identified that facilitators supported the integration of the client checklist, the LoTS care manual and the assessment booklet within each service. However, the LoTS care assessment booklet was the only component of the intervention routinely used in practice at the time of fieldwork. Adaptations to the system's components were also acknowledged. The system was malleable to change, however, additions to the assessment structure suggested that the new tool was not extensive enough for the purposes of the services. Further to this, the content of the LoTS care structure was compared against the Single Assessment Process tools previously used and revealed that there was a large overlap in their scope. Up to four new assessment domains were introduced and it was postulated that this might have repercussions on the extent to which the system of care enhanced service delivery.

Chapter six examined the activities that were expected in the delivery of the system of care. The inquiry revealed that the problem-solving techniques advocated at the training did not resonate with the Coordinators and were not disseminated amongst the teams. The Chapter also revealed that the assessment booklet was implemented using well established processes i.e. as an initial 'MDT' assessment at service one and as part of the stroke nurse reviews at service two. These processes impacted on the type of care plans documented. The Coordinators recorded actions, as opposed to goals as anticipated. The findings emphasised that established routines and resource limitations acted as barriers to change. The implication was that service delivery was not enhanced by the system of care through increasing the amount of contact or the type of interaction provided by the Coordinator. Identifying new problems as they emerged over time and clarifying actions had been completed were a continuation of previous practices, which relied on the multidisciplinary team structure.

Chapter seven examined whether the educational materials provided in the LoTS care manual were used to inform the Coordinators practice, promoting the use of evidence based service responses. The proposition was explored with consideration of the boundaries of the Coordinator role established in chapter six. The main finding was that the Coordinators prioritised the tacit knowledge of their colleagues over the LoTS care manual. Team meetings and informal liaison facilitated an informal learning process, which enabled new staff to address the problems they

identified. Experienced Coordinators reported using the manual to confirm their practice rather than guide their actions. One Coordinator who was new to the role and the community team described that the manual had informed their practice. However, their service responses were still shaped by the boundaries of the role established at their service and local service availability. Therefore although they were informed how to address certain problems, this did not necessarily reflect a change in service practice. One Coordinator, who had assimilated the information in the manual to develop a local file, described that they disseminated any new information amongst their team colleagues via the team channels described. This finding highlighted the dynamic way in which new knowledge was absorbed by the team and became a valued source of information.

Chapter eight examined how the stroke specific assessment structure enhanced service delivery. The assessment booklet was embedded as part of routine practice and the domains documented as addressed. However, experienced professionals described little change in practice through using a stroke specific structure in comparison to the generic tools previously used. Professionals with less experience (at service one) suggested that the structure addressed their knowledge gaps and promoted a more consistent coverage of each area. However, this was offset by the fact that the service tools previously used also aimed to extend the scope of a uni-disciplinary assessment, that the absence of a speech and language screen was described as a gap in a tool designed to be comprehensive of post-stroke problems and the fact that some areas in the structure i.e. sexual function were avoided in certain circumstances. Further to this, successful problem identification was mediated by the circumstances of the assessment i.e. the interaction between the patient and the professional. Therefore, mandatory use of the assessment booklet improved the assessment structure, but whether this enhanced problem identification was hard to discern.

9.3 Summary of findings

The components of the system of care were embedded within each service, but the assessment booklet was the only tool routinely used in practice. Fieldwork revealed that the Coordinators implemented the system according to local policies, which

resulted in its use as an initial 'MDT' assessment at service one, and as part of a stroke review process at service two. The strategies employed to enhance service delivery worked to varying extents, depending on the context, but not always with the output anticipated. Drawing upon the principles of realist evaluation provided a useful mind-set with which to examine these strategies. The aim was to uncover what it was about the system that had worked, for whom, how and in what circumstances, see table 25 below for overview of findings.

Table 25: What worked, for whom, how and in what circumstances?

What worked?	For whom?	How?	In what circumstances?
- Assessment booklet embedded in routine practice - Dissemination of manual	- Professionals familiar uni-disciplinary role - Professionals from non-stroke background - Experienced stroke care coordinators	**Service level** Structure introduces up to four new domains Structure used to clarify content of assessment for Coordinators Local information file developed to inform service responses Structure evidences stroke reviews **Practitioner level** Structure used as a conversation guide Structure informs the assessment of new areas Structure prompts discussion of each domain Manual confirms existing practice Recommendations informally disseminated via team structure Manual used as a training tool Manual used to inform practice	- Community stroke services providing a coordinating role - When use of the assessment tool is mandatory - In services where professionals from different backgrounds act as Coordinator - Where system of care has a champion - To provide protection from litigation - To respond to problems not frequently addressed

Realist principles provided the conceptual tools to explore the 'black box' of this complex intervention. The principles helped focus the inquiry on certain mechanisms (from the numerous identified) that were considered key in achieving the

intervention aims. These mechanisms were then linked to specific contexts during fieldwork and can hopefully be useful beyond the study setting by highlighting where the mechanisms have and have not worked. However, difficulties were also noted in applying the realist principles e.g. sampling using the contexts articulated in the CMO propositions was problematic. The researcher did not have access to specific information about each Coordinator participating in the study. Therefore the sample selection was based on the information available, which reflected service level variations and pragmatic considerations (see chapter three). Luckily both research sites included Coordinators from varied backgrounds, which enabled the starting propositions to be examined. Another issue was that the theories changed rapidly in the field, and this required the researcher to adapt and investigate new explanations. Whilst this is expected using the realist approach it required good access to the research participants, as evolving explanations needed discussion and clarification. Finally, the CMO propositions hypothesised enhancements in service practice. These enhancements were not directly linked to the patient and carer outcomes measured as part of the LoTS care trial. Therefore how and why one, or a combination of the outputs explored in this study improved patient outcomes is not clear. However, this problem is not necessarily linked to the realist principles, but to the resource limitations of the study.

In the context of two multidisciplinary stroke teams a number of factors were identified that mediated the impact of the system of care. Some prominent themes included the use of the Single Assessment Process and the multidisciplinary team structure and their influence is reflected upon below.

9.4   Reflection on findings

Chapters five and six examined how the system of care was embedded and implemented within each service. Explanations drew on the premise that local facilitators and barriers shape how complex interventions unfold in practice (Greenhalgh et al., 2004). A number of facilitators i.e. system readiness for change, a good system fit and a 'champion' of the intervention (at service one) were found to support the integration of the system's components (Greenhalgh et al., 2004, Barnett et al., 2011). The system was also flexible, which meant it was adapted to local circumstances like many other national initiatives (Manzano-Santaella, 2011). The role of Coordinator at service one was to provide an initial 'MDT assessment'

and refer on to appropriate agencies where necessary. The Coordinators at service two performed a similar role over three years, which they described as 'signposting'. Whilst flexibility in the system or 'fuzzy boundaries' is another facilitator of change, the iterative process of assessment, care planning, monitoring and review anticipated were not realised in practice. The implementation principles advocated by the intervention architects did not resonate with either service; this combined with limited local resources meant that the system of care was implemented according to local policies. For this reason, gaps in the processes of care that the system had initially intended to address persisted.

Assuming that the intervention components were implemented according to local policies, the next point of inquiry became the extent to which the system of care enhanced the processes that were performed by the Coordinators. One of the assumptions underpinning the theory of change was that existing community services were not adequately identifying the range of problems experienced post-stroke. To address this problem a stroke specific assessment structure was developed and its use was mandated as part of the intervention group. This strategy led to the routine use of the LoTS care assessment booklet; however, providing a needs led assessment was an initiative that reflected policy initiatives that had been introduced to the health and social care system over the last 25 years (Department of Health, 1989, Department of Health, 1990, Department of Health, 2000b). The Single Assessment Process was one such initiative (Department of Health, 2001b). The Overview assessment, developed as part of this process, was designed to provide a holistic structure to identify the needs of the elderly population. Single Assessment Process tools had been adopted by the two services and on introducing the system of care a holistic assessment designed for the elderly population was replaced with one designed for the stroke population.

The novel attribute of the system of care was that it targeted the needs of stroke survivors. The assumption was that this would enhance service delivery through extending the scope of the assessment. In reality this introduced up to four novel domains, one of which (sexual function) was sometimes avoided at the practitioner level due to its sensitivity. The structure was described to streamline the assessment process at service one and evidence the stroke reviews at service two.

Coordinators' with experience of performing holistic assessments described that the new structure produced a limited impact i.e. in the extent to which it informed and consequently extended their assessment. Coordinators with less experience reported that the structure addressed gaps in their knowledge; however, this was mediated by the fact that they were expected to perform a holistic assessment regardless of what tool was used and their team colleagues supported the elicitation of appropriate information.

The limitation of the structure in extending the scope of the assessment was further emphasised, as the structure was usually documented as completed, but this did not indicate that all domains had been discussed e.g. sexual function was avoided on occasion. Therefore introducing novel domains did not necessarily lead to their discussion in routine practice. Completing the assessment structure can be reduced to the administrative task of ticking a box, if Coordinators do not feel confident in their abilities to address each domain. The use of assessment structures in this way was also raised as a concern in the implementation of the Single Assessment Process (Abendstern et al., 2008). In this field, discussion focused on whether the assessment was patient centred or service orientated when such a structured approach was used (Abendstern et al., 2008). The LoTS care structure focused on problems related to stroke, which reflected the needs of the service, however in reality problems can extend beyond the individuals condition. The Coordinators had to resolve these tensions in the system, which was observed during fieldwork when problems unrelated to the stroke incident were identified.

The findings demonstrated that the stroke specific structure was considered an improvement, but whether this extended the scope of the assessment was dependent on 1) the background and experience of each Coordinator, 2) their confidence to address each domain and 3) the scope of the assessment tool previously used by their service. Further to this, using a stroke specific assessment might not facilitate the identification of all problems pertinent to the service user, as these can extend beyond the stroke specific remit of the structure. Other barriers to accurate problem identification were also identified at the patient level e.g. personality and impairment linked barriers. The findings highlighted that an appropriate assessment structure was only one component in successful problem

identification. Other components that contributed to successful problem identification were not adequately targeted by the intervention's improvement strategies.

The LoTS care manual was disseminated to the services as an educational tool to enhance the Coordinators' service responses. Dissemination of written educational materials has often been employed in order to change professional practice (Thomas et al., 1999, Giguere et al., 2012). However, this strategy has had limited success when used alone and as part of a multifaceted intervention (Wensing and Grol, 2005, Grimshaw et al., 2004, Effective Healthcare Bulletin, 1999). The findings from this study supported previous work. It indicated that the manual did not introduce major changes to the management of post-stroke problems, despite the fact that new knowledge was absorbed by the service. The reason for this was that the Coordinators worked within boundaries established by their service. The actions they completed required knowledge of local service availability and the Coordinators preference was to liaise with colleagues who held context specific information i.e. 'tacit knowledge' (Kothari et al., 2011). The chapter highlighted that new knowledge was usually acquired informally and was facilitated by the team structure. Similar findings have also been reported in primary care (Gabbay and May, 2004). This finding might be useful for future intervention strategies aiming to disseminate new information to health care professionals.

9.5   Significance to the LoTS care trial

The LoTS care team conceptualised the problem in community stroke care at the practitioner level. To enhance service practice the LoTS care team intended to promote 1) an iterative process of assessment, monitoring and review, 2) a comprehensive post-stroke assessment and 3) evidence based or recommended service responses. The findings from this study revealed that the system of care 1) did not increase the amount or type of contact provided by the Coordinator, 2) that both teams were aware of many domains that needed addressing post-stroke and used a structure and holistic approach to capture these, and 3) that service responses were performed within certain boundaries and were informed by numerous sources, most notably team colleagues. The system of care worked to varying extents (in specific contexts), however it seems likely that the enhancements realised in practice would not be captured by the patient and carer outcomes

measured as part of the LoTS care trial. However, the links between service delivery and patient outcomes were not thoroughly explored in this thesis. When helping to interpret the trial outcomes most insight comes from the idea that the services were complex adaptive systems in their own right (Begun et al., 2003). In particular the notion that complex systems change over time and through learnt experience resonated with the study findings.

Both services had identified gaps in their practice; as a result they actively sought out opportunities to improve i.e. participation in the LoTS care trial. However, there was indication that a stroke specific assessment tool would have been produced by the services if the system of care had not been available e.g. a stroke management plan was introduced at service two to supplement their documentation. Further to this, national policy initiatives were also driving change e.g. at service one the provision of stroke reviews was piloted in response to the National Stroke Strategy. The community stroke services in the control group were not offered the intervention resources; but this does not mean that they did not have opportunities to improve their practice. They had the ability to actively seek out information, learn from experience and change as they did so, as in the two case study sites. Further to this, they were also exposed to the same national drivers of change, such as the quality markers in the National Stroke Strategy.

These reflections emphasise that the system of care was one influence on the natural development of the community stroke services participating in the LoTS care trial. However the services were also subject to many other influences (local and national) that shaped how they developed over time. Therefore the trial might be better conceptualised as a complex adaptive system inserted into a complex adaptive system, compared with another complex adaptive system (Pawson et al., 2004). This makes comparisons between the two groups using standardised outcomes problematic. In this context the RCT might not be the most appropriate research design for evaluation purposes (Mackenzie et al., 2010).

9.6   Reflection on method

The system of care was a complex intervention that aimed to enhance various aspects of the Stroke Care Coordinator service. It was the combination of these changes interacting over a prolonged period of time that were expected to 'work' to address the needs of stroke survivors. This study attempted to capture the system at work focusing on how the components were implemented, and the extent to which service delivery was enhanced. Case studies enabled the implementation activities and the mechanisms of change prioritised for investigation to be examined in detail and in context. However there were also limitations to the study.

The LoTS care team recruited two types of service to participate in the trial; individual Stroke Care Coordinators and community stroke teams with one or more Stroke Care Coordinator. The sampling strategy used in this study attempted to account for this variation by identifying one individual service and one team to use as case studies. However, unforeseen circumstances and pragmatic considerations prevented the use of an individual service. For this reason, two multidisciplinary teams were selected as research sites. This eventuality meant that examination of the theories of change took place within this context, which was found to mediate the service outputs. Examination of the same theories in a different context might reveal more pronounced changes.

This study focused on certain points in the intervention logic in a limited number of contexts. The aim of realist evaluation is to provide knowledge cumulation, as opposed to replication, by testing the theories of change in different contexts (in particular those which are expected to mediate a successful outcome)(Pawson and Tilley, 1997). This study went through one cycle of what should be an iterative process of theory generation and testing. However, this produced some useful insight into how, why and in what circumstance the theories applied or failed to apply, and the significance of this to the system of care as a whole. The use of alternate methods e.g. a survey of all intervention sites might have established the contexts in which the assessment structure and manual introduced more pronounced changes, and perhaps even the implementation principles. However, the use of case studies enabled a number of theories to be examined in detail using

numerous sources, which provided a detailed account of the complex processes under investigation. It is hoped that this contributed, in a modest way, to understanding how and why the strategies employed promoted change, which might be useful beyond the study context for development of future interventions.

Data collection was performed after the components of the system of care had been implemented in practice for many months. For this reason, the processes involved in embedding the components in routine practice were not captured as part of fieldwork. The researcher observed the implementation of the system of care at a time when Coordinators were familiar with the content of the assessment structure and had established what parts of the manual were useful to their practice. Examination of this stage of the implementation process might have influenced the findings, as improvements had become part of the Coordinators established practices and possibly not articulated during discussions. However Coordinators who were present at the start of the trial were asked to reflect on this time, which established some of the initial service responses to the system of care. In the context of service one this revealed that a local information file and a service checklist had been developed to complement the intervention components.

The study was also limited through its focus on the service outputs. An alternate research design might have used stroke survivors as the case. This approach would enable the researcher to examine the problems and needs experienced by the service user and the role played by the intervention resources in their successful resolution. This strategy would provide insight of the service user's perspective and the extent to which they felt their needs had been addressed by the service. However, the decision was made to look closely at the Coordinators and the service in which they worked, as this was where the change efforts of the intervention were directed. Further to this, with limited time and resources certain parts of the intervention logic need to be prioritised for investigation. Consideration was given to the aspects that were deemed significant to the process of change and which could be investigated appropriately within the study limitations.

9.7 Implications for policy, practice and recommendations for future research

The LoTS care trial demonstrated that there was no significant difference in the outcomes of interest between the intervention and control group. The evidence, therefore, does not support the systems use in routine practice over usual care. However, the National Stroke Strategy now recommends that stroke reviews be performed at specific intervals, this was advocated based on stakeholder opinions rather than the evidence base. National policies can promote or mandate what type of services should be provided in the community setting; however national policies are interpreted and adapted at a local level to reflect population needs and resources. At the practice level the LoTS care assessment booklet could be used to implement the stroke reviews advocated; however, it now forms one of many tools that have emerged in response to the National Stroke Strategy and there is no evidence to suggest that there are patient and carer benefits from using this tool over any others. Community stroke services will therefore choose the tool most appropriate in their locality and might adapt these further depending on their needs.

The LoTS care system of care was similar to policy initiatives, as it was designed for national use but malleable to local circumstances. This theory-driven evaluation has provided insight into how, why and to what extent a complex intervention was absorbed, implemented and enhanced the practice of two community stroke services. The findings support previous studies that highlight facilitators and barriers to change at the micro, meso and macro levels (Effective Healthcare Bulletin, 1999, Greenhalgh et al., 2004). Strategies to promote change need to consider these contextual levels and the barriers that exist within them in order to be successful. The study findings demonstrated that the main strategies employed by the LoTS care team (provision of a new assessment structure and dissemination of education materials) worked, but not always in the way anticipated (depending on the context) and that the impact was mediated by service level characteristics. Consideration of context would provide insight into what changes are required to improve practice overall, which is likely to differ between localities, and would also highlight the resources needed to bring these changes about. With this in mind a list of recommendations for future research in the area is provided.

- The needs of the community dwelling stroke population are multifaceted and change over time. Unmet need might be better understood when investigated in a holistic and qualitative manner. This approach would account for mediating personal and environmental factors and could also consider whether needs are related to the stroke incident or other life events.

- It is unlikely that one service would be able to address all needs experienced by community dwelling stroke survivors, due to their complex nature. However, a different service aim is to coordinate care inputs on their behalf through linking and signposting to relevant organisations. This type of service exists in some localities, as indicated by the services recruited to LoTS care trial and are also advocated in government policy.

- With this in mind, initiatives aiming to enhance community stroke services should examine existing practices and identify areas that need improvement, which could differ between localities. In the case of the system of care, the stroke specific assessment structure was an improvement on previous tools, but the Coordinator's might need further support to develop assessment skills in areas outside their expertise.

- Consequently, appropriate strategies to generate change with the aim of service improvement should be identified based on theories of behaviour/ organisational change and evaluation of outcomes should reflect what the interventions are able to affect.

- Educational interventions that aim to increase knowledge in an effort to change behaviour could draw upon 'champions' within the service. These people could exploit the informal channels used by professionals to exchange and absorb new knowledge, which might prove more successful than the dissemination of educational materials alone.

These recommendations were made in regards to community stroke care, but could be applied to all long-term conditions. Community services increasingly target

specific conditions, which is reinforced by policy documents such as the National Service Frameworks. However the needs of service users will not always be directly linked to their condition. To understand how needs can be identified and addressed and how they link (or do not link) to the more tangible patient outcomes will require a qualitative approach; this applies to all service users rather than specific condition(s). Further to this, in order to improve practice, service context needs to be considered i.e. how local facilitators and barriers might impact on the implementation of improvement strategies and the hypothesised mechanisms of change. It is through exploring these factors that an understanding is developed of how the intervention has worked to produce which outcomes, and this applies to all complex interventions not only those delivered in community stroke care.

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APPENDICES

Appendix i: Domains for the Single Assessment Process

Users Perspective
Problems and issues in the user's own works
User's expectations
Clinical Background
History of medical problems
History of falls
Medication use
Disease Prevention
History of blood pressure monitoring
Nutrition
Vaccination history
Drinking and smoking history
Exercise pattern
History of Cervical and breast screening
Personal Care and physical well-being
Personal hygiene including washing, bathing, toileting, and grooming
Dressing
Pain
Oral health
Foot care
Tissue Viability
Mobility
Continence
Sleeping patterns
Senses
Sight
Hearing
Communication
Mental Health
Cognition including dementia
Mental health including depression
Relationships
Social contacts, relationships and involvement
Caring arrangements
Safety
Abuse or neglect
Other aspects of personal safety
Public safety
Immediate Environment and resources
Care of the home
Accommodation
Finances
Access to local facilities and resources

Appendix ii: SCC Interview Schedule

1 - Clarify observations

2 – Discussion of the theories of change

a) Can you tell me a bit about what happens when you first visit a patient in your coordinator role?

- What do you discuss with the patient?
- What documentation do you take with you?

b) Can you tell me more about how you identify patient problems?

- How does LoTS care fit into this?
- Can you tell me about how you use the LoTS care paperwork (checklist, care plans, manual) during your assessment?
- Are you comfortable covering all sections of the care plan?
- How does this help you to identify problems (if at all)?
- Can you provide any examples where it has worked particularly well? What was the circumstance?
- Have you found any problems/challenges using the LoTS care paperwork?
- Can you provide any examples? What was the circumstance?
- How do you involve patients in this process?
- How do you decide how to prioritise problems?
- Do you ever disagree with patients about this?
- What happens in these circumstances?
- Is it easier to involve some patients than others? Can you provide an example? What were the circumstances?

c) How do you decide what to do about patient problems?

- How does LoTS care fit into this?
- Can you tell me about how you use the LoTS care paperwork during this process (Care plans to document, Manual for guidance)?
- How has the manual helped you to address patient problems (if at all)?
- Can you provide any examples where the manual has been really helpful to you? What were the circumstances?
- Are their particular types of problems that the manual is more useful for than others?
- What problems/challenges have you faced using LoTS care documents when addressing patient problems?
- Can you explain a bit more about this? What were the circumstances?
- Do you involve the patient when deciding what to do about their problems?
- How are patients involved?
- Does this work better with some patients than others? In what circumstances?

- Are there ever problems you don't know what to do with?
- What happens in these circumstances?

3) How do you follow up and/or review the problems identified and their solutions?

- Do you find the LoTS care documentation useful in this process? How?
- What circumstances has it been most useful in?
- Have you ever had any experienced any problems/challenges when reviewing problems?
- What happens if a problem has not been resolved or has not improved?
- How do you involve the patients in this process?
- How do you decide when to discharge a patient?

4) How does LoTS care compare with your previous assessment processes?

- How is the documentation different? (Questions asked, layout)
- Do you think you involve the patient more in indentifying problems and solutions?
- Do you think you identify more stroke related problems using LoTS care?
- Have you noticed any differences in treatment options or referrals to services to address patient problems as a result of using LoTS care?
- Do you think the problems identified and their solutions are reviewed more regularly as a result of LoTS care?
- How do you think the LoTS care assessment is received by patients in comparison to your previous assessment process?
- Would you recommend using this assessment? Can you explain a bit more about this?

5) – Is there anything else you like to add?

6) - Thank the SCC for their time and participation in the study.

End of interview

Appendix iii: LoTS care assessment sections and questions

Contact 1 *(Community-based)*

Not including telephone calls to make appointments

Date: [Day | Month | Year]   Carer involved? [Y] [N] [n/a]   Type of contact: ☐ Face-to-face   ☐ Telephone

Your name [___]   Location: ☐ Home   ☐ Clinic

Profession *e.g. nurse* [___]   **NHS Band** [___]   ☐ Other, specify: [___]

☐ Client checklist provided in advance of the assessment

Carer information

Does the patient have a carer?
Defined as: main informal carer who provides the patient with practical support a minimum of once per week

☐ **Yes**

☐ **No**

Was a carer assessment completed?

☐ **Yes**

☐ **No** ⟶ Reason assessment not completed:

     ☐ Carer assessments routinely provided by other services
     ☐ Carer not present
     ☐ Carer declined
     ☐ Not offered *(reason)*:
     ☐ Other *(reason)*:

☐ **Patient does not have a carer (as per definition) but has care package provided** [___] *Number of times a day/week*

Patient assessment questions

Remember to ask all of the questions *If there is a problem but it is not going to be addressed now, please tick the problem box and record in the action plan that it will be revisited next time.*	**Response**		**If NOT asked:** *indicate why*	
	No problem. No further action.	Problem. Please go to ACTION PLAN	Already addressed	Other. Please explain in notes section.
Transfer of Care: Reference guide 1				
Has a discharge plan been prepared by the hospital? Have you had a home visit? What was the outcome? *Discuss issues around knowledge and understanding of their care plan, their involvement, falls management and sources of information.*	☐	☐	☐	☐
Communication & Information: Reference guide 2				
Have you been given clear information about your condition, treatment and services available?	☐	☐	☐	☐

Patient's Name [___]   *Patient's D.O.B* [Day | Month | Year]   NHS number: [___]

Contact 1

Remember to ask all of the questions *If there is a problem but it is not going to be addressed now, please tick the problem box and record in the action plan that it will be revisited next time.*	Response		If NOT asked: *indicate why*	
	No problem. No further action.	Problem. Please go to ACTION PLAN	Already addressed	Other. Please explain in notes section.
Medicines & General Health: Reference guide 3				
Do you have any problems with your medication? *For example, side-effects, drug cocktail, non-prescription drugs.* Is medication being regularly reviewed by a doctor/nurse? *Medication can be recorded on page 4.*	☐	☐	☐	☐
Do you have any problems taking your medication? *For example, opening packets, remembering, swallowing (check for swallowing assessment).*	☐	☐	☐	☐
Do you have any other health problems? *Ask about smoking cessation, alcohol consumption, diet and weight loss.* Check if other health problems are being regularly reviewed.	☐	☐	☐	☐
Pain: Reference guide 4 *(assessment scale available)*				
Do you have any pain? Is the pain being treated? Is the treatment helping?	☐	☐	☐	☐
Mobility / Falls: Reference guide 5 *(assessment scale available)*				
Can you get around indoors?	☐	☐	☐	☐
Can you get out of your house?	☐	☐	☐	☐
How confident are you about carrying out various daily activities without falling?	☐	☐	☐	☐
How do you feel about your recovery so far? *Discuss patterns of physical and emotional recovery*	☐	☐	☐	☐

Patient's Name _____

Patient's D.O.B Day Month Year

NHS number:

Contact 1 patient assessment questions *(continued)*

Remember to ask all of the questions *If there is a problem but it is not going to be addressed now, please tick the problem box and record in the action plan that it will be revisited next time.*	Response		If NOT asked: *indicate why*	
	No problem. No further action.	Problem. Please go to ACTION PLAN	Already addressed	Other. Please explain in notes section.
Personal Hygiene & Dressing: Reference guide 6				
Are you having any difficulty with personal care like washing, cutting your nails, oral hygiene or dressing? Do you ever need help? *If applicable, discuss satisfaction with homecare services (e.g. dressing, bathing).*	☐	☐	☐	☐
Shopping & Meal Preparation: Reference guide 7				
Can you prepare your own meals?	☐	☐	☐	☐
Can you go shopping?	☐	☐	☐	☐
Are you getting the right food?	☐	☐	☐	☐
House & Home: Reference guide 8 *(assessment scale available)*				
Can you do your housework? Does anyone help you with your housework?	☐	☐	☐	☐
Do you have any problems with your accommodation? *If applicable, discuss satisfaction with homecare services (e.g. cleaning, shopping and laundry).*	☐	☐	☐	☐
Cognition: Reference guide 9 *(assessment scale available)*				
Do you often have a problem remembering things that happened recently? Do you often forget where you have put things? Do you find it difficult to concentrate?	☐	☐	☐	☐

Patient's Name _____ Patient's D.O.B Day | Month | Year NHS number: | | | | | | | | | |

Contact 1

Remember to ask all of the questions *If there is a problem but it is not going to be addressed now, please tick the problem box and record in the action plan that it will be revisited next time.*	Response		If NOT asked: *indicate why*	
	No problem. No further action.	Problem. Please go to ACTION PLAN	Already addressed	Other. Please explain in notes section.
Driving & General Transport: Reference guide 10 *(assessment scale available)*				
Do you have trouble with transport?	☐	☐	☐	☐
Finances & Benefits: Reference guide 11				
Do you have any difficulty managing your money?	☐	☐	☐	☐
Are you able to pay your bills?	☐	☐	☐	☐
Are you receiving all the benefits you are entitled to? *Use a benefits checklist.*	☐	☐	☐	☐
Continence: Reference guide 12 *(assessment scale available)*				
Do you ever have accidents with your bladder/bowel? How is this being managed?	☐	☐	☐	☐
Sexual Functioning: Reference guide 13 *(assessment scale available)*				
Some people after a stroke experience sexual problems such as lack of interest or practical difficulties. Have you experienced any changes sexually since your stroke?	☐	☐	☐	☐

Patient's Name _____

Patient's D.O.B | Day | Month | Year |

NHS number: | | | | | | | | | | |

Contact 1 patient assessment questions *(continued)*

Remember to ask all of the questions *If there is a problem but it is not going to be addressed now, please tick the problem box and record in the action plan that it will be revisited next time.*	Response		If NOT asked: *indicate why*	
	No problem. No further action.	Problem. Please go to ACTION PLAN	Already addressed	Other. Please explain in notes section.
Patient Mood: Reference guide 14 *(assessment scale available)*				
Have you recently felt very sad or fed up?	☐	☐	☐	☐
Have you felt anxious, frightened or worried? *Do you find it difficult to control your emotions?* *Discuss as appropriate frustration and irritability.* Have you been offered or are you having any treatment?	☐	☐	☐	☐
Do you have a partner, relative or friend you feel close to? Do you get on well? Can you talk about your worries or problems with them? *Discuss feelings of burden.*	☐	☐	☐	☐
Patient Social Needs: Reference guide 15				
How do you spend your day? Do you have enough to do? Are you happy with your social life? Do you wish you had more social contact with others? *Discuss work as appropriate, changes in role, relationships, personality, attitude and confidence. Enquire about self image and lack of energy.* *Discuss patient's perception of life since the stroke as compared with pre-stroke, and any thoughts about the future.*	☐	☐	☐	☐
Other				
Are you having any other problems relating to your stroke? *For example, swallowing, speech & language difficulties, sleeping, vision, numbness, oral health? Enquire if the patient has set self goals and what they are.* *Ask about their expectations and general patterns of physical and emotional recovery.* Discuss motivation and how much control they feel they have in their recovery.	☐	☐	☐	☐

Contact 1 goal and action planner

Contact 1

Client information: During your assessment you will plan and agree some goals to work towards or actions to take with your stroke care co-ordinator (SCC). The actions and goals may be set for you or for your SCC. After you have attempted your goals and actions, record the outcome below.

Duration of assessment contact (time spent with patient) ☐☐ (hours/mins)

Time spent discussing patient in MDT – *please complete table on back page.*

Time for additional note writing ☐☐ (hours/mins)

Problem (Please number problems)	Assessment question(s)/ Related reference guide(s) number	Goal or action	Patient / SCC	Date set	Date review	Review of outcome Please write a: Goal achieved, b: Nearly there but extra guidance required, c: Struggling with goal – To be reviewed in next contact	Duration spent on each SCC action between date set and date review. (HH:MM) (exclude assessment contact time, include phone calls etc.)
1. Difficulty going shopping because of parking and walking problems	5, 7 & 10	Obtain Blue badge	Patient	01.02.2009	01.03.2009	a. Blue Badge obtained	20 mins

LoTS care trial team use only: Reference guides used: 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 Other

Total number of problems identified ☐ Total number of goals / actions: ☐ Total number of patient goals / actions: ☐ Total number achieved: ☐ Total duration: ☐☐

Patient's Name ___ D.O.B ___ NHS number: ___ **12**

Patient's Name ___ D.O.B ___ NHS number: ___ **13**

Appendix iv: Example of Respondent Validation Feedback form

How does LoTS care help you to identify post-stroke problems
Informed of what post-stroke problem areas to cover (slides 11 and 12)
My explanation:
The LoTS care assessment booklet was the main component of the intervention that you have used as part of the system of care i.e. the main component that has influenced you when conducting the holistic (coordinator) assessment. As an Occupational therapist, with experience of working in the community, you were familiar with many of the assessment areas included as part of a comprehensive post-stroke assessment. This is because many of the assessment areas overlap with your specialist expertise, e.g. House and home, Meal preparation, Cognition, and because you have undertaken a similar holistic assessment before joining the CSRT. However, sexual functioning and driving were areas that you had not covered routinely, therefore LoTS care did prompt you to cover these areas as part of a comprehensive post-stroke assessment. Further to this, the content of the LoTS care assessment has been informative to you for certain problem areas that you would not usually consider as an occupational therapist e.g. in medication and general health, you mentioned that you consider how patients are able to take medication (e.g. blister packs) but not what is actually taken, which is more in the nursing remit. Therefore it has complemented your existing knowledge and has helped you to probe for problems that you would not automatically cover as part of your OT role.
Your clarification:
Can you explain why you do/ do not agree with the above? **OR - What do you feel has informed you of what areas need to be assessed as part of a comprehensive post-stroke assessment? (own knowledge and experience/ MDT)** • *Have I got this right about how it has informed you/ raised your awareness, or is it more that it was a reminder to cover these areas?* • *Are there any other examples of areas in which LoTS care has informed you of types of problems outside your OT remit?*

Appendix v: LoTS care implementation principles

1. **Patient-centred = Comprehensive coverage of problems identified by patients and carers**

2. **Provide assessment areas before assessment whenever possible**

3. **Ask all questions (ToC as appropriate)**

4. **Keep accurate records**

5. **Problem solving approach with collaborative goal setting**

6. **Follow-up on actions**

7. **Review goals**

8. **Not prescriptive – individual creativity**

9. **According to local services/resources**

10. **Within patient's own environment wherever possible**

11. **Timing/duration of intervention (RCP NCGS & NSS*)**

12. **Cut-off time**

13. **Flexible approach to carer assessment**

Appendix vi: Guidance on Identifying and Discussing Sexual Problems

- **Prepare the patient and carer.** Some level of relationship needs to be established before the topic can be broached. The timing of the question in the assessment is quite important. A good leading question might be:
- "We've talked about some of the changes you and your partner have gone through, have you experienced any changes in your intimate life?" (or see assessment schedule for question)
- But be aware of vagueness. If they don't understand or engage follow on by:
    - Giving your rationale, *for example*:
    - "This might be a bit embarrassing / difficult to talk about but its very helpful for me to know....."
- **Building a relationship** - Core conditions for building effective relationships include *Respect* (remembering patients name, active listening), *Empathy* (share related experiences of your own and reflect on others experiences) and *Genuineness* (talk appropriately about yourself and share feelings appropriately).
- **Normalise the problem for them**. Many stroke patients have the same difficulties (without having to offer unrealistic expectations).
- **Do the couple communicate well?** If one partner is unable to talk to the other partner about their worries, gently probe into why this is. If appropriate, establish how comfortable they would be discussing the problem with their GP.
- Identify any fears or worries relating to sex.
- Establish:

    1. The current level of physical contact that the couple have (e.g. cuddling);
    2. History prior to stroke.

- **Offer an alternative** if they seem to be finding the question difficult / embarrassing to answer say so.
- "This seems to be a difficult question for you to answer, what would be more helpful?"
- **Be aware** of the person's priorities for example, greater concern over physical health.
- **Give them space**, for example by allowing people time to consider their answer. The counselling charity Relate suggests removing eye contact (for example, by jotting down notes) to remove some of the intensity from the situation and allow them time to gather themselves.
- **Be comfortable with the language you use**. Avoid closed questions and words that make you feel uneasy or embarrassed. Plan questions you are comfortable with, and practice with a colleague if you feel it will help.
- **Listen** for example, talk about what the person is saying, and use their ideas in your next question.
- **Deal with the problem respectfully.** Opening the door for patients to talk and then shutting it (by suggesting that you pass their problem onto someone else) might imply that the problem is too hot to handle. The key to this is to admit that you are not an expert and cannot handle everything. This will make the patient feel more safe (removing some of the balance of power) and also avoids giving them false hope.
- **Don't make assumptions,** for example, that they have been sexually active prior to the stroke, or that just because they are mature in years that they no longer feel sexual or have a sexual life.
- **Containment**, effectively closure, for example, have a prepared script.

- - "I understand it's a problem (acknowledgement), I've made a note and I can contact some one your behalf or go and find out the right information (demonstration of attempt to solve problem)."
- Suggested prompts for establishing the cause of erectile dysfunction

What is the problem with your erection?
- Establish that the problem really is erectile dysfunction (not premature ejaculation or sexual dysfunction due to Peyronie's Disease). Be aware of the social and cultural influences on the patient's response and modify subsequent questions appropriately.

How long has there been a problem?
- Sudden onset suggests psychological cause (major depression or anxiety). Gradual onset suggests organic cause (i.e. vascular disease, Diabetes, medications etc).

Are there times when it is worse?
- Suggests situational (e.g. new partner) or global erectile dysfunction (absence of early morning erection or unresponsive to self-stimulation).

Do you regard your sex drive as being normal?
- How has the interest in sex changed, for example compared with 5 years ago? Lower sex drive could reflect significant reduction in androgen levels (only moderate effect of testosterone on sexuality in older men), although underlying anxiety and depression are more probable causes.

What is your partner's attitude towards the problem?
- Try to establish insight into the quality of the relationship. Try to establish if there is any underlying performance anxiety. Is this a secondary effect of the problem? Does the partner know that the patient is discussing this issue? If not, what would they say if they knew?

What do you think is causing your erection to fail?
- Worth sharing views on possible iatrogenic factors and possible links with the cause of the problem.

Have you or your partner done anything about it?
- Worth knowing if the patient has already sought advice or obtained any treatment before discussing it with you.

What are you or your partner hoping to gain from any treatment that may be available?
- Assess expectations of patient from treatments they are aware of. Consider whether these seem realistic or not.

Is there anything else I should know?

- **Note 2:** RCP Guidelines 2008, recommends that patients with erectile dysfunction be assessed for the use of sildenafil or an equivalent drug.

Appendix vii: Goal planning guidance provided in the LoTS care Manual

Goal planning

Goal planning is considered an essential part of contemporary rehabilitation practice (Levack *et. al.*, 2006). In the National Clinical Guidelines for Stroke (RCP, 2008) the fundamental processes of healthcare delivery are outlined as problem solving approaches that encompass assessment and diagnosis, goal setting (planning), support and treatment, and evaluation. These approaches are addressed in the system of care for stroke.

The RCP specifically recommend that every patient involved in the rehabilitation process should:

- Have their wishes and expectations established and acknowledged;
- Participate in the process of setting goals unless they choose not to or are unable to participate because of the severity of their cognitive and linguistic impairments;
- Be given help to understand the nature and process of goal setting and be given help (e.g. using established tools) to define and articulate their personal goals.

And have goals that are:

- Meaningful and relevant;
- Challenging but achievable;
- Include both short-term (days/weeks) and long-term (weeks/months) targets;
- Include both single clinicians and also the whole team;
- Documented with specified time bound measurable outcomes;
- Have achievement evaluated using goal attainment;
- Include family members where appropriate;
- Used to guide and inform therapy and treatment.

Appendix viii: Examples of Algorithms

3

SEXUAL FUNCTIONING- REFERENCE GUIDE 13

Sexual problem present that is of concern to patient and partner

↓

Full history taking
(see Sexual Functioning Questionnaire – **Assessment Scales** in **References**).
Refer to guidance on next page.

Sexual desire (limited or no sexual activity)	Relationship issues	Enjoyment (sexual activity but reduced pleasure)	Orgasmic dysfunction	Erectile dysfunction

Consider possible causes to guide appropriate service response.

Fear (recurrent stroke, rejection) Self-image Fatigue Depression Medications Incontinence	Difficulty expressing emotions Relationship problems (long-standing / post-stroke)	Fear Pain (Note 1) Practical difficulties Spasticity Incontinence Altered arousal	Other illnesses Medications Anxiety Relationship difficulties (past or present)	Reduced androgen levels Depression Smoking Alcohol Medications Other illnesses

Recent test for diabetes / androgen levels?

Yes → Test results 'normal'

No → Refer to GP. Review 2 weeks.

Problems:

Psychological (fear after stroke, self image)

Physical problems (pain in certain positions, limb weakness, incontinence, sensation, communication difficulties)

- Explore in open discussion, simple remedies with both stroke patient and partner. (Non-sexual contacts, different positions, pillow support, lubricants (mild discomfort), non-verbal cues for 'I love you' i.e hand to chest).
- Provide reassurance (changes expected with age and after illness) & appropriate literature (see **box file).**

Complex physical problems

(Vaginismus, lubrication/vaginal dryness. Disease or medications side-effect). Discuss GP referral options:
- Pelvic examination (females)
- Medications review
- Physical assessment and treatments (range of treatments for ED)
- Combined physical and psychological therapies might be required

Complex psychological problems

(Long-term relationship difficulties, possible mood disorder (► **Ref Guide 14**)
Discuss referral options:
- Psychosexual counselling (e.g. RELATE)
- GP

Review progress after one month (depending on treatment) and continue to monitor.

MOBILITY/FALLS - REFERENCE GUIDE 5

MOBILITY

Patient has ongoing mobility problems and has not recently been reviewed / treated by a therapist

↓

Refer to local physiotherapy services

FALLS

Assessment suggests patient has increased risk of falling and / or history of falling.

↓

Has a falls evaluation been performed recently? —— **Yes** ——→

No/don't know ↓

Liaise with community physiotherapist trained in falls assessment or specialist falls service regarding carrying out full evaluation involving (**Assessment Scales** in **References**):
- Assessment for fear of falling;
- Recording details of falls history;
- Checking notes for pre-discharge examination on patient vision, gait and balance;
- Enquiring or checking notes about medications (Especially: four or more medications and sedative medications confer greater risk of falls. Ask about side effects, particularly dizziness.);
- Assessments of visual and cognitive impairment, urinary incontinence, home hazards;
- Checking blood pressure in standing and lying.

Is patient being provided with package of interventions to reduce risk of falls?

Yes ↓

Ensure patient and carer clear on prevention management of falls.

No ↓

Appropriately trained health professionals, experienced in the assessment and management of falls and falls prevention should identify an individually designed intervention package for each patient. This multifactorial intervention package should address all the relevant risk factors for falls identified in the falls assessment for that particular patient. It will include some of the following:
- Provide re-assurance;
- Advice on appropriate use of mobility aids;
- Make enquiries with clinician (see patient notes) with lead responsibility for monitoring medication about reviewing and modifying drugs (i.e. reduction);
- Individually prescribed home programme of muscle strengthening and balance retraining;
- Treatment of postural hypotension;
- Home hazard assessment and modification for patients with a history of falls;
- Specialist falls prevention programme (particularly where fear is a major factor);
- Vision assessment and referral;
- Information on preventing and managing further falls.

DRIVING - REFERENCE GUIDE 10A

10A

Please ensure that you have read the text before using this algorithm.

Does patient wish to return to driving in near future? —No→ Review in 3 months → Advise patient to obtain a Statutory Off Road Notification (**SORN**) from the DVLA (if keeping their car) → ►**Ref Guide 10B**

↓ Yes

>1 month since stroke? —No→ Assess abilities likely to affect driving. Review after appropriate period.

↓ Yes

Was patient a regular driver before stroke? Does patient hold a full driving licence? —No→ Advise patient to contact DVLA

↓ Yes

Assess abilities likely to affect driving. (Note 1) Residual deficit present? Consider cognitive screening test. —Yes→ Provide written advice to GP on residual deficits (Note 2). Advise patient to complete B1 form (Note 3) (if able) and return to DVLA and to notify insurance company (if appropriate).

↓ No

Has patient discussed fitness to drive with GP (in last 3 months)? → Refer to GP (checks for residual deficits)

DVLA outcome → Licence revoked or application rejected (Note 4)

DVLA recommendations → Further DVLA examination

↓

Consider cognitive screening test

↓

Further assessment of driving or driving test

Test taken but not passed | Test declined or passed

Advise patient. Requires fuller assessment of why failed by OT and psychologist. Patient wishes to proceed with driving test/assessment? —Yes→ Refer patient to local assessment / mobility centre (see www.dvla.gov.uk for contact details). List of contacts available in **box file.**

↓ No

Review in 3 months | Driving test failed (Note 5)

14

PATIENT MOOD - REFERENCE GUIDE 14

Assessment suggests possible mood problem (Depression, Anxiety)

Pre-existing or post stroke depression already identified in hospital

No treatment (provided or currently being taken)

Screen for depression (**Assessment Scales** in **References**)

Current treatment but with persisting mood problems

Possible depression Review ≥ 2 weeks

Persistent depression

Duration ≥4-6wks — No → Review at 4-6 weeks of treatment

Consider presence of cognitive impairment

Yes

Non-compliance?**Note** — No → Refer GP for alternative Treatment Review 4-6 weeks Monitor 6 months

Screen for anxiety (**Assessment Scales** in **References**)

Yes

Anxiety

Side effects? — Yes

For severe persistent anxiety Refer to GP/psychologist for treatment: De-sensitisation CBT (re-assessment by clinical psychologist)

No

Patient preference

Provide verbal / written information
Discuss—possible causes of mood problems (personal, non-stroke related/ practical, clinical stroke related)
Discuss—Impact of mood on participation in rehabilitation

Persistent depression

Offer & discuss treatment approaches

Anti-depressants

Declined

Accepted

Practical/social approaches

Exercise
Social interaction

Clinical approaches
Address all other clinical stroke related problems

Enhanced by goal setting with Practical problem solving

Review 1 month

Refer to GP

Review 4-6 weeks Monitor 6 months

Review 4-6 weeks Monitor 6 months

Persisting mood problems

Note: Check for OTC medication esp. St John's Wort - advise against its use in patients taking prescribed anti-coagulants.

3

REFERENCE GUIDE 3
MEDICINES & GENERAL HEALTH

Discuss risk factors for stroke recurrence and identify need for support and advice for lifestyle modifications: smoking cessation therapy (local surgery clinics), moderate alcohol consumption, low salt and fat intake (local patient information sheets from dieticians, weight loss and regular exercise (local schemes may offer classes for people with disabilities).

Discuss presence of other health problems (check for regular reviews as appropriate).

Ensure aware of reason for medication, how and when to take, and how to obtain further supplies.
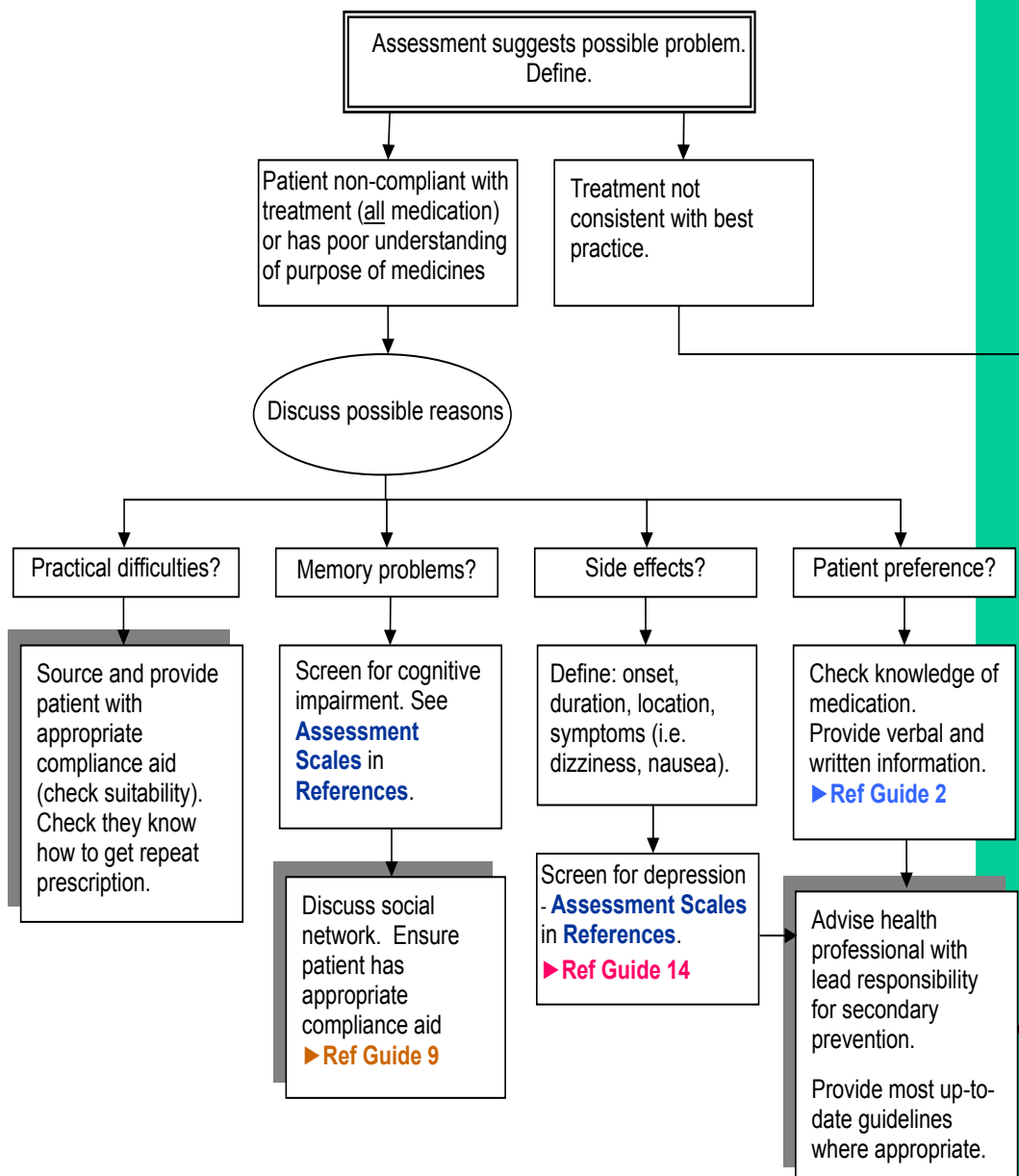
Review carer health.

Assessment suggests possible problem. Define.

Patient non-compliant with treatment (<u>all</u> medication) or has poor understanding of purpose of medicines

Treatment not consistent with best practice.

Discuss possible reasons

Practical difficulties?

Source and provide patient with appropriate compliance aid (check suitability). Check they know how to get repeat prescription.

Memory problems?

Screen for cognitive impairment. See **Assessment Scales** in **References**.

Discuss social network. Ensure patient has appropriate compliance aid ▶**Ref Guide 9**

Side effects?

Define: onset, duration, location, symptoms (i.e. dizziness, nausea).

Screen for depression - **Assessment Scales** in **References**. ▶**Ref Guide 14**

Patient preference?

Check knowledge of medication. Provide verbal and written information. ▶**Ref Guide 2**

Advise health professional with lead responsibility for secondary prevention.

Provide most up-to-date guidelines where appropriate.

Appendix ix: Easy-Care assessment sections and questions

	Section	Questions and Prompts
1.	**Seeing, Hearing and Communication**	Can you see? Can You hear? Do you have difficulty making yourself understood because of problems with your speech? Can you use the telephone?
2.	**Looking after yourself**	Can you keep up your personal appearance? Can you dress yourself? Can you wash your hands and face? Can you use the bath or shower? Can you do your housework? Can you prepare your own meals? Can you feed yourself? Do you have any problems with your mouth or teeth? Can you take your own medicine? Have you had any problems with your skin? Do you have accidents with your bladder? Do you have accidents with your bowels? Can you use the toilet? Can you move yourself from bed to chair, if next to each other? Do you have any problems with your feet? Can you get around indoors? Can you manage stairs? Have you had any falls in the last six months? Can you walk outside? Can you go shopping? Do you have any difficulties getting public services?
3.	**Your safety and relationships**	Do you feel safe inside your home? Do you feel safe outside your home? Do you ever feel threatened or harassed by anyone? Do you ever feel discriminated against for anyone reason? Do you receive help from any family, friends or neighbours? Is there anyone who could help you in case of illness or emergency?
4.	**Your accommodation and finance**	In general, are you happy with your accommodation? In the last year have you had difficulty keeping your house warm? Do you have concerns about the size and space of your home? Do you have concerns about the condition of your accommodation? Do you have concerns about the location of your home? Do you have concerns about the cost of your home? Are you able to manage your money and financial affairs? Would you like advice about financial allowances or benefits?
5.	**Looking after your health**	Do you take regular exercise? Do you get out of breath doing normal activities? Do you smoke any tobacco? Do you think you drink too much alcohol? Has your blood pressure been checked recently? Do you have a flu jab each winter? Have you had any screening tests in the last three years? Do you have any concerns about your weight or fluid intake? Do you have any special dietary needs?
6.	**Your well being**	Are you able to pursue leisure interests, hobbies, work and learning activities which are important to you? In general would you say your health is? Do you feel lonely? Have you suffered from any recent loss or bereavement? Have you had trouble sleeping in the past month? Have you had much bodily pain in the past month? During the last month, have you often been bothered by feeling down, depressed or hopeless? During the last month, have you often been bothered by having little interest or pleasure in doing things?
7.	**Your memory**	Have you any concerns about memory loss or forgetfulness?
8.	**Other**	

Appendix x: Overview assessment sections and questions

	Section	Questions and Prompts
1	General Health,	Do your have any allergies? Do you have any diagnosed medical conditions? Do you have nay concerns about your health/well being? Do you have any regular tests? (blood tests/ blood pressure) when did you last see a doctor? Have you been in hospital recently? Do you have difficulty with, breathing, eating /drinking, swallowing/choking, sleep pattern, pain, skin condition/tissue viability, Continence –urine or bowels, foot or nail care, oral health, unplanned weight loss/gain past 3mths. Alcohol intake, smoking history, height weight.
2	Personal safety	Have you concerns about your personal safety? Do you live alone? Do others have concerns about your safety? Do you have difficulty summoning help? Do you have any of the following, keyholder/keysafe/lifeline
3	Medication issues	Do you have difficulty getting your prescribed medication? Do you have difficulty getting medication out the container? Do you have difficulty in taking the prescribed amount? Do you take over the counter medication? Do you look after your own medication? Have you missed any doses of your medication recently, is so why? Do you need to be reminded to take your medication? When was the last time you had you medication reviewed?
5	Personal Care and Domestic Needs	Doing housework? Doing laundry? Washing and bathing? Using toilet/commode? Preparing food and drinks? Doing shopping? Do you need a special diet? Keeping warm / cool?
6	Mobility issues	Do you have any difficulty with: getting around the house? Transferring in/out of bed? Transferring in/out of chair? Getting in/out of property? Getting up/down stairs? Do you use anything to help with mobility indoors? Do you use anything to help with mobility outdoors? Have you had two or more falls in the last six months?
7	Sensory needs	Do you have difficulty with sight? Hearing? Speech? Communication?
8	Emotional well being	Do you have difficulty with: Disorientation, feel confused or have any problems with co-ordination? Concentrating or remembering? Anxiety/ distress/ mood changes? Depression/low in mood/sad? Do you rely on others for all your care? Do you rely on others for part of your care? Do you feel socially isolated? Have you experienced a loss or bereavement recently?
9	Environmental Needs and Resources	Do you have a Blue Badge? Are you able to access public transport/ring and ride? Are you bale to access local shops? Are you able to access leisure activities and work? Are you able to get in /out of care? Is your accommodation suitable to your needs? Have you got any heating issues?
7	Financial Advice	Do you currently receive any of the following? Disability living allowance/ Mobility- attendance allowance, if so what level? Do you have difficulty managing finances? Are you dependent on others to manage your finances? Would you like a benefits review?
	Relationship and Carer support	Do you get regular support from others? Do they need support? Are you able to maintain social contacts? Do you have any cultural/spiritual/religious considerations that wee need to be aware of?