Citation for published version

Abrahamson, V. (2017) How does the review process support adults in the first year post-stroke? Doctor of Philosophy (PhD) thesis, University of Kent,.

DOI

Link to record in KAR

https://kar.kent.ac.uk/66259/

Document Version

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How does the review process support adults in the first year post-stroke?

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Submitted in accordance with the requirements for the degree of Doctor of Philosophy

Centre for Health Services Studies

University of Kent

September 2017

Acknowledgements

I would like to express my sincere thanks to all those who participated in this study. Special thanks go to the patients, carers, Stroke Nurse Specialists and Stroke Association staff who gave their time so generously and without whom the study would not have been possible. I am also very grateful to the NHS Trusts, Stroke Consultants and the Stroke Association for supporting the study.

I would like to thank my supervisors Professor Patricia Wilson and Professor Stephen Peckham for their advice, support and guidance over the past three years. In particular, I would like to thank Professor Wilson for her unerringly astute feedback, kindness and humour.

My thanks also to Robin Cant for his support, advice and friendship.

I would also like to thank my colleagues, friends and family for their support and advice.

Finally, I am very grateful to the Economic Social Research Council for funding the study.

Abstract

Background: Reducing stroke related mortality and morbidity is a Government priority. In 2007, the National Stroke Strategy recommended reviewing stroke survivors at six weeks, six months and annually thereafter but there is much variation in implementation and limited evaluation. While there is evidence of unmet need post-stroke there is little evidence to suggest that the review process ameliorates it.

This study aimed to identify the purpose and outcomes of the review process from the perspective of patient, carer, provider and commissioner and to identify the mechanisms by which these were achieved. As many patients are still engaged in rehabilitation at six weeks post-stroke, a six-week review is of less significance than a six-month one by when services have usually withdrawn and patients report feeling abandoned. The annual review is not widely available and therefore this study concentrates on the six-month review.

Method: A multiple case study approach underpinned by critical realism informed the research design and allowed in-depth exploration of the six-month review. Case studies draw on multiple sources of evidence to allow triangulation, develop convergent evidence and thus strengthen construct validity. Three sites in the South East Coast region were chosen for their different approaches set within the context of local policies and demographics. Data sources included interviews with patients, carers, providers who carried out reviews, service managers and commissioners; observations in clinical settings; and local policy and service documentation. This allowed multiple perspectives in order to explore the underlying mechanisms of the review. Patients were interviewed approximately six weeks post-discharge and again after their six-month review. Overall, 46 patients, 30 carers and 28 professionals were interviewed between December 2015 and October 2016. Twenty-nine reviews were observed. The age range of patients was 28-91 years and slightly more than half were male.

Data analysis drew on three approaches selected for a particular strength: thematic analysis was chosen for its clear and succinct account of coding and epistemologically neutral stance (Braun and Clarke 2006); Yin's (2014) case study analysis provided helpful suggestions for theory development; and Bazeley's (2013) comprehensive text provided a model for analysis and theory development compatible with critical realism. Data was managed using Nvivo 11. Within each site, all data sources were coded in an iterative process to develop the coding framework and an understanding of site specific issues. Data was then explored across sites before building a typology of patients in order to develop a theoretical understanding of the review process that could be extended to a broader context.

Findings: Six-month reviews carried out by stroke nurse specialists were found to be more medically orientated than those completed by a Stroke Association co-ordinator who focused on social issues. Reviewers regarded them as an opportunity to address unmet need but expressed different opinions as to what this encompassed. Managers and commissioners were mainly concerned with outcomes focused on (cost-) effectiveness. Patients' views were influenced by their experiences of the care pathway, orientation to rehabilitation and the nature of their relationships with clinicians during their rehabilitation. Those who reported a positive experience of care and took a proactive approach to rehabilitation were likely to self-manage their condition and find the review helpful. Their comments emphasised that they valued reassurance, information and advice. A second group was positive about rehabilitation but largely on their own terms and rejected advice from reviewers. Finally, a small number who did not find the review helpful had pre-existing long-term conditions and/or complex social circumstances. They were critical of services, did not trust reviewers or clinicians in general, and were focused on issues outside the remit of the review.

Discussion: The medical and social paradigms which framed the review process each had their own strengths but some patients, particularly those with complex social circumstances and co-morbidities, needed elements of both within an individually tailored approach. There was a tension between the structure imposed by policy and the agency and wish of reviewers and patients to individualise the process. Encouraging self-management was a key aspect of the review but was limited by the nature of the intervention and gaps in community services. The review acted as a gateway to further services, for example clinical psychology, although such services were not always available.

Recommendations: The six-month review needs to be embedded into the care pathway and strategies for secondary prevention reviewed and consolidated at each stage. Reviewers should be allowed the freedom to individualise the process on a needs-led basis rather than adhering to a rigid framework dictated by policy. The six-month review ought to relate back to therapy goals and forward to community services to encourage participation in valued activities, and community integration, which are the key goals of rehabilitation.

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Abbreviations

6MR	Six-month review
ASU	Acute stroke units
CCG	Clinical Commissioning Group
ESD	Early supported discharge
GM-SAT	Greater Manchester Stroke Assessment Tool
GP	General Practitioner
HASU	Hyper acute stroke unit
ICF	International Classification of Functioning, Disability and Health
NHS	National Health Service
NICE	National Institute for Health and Care Excellence
SEC SCN	South East Coast Strategic Clinical Network
SA	Stroke Association
SNS	Stroke nurse specialist
SSNAP	Sentinel Stroke National Audit Programme
TIA	Transient ischaemic attack
UK	United Kingdom

Glossary

Term	Description
Adherence	The degree to which an individual correctly follows medical advice. Non-adherence results when a patient does not initiate or continue advice that a clinician has recommended. Previously termed compliance.
Atherosclerosis (or arteriosclerotic vascular disease)	The gradual build-up of fatty material (atheroma), commonly cholesterol that forms plaques on the arterial walls. This causes arterial stenosis, or narrowing of the artery, hardening of the arterial wall and ultimately a stroke.
Atrial fibrillation	One of the most common causes of an abnormal heart rhythm (arrhythmia) involving the atria (upper chambers of the heart). Symptoms include palpitations but the condition may be asymptomatic. It can lead to a stroke.
Cardiovascular disease	All the diseases of the heart and circulation including coronary heart disease, angina, heart attack, congenital heart disease and stroke.
Case study	An empirical inquiry that investigates a contemporary phenomenon (the 'case') in depth and within the real-world context, especially when the boundaries between phenomenon and context are not clearly evident.
Cerebrovascular disease	Conditions caused by vascular disease of the cerebral circulation. Arteries supplying blood to the brain are affected; commonly causing stroke, TIA, subarachnoid hemorrhage or vascular dementia.
Co- morbidity	The presence of more than one (or multiple) long-term conditions.
Dysarthria	Speech disturbance caused when the muscles producing speech are impaired. It makes speech hard to understand and often co-exists with dysphasia.
Dysphasia (or aphasia)	The terms are often used interchangeably but aphasia refers to complete inability and dysphasia to partial inability. Expressive dysphasia presents as difficulty communicating, while receptive dysphasia refers to difficulty comprehending speech. Most people have a combination.
Dysphagia	Difficulty swallowing because the relevant muscles are impaired.
Embolus	An embolus is a particle, most frequently a thrombus, which travels in the arterial bloodstream, originating from elsewhere, usually the heart or

	chest, and can cause an embolic stroke (the blockage of an artery by a travelling particle).
Greater Manchester Stroke Assessment Tool (GM-SAT)	A tool used to carry out the 6MR which aims to identify unmet needs. It consists of 38 items with yes/no answers and an algorithm for each question.
Hemiparesis	Muscle weakness down one side of the body due to contralateral damage to the cerebral cortex. The location of the stroke will determine the exact area of weakness. Previously referred to as hemiplegia, which means complete paralysis of the affected side.
International Classification of Functioning, Disability and Health (ICF)	A biopsychosocial model devised by the World Health Organisation (2002) that can be used to assess how a particular condition affects body structures and functions, participation in activities and the impact of the environment.
Illness burden	This encapsulates the impact of chronic, or long-term, illness and includes all the tasks that must be undertaken to manage it in daily life.
Long-term conditions	Health conditions that last a year or longer, impact on daily life and require ongoing care and support.
Minimally disruptive medicine	This concept refers to the time and effort required to adhere to treatment regimens and aims to impose the smallest possible burden on patients. It relates to treatment (and illness) burden.
Polypharmacy	The concurrent use of multiple (four or more) medications generally with adults aged over 65 years with multiple long-term conditions.
Realism	Realism takes a middle road between interpretivism and positivism. A realist ontology accepts that knowledge is provisional and has an interpretative element but does not accept multiple realities. Critical realism is one strand of realism associated with Roy Bhaskar (1944-2014).
Rehabilitation	The process of regaining optimal physical, cognitive, emotional, communicative and social function after an event such as a stroke. Rehabilitation is usually led by a multi-disciplinary team including doctors, nurses, occupational therapists, speech and language therapists and physiotherapists.
Self-management	Taking responsibility for one's own behaviour and well-being. It may include adhering to medication regimes and healthy lifestyle advice.

Sentinel Stroke National Audit Programme (SSNAP)	A national audit of stroke care in England, Wales and Northern Ireland that aims to improve quality of care by auditing services against evidence-based standards.
Six-month review (6MR)	An assessment of need, six-months after a stroke, to identify any interventions or services that a patient and/or their carer may require.
Stroke (or cerebrovascular accident)	Defined as a neurological deficit of cerebrovascular cause that persists beyond 24 hours or is interrupted by death within 24 hours. Ischaemic stroke is caused by a clot or embolus in the cerebral circulation. The part of the brain deprived of oxygen dies, resulting in loss of localised function. Haemorrhagic stroke refers to a blood vessel in the brain that ruptures and bleeds into the surrounding tissues; the presentation is different to that of ischaemic stroke.
Thrombus	A blood clot (thrombus) that commonly forms around atherosclerotic plaques in an arterial wall. A thrombus can lead to an embolic stroke if it breaks off and travels in the blood stream.
Transient ischaemic attack (TIA)	Stroke symptoms and signs that resolve within 24 hours. Symptoms usually resolve within minutes to hours but require urgent investigation because a TIA may be the precursor to a stroke.
Treatment burden	Patients are required to carry out work to manage a long-term condition and must possess the capacity to do so. When demand exceeds capacity, treatment becomes burdensome.

Chapter 1: Introduction

1.1: Introducing the thesis

Reducing stroke related mortality and morbidity is a Government priority: it is the fourth most common cause of death in the United Kingdom (UK) but the third biggest in Scotland. Every year approximately 110,000 people in England have a stroke and 40,173 people died of stroke in the UK in 2015 (Stroke Association 2017). The total cost is estimated at £7 billion annually (Department of Health 2007). There is evidence of unmet self-reported need in nearly 50% of stroke survivors between 1-5 years post-stroke (McKevitt et al. 2011) and high rates of social isolation, depression and anxiety amongst the estimated 300,000 people in England with moderate to severe stroke-related disability (Department of Health 2007).

The National Stroke Strategy (Department of Health 2007) recommended reviewing stroke survivors at six weeks, six months and yearly thereafter to identify and address on-going need. However, there is much variation in implementation and availability of the review, and limited evaluation of process or outcome (National Audit Office 2010; Royal College of Physicians 2015b). Many patients are still receiving services at six weeks and few places offer yearly reviews. Therefore, this study focuses on the six-month review (6MR).

This chapter provides an overview of the thesis and an introduction to the topic. The rationale for carrying out the study is discussed before presenting the research questions and an overview of the chapters.

1.2: Motivation for the study

My interest in the topic stems from working as an occupational therapist. My experience of stroke rehabilitation in the UK was of poorly run wards and inadequate nursing care. Poor communication within and across services resulted in fragmented and non-person centred care and there was little follow-up once patients went home. This contrasted to my previous experience in New Zealand where the ward was efficient, friendly and everyone, including carers, participated in rehabilitation. Staff and resources were sufficient and aftercare included outpatient and support groups, rehabilitation at home, vocational rehabilitation and ongoing support for as long as needed. We developed strong therapeutic relationships with patients and their families over several months which highlighted the dissonance with the unit I worked on when returning to the UK.

Initially, the six-month review appeared to be a pragmatic approach to ameliorating some of the needs that I had observed and I was curious to see how policy would translate into practice. I wanted to know how it would work, what impact it would have on patient and carers' daily lives and what might be the enablers and barriers. In particular, I was interested in how the review might contribute to health promotion and secondary prevention. My master's thesis had evaluated the role of occupational therapists in health promotion on a stroke ward and although all therapists wanted to address this, they acknowledged that they lacked the time and skills (Abrahamson 2006). While this may have changed from when I carried out the study, the occupational therapy undergraduate degree programme I taught on more recently could only offer a basic introduction to these topics. Therefore, I wanted to explore the remit of the 6MR against a background of clinical experience and policy changes since I had qualified.

1.3: Research questions and the approach to answering them

The thesis is concerned with what the 6MR means for patients and carers in terms of contributing to their overall recovery. The review is premised on the notion that stroke services do not sufficiently meet patients' needs and while there is evidence of unmet need, there is little evidence that the 6MR ameliorates it. This led to the following research questions:

1. What is the purpose of the review process from the perspective of patient, carer, provider and commissioner?
2. What are the intended and/or unintended outcomes of the review process from the perspective of patient, carer, provider and commissioner?
3. By what mechanisms does the review process achieve the intended outcomes? What are the enablers and barriers?

I have used the term 'patient' as short-hand for 'the person who has had a stroke'. Similarly, the term 'carer' refers to the spouse, partner, family member or friend who helps the stroke survivor on a regular basis. Although this may be criticised as reflecting a medical orientation, this is not the case. Simply, the alternatives, such as service user or stroke survivor, are clumsy and carry their own connotations. I discussed this with a stroke survivor who agreed that patient and carer, although not ideal, are suitably unambiguous terms.

1.4: Organisation of the study

The thesis is organised into seven chapters as follows:

Chapter 1 - Introduction. This chapter provides an overview of the thesis, introduces the topic and presents the research questions.

Chapter 2 - Literature review. The chapter starts by explaining the aetiology of stroke, risk factors and why it is a public health priority in the UK. The personal long-term consequences of stroke are explained using the International Classification of Functioning, Disability and Health (ICF) (World Health Organization 2002) which is a conceptual model widely used in stroke research. Current models of stroke services are described, with the emphasis on early supported discharge and community rehabilitation (Department of Health 2007). This leads to a review of the literature on unmet need before considering the policy drivers and clinical guidelines that intend to ameliorate it. The chapter finishes by considering the availability of the review, evidence of effectiveness and different tools used to carry it out.

Chapter 3 - Methodology and method. This chapter is divided into two main sections. The first section concentrates on the theoretical underpinning of the study and seeks to justify why critical realism was selected to underpin a case study design. The second section explains the case study design including data collection methods, sampling decisions, analysis and a description of the sample.

Chapter 4 - Findings: Organisation of stroke services and the patient journey from stroke to 6MR. The chapter starts with a description of the case study sites. It then explores respondents' experiences during the inpatient phase, transition home and first few months post-discharge. A typology is developed that reflects patients' responses to the experience of negotiating the care pathway.

Chapter 5 - Findings: The six-month review. This chapter concentrates on the purpose and outcomes of the 6MR from the perspective of all stakeholders, particularly reviewers and patients. It compares approaches across the three sites and uses case studies to illustrate the findings, drawing on chapter four's typology to differentiate the response to review.

Chapter 6 - Discussion. Developing the findings, this chapter explores the underlying mechanisms that explain why the 6MR appeared to have limited impact. It draws on the notion of biographical disruption, the illness trajectory and the therapeutic relationship prior to developing a conceptual framework underpinned by the concept of minimally disruptive medicine and burden of treatment.

Chapter 7 - Conclusion and recommendations. The last chapter reviews the research questions and addresses study limitations. It concludes by discussing the implications for policy and practice and makes recommendations for further research.

1.5: Chapter summary

This chapter provides an overview of the thesis. It introduces the background to the study, the research questions, underlying methodology and case study design. The organisation of the thesis has been described in order to orientate the reader.

Chapter 2: Background to the study

This chapter outlines the background to the review process in terms of national policy, local implementation and the evidence base. It considers the public health implications of stroke and the impact on the individual. The stroke care-pathway, as informed by policy, is described in order to contextualise the review process. The chapter starts with a description of the search strategy to identify relevant literature appertaining to the six-month review (6MR).

2.1: Searching the literature

A preliminary literature search was completed to identify studies relating to community rehabilitation, self-management, secondary prevention, community (re)integration, continuity of care, evidence of unmet need and the review process (Table 1). I knew that my research question would focus on the 6MR but was looking for literature that linked it with other concepts that were prevalent in the stroke literature at the time and reflected policy drivers. I limited to literature from 2007 onwards, when the National Stroke Strategy introduced the 6MR (Department of Health 2007), written in English and pertinent to the UK healthcare system.

Table 1: Scoping the literature

General area	Specific search terms combined with stroke*
Terms related to the stroke care pathway	• Discharge OR post-discharge • Transition • Early supported discharge • Community (stroke) rehabilitation • Six-month review OR annual review • Continuity of care • Integrated care
Concepts relevant to life after stroke	• Community (re) integration • Participation OR engagement • Social networks OR family support
Concepts relevant to the six-month review	• Unmet need • Self-management OR self-care • Secondary prevention • Health promotion • Lifestyle factors

Although the above search generated many interesting papers, including some related to unmet need, there was almost no mention of the 6MR, which confirmed that it was a gap in the literature. One protocol has been published that aims to ascertain the value of follow-up at six months (Jenkins and Price 2014) but the authors are still collecting data (Abrahamson 2017).

Once the research question had been refined, 'PICO' was used to narrow the search:

- **Population:** Adults aged 18 years and above (the age at which patients are treated in adult stroke units) who had a stroke and received National Health Service (NHS) treatment in England, including those for whom it was their first stroke, a recurrent stroke and/or had other long-term conditions.
- **Intervention:** Six-month and yearly review; standardised or non-standardised tool used to carry out the review.
- **Comparison:** Standard care.
- **Outcomes:** Indicators of unmet need; patient satisfaction; patient recorded outcome measures; knowledge and understanding; self-management; continuity of care; community integration.

Search terms were MeSH and alternatives (depending on the database) and [All Fields] were included. Limits applied were English language and 2007 onwards, as previously stated. All study designs were included. Searches were carried out at the start of the doctorate (autumn 2014) and updated while writing the literature review (winter 2016) and discussion (summer 2017). Appendix 1 gives an example of an updated literature search for unmet need. Zetoc alerts were used throughout the study period and included specific journals and authors. The following search terms (Table 2) and sources of evidence (Table 3) were used:

Table 2: Search terms for literature review

MeSH term	Alternative search terms [All Fields]
Stroke	'cerebrovascular accident' OR CVA OR 'brain ischaemia' OR stroke*
'Patient discharge'	post-discharge, transition
'Concurrent review'	review OR 'six-month review' OR 'annual review' OR 'yearly review' OR 'structured reassessment'
'Needs assessment'	'unmet need' '**G**reater **M**anchester **S**troke **A**ssessment **T**ool' OR GM-SAT '**P**ost-**S**troke **C**hecklist' OR PSC '**L**onger-term **U**nmet **N**eeds after **S**troke' OR LUNS
'Outcome assessment (healthcare)'	'outcome measure'

Rehabilitation ‘Treatment outcome’ ‘Patient care planning’ Self-care	rehab* OR rehabilitation OR therap* ‘early supported discharge’ OR post-discharge OR transition outcome* ‘goal setting’ ‘self-management’

Table 3: Sources of evidence

Category	Specific source
Databases	PubMed PsychInfo Scopus Cumulative Index to Nursing & Allied Health Literature (CINAHL) NHS Evidence Search Cochrane Library The Database of Research in Stroke (‘Doris’) National Institute for Health Research Network Portfolio Google Scholar (for specific authors or papers)
Grey literature	Sentinel Stroke National Audit Programme Clinical Commissioning Group websites of case study sites Trust websites of case study sites
Policy	Department of Health National Institute for Health and Care Excellence Royal College Physicians Scottish Intercollegiate Guidelines Network South East Coast Strategic Clinical Network
Organisations	Stroke Association Kings Fund The Health Foundation

2.2: Stroke: a major health issue

This section starts with a definition of stroke and describes the causes and the categorisation of stroke. Key risk factors are discussed because these are relevant to primary and secondary prevention, the latter being a component of the 6MR.

Stroke has been defined by the World Health Organisation as a clinical syndrome consisting of 'rapidly developing clinical signs of focal (at times global) disturbance of cerebral function lasting more than 24 hours or leading to death with no apparent cause other than a vascular origin' (Hatano 1976, p541). This differentiates it from transient ischaemic attack (TIA) which is defined as stroke symptoms and signs that resolve within 24 hours but as symptoms usually resolve within minutes to hours, any longer lasting neurological signs should be considered a stroke (NICE 2008). The incidence of stroke following TIA can be as high as 18% at 90 days (Johnston et al. 2007; Selvarajah et al. 2008) hence rapid assessment is essential to reduce the incidence of potentially avoidable strokes (Royal College of Physicians 2016a). Lacunar infarcts, a type of ischaemic stroke, can be mistaken for TIAs, may be asymptomatic and can only be seen with a magnetic resonance imaging scan (Dawson et al. 2013).

There are several different categorisations of stroke reflecting its complex aetiology and although the World Health Organisation definition is still current, it requires updating to reflect knowledge advances based on brain and vascular imaging (Sacco et al. 2013). The 24-hour inclusion criteria for cerebral infarction is inaccurate because permanent injury can occur much sooner and conversely, reversibility of ischaemia is possible with rapid treatment (Sacco et al. 2013). Also important are asymptomatic, or silent strokes, which appear on imaging but without a history of acute neurological dysfunction (Dawson et al. 2013).

The imperative for rapid treatment led to the 'FAST' campaign developed by the Stroke Association (SA) in partnership with other experts and launched in 2009 (Public Health England 2015). This was in response to the National Stroke Strategy (Department of Health 2007) which highlighted poor public awareness. It emphasised that stroke is a medical emergency requiring urgent assistance. The acronym represents:

- **F**acial weakness: can they smile? Has their mouth or eye drooped?
- **A**rm weakness: can they raise both arms?
- **S**peech problems: can they speak clearly?
- **T**ime to call an ambulance

2.2.1: The mechanism of stroke

This section describes the aetiology of stroke, the main types of stroke and known risk factors. It starts with a brief overview of the brain to help understand the mechanism of stroke and the impact on function.

The largest part of the brain is known as the forebrain and includes the cerebral cortex, limbic system and basal ganglia. The cerebrum is divided into two hemispheres connected by the corpus callosum which allows communication between them. The left hemisphere controls the right side of the body and vice versa. The cerebral cortex, or outer layer of grey matter, has gyri (ridges) and sulci (furrows) and is the area where conscious thoughts and voluntary actions take place. Most sensory input from the environment is processed in the cerebral cortex and leads to a motor output. Each area of the cortex corresponds with a particular function so damage to, for example, the left motor cortex can result in right-sided weakness, or hemiparesis (previously termed hemiplegia). Behind the cortex, the cerebellum co-ordinates subconscious movements including balance and co-ordination in response to sensory input. The lower brain stem includes the midbrain, pons and medulla oblongata and is responsible for vital functions including breathing, heartbeat and blood pressure (Tortora and Derrickson 2008).

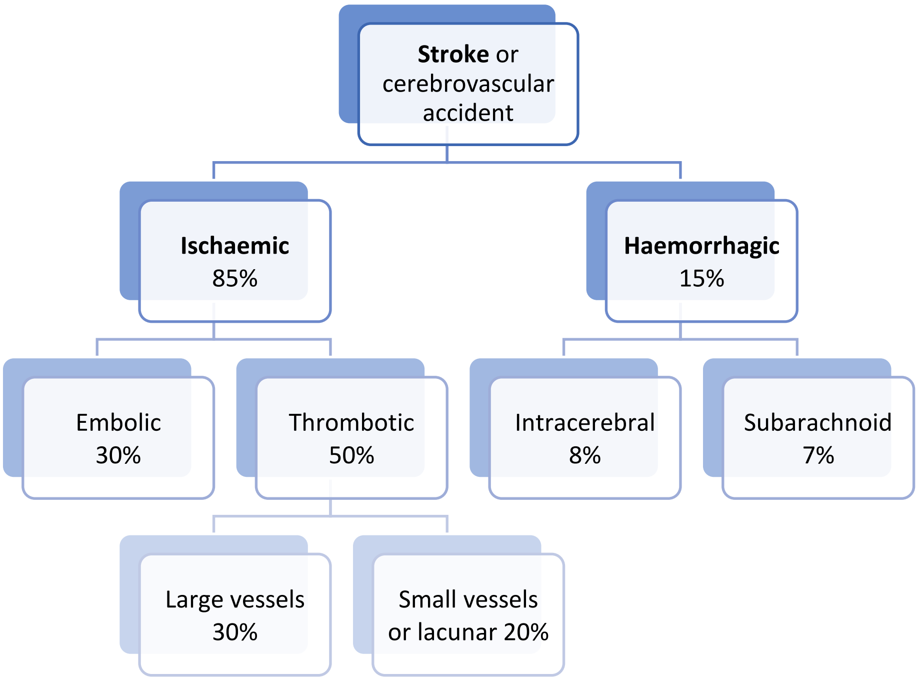
A stroke is caused by interruption of the blood supply to the brain commonly triggered by blockage of an artery by a clot (thrombus or embolus) or bleed (haemorrhage). This interrupts the supply of oxygen and nutrients to a specific part of the brain resulting in tissue death, or the death of nerve fibres made up of neurons. Neuronal death is considered irreparable but the nervous system has a high level of plasticity and surrounding areas appear to take over the function of damaged neurons through a process known as axonal and dendritic sprouting. This is the basis of rehabilitation, which capitalises on neuroplasticity (section 2.4.3). There is also some spontaneous recovery as cerebral oedema (brain swelling) subsides and viable neurons are reactivated (Tortora and Derrickson 2008).

The brain is supplied with oxygenated blood and nutrients by arteries that arise from the cerebral arterial circle (or Circle of Willis) which is an arrangement of blood vessels at the base of the brain. The most common site of stroke is the middle cerebral artery, a major branch of the cerebral arterial circle that delivers blood to the frontal, parietal and temporal lobes and often results in severe impairment including hemiparesis, sensory loss, visual field loss and aphasia (receptive and expressive language impairment) (Tortora and Derrickson 2008).

2.2.2: Different types of stroke

Stroke is classified under the current tenth edition of the International Classification of Disease as a disease of the circulatory system but the next edition, due 2018, will classify it as a disease of the brain, reflecting its location and treatment needs (World Health Organization 2016). There are two main types of stroke, ischaemic and haemorrhagic. Figure 1 presents a simplified classification of these with sub-types:

Figure 1: Simplified classification of stroke



(Leatherman, Sunderland and Airoldi 2008, p9)

N.B. Other causes account for 5% of strokes and have not been included for simplicity

The most common type is ischaemic which accounts for approximately 85% of strokes and is caused by a thrombus or embolus blocking or narrowing an artery that supplies blood to the brain. Often the artery has narrowed due to the formation of multiple plaques. This arterial stenosis is due to atherosclerosis (or arteriosclerotic vascular disease) which is a build-up of fatty materials such as cholesterol that cause the arteries to 'harden' or 'fur'. A chronic inflammatory response in the artery walls, largely due to the accumulation of macrophage white blood cells and promoted by low density lipoproteins (plasma proteins that carry cholesterol and triglycerides), compounds the problem (Tortora and Derrickson 2008).

Thrombotic strokes are more common than embolic and occur when arteries leading to or within the cerebral cortex become blocked or narrowed. The thrombus (blood clot) usually forms around atherosclerotic plaques. Since blockage of the artery is gradual, onset of symptoms is also gradual. A thrombus can lead to an embolic stroke if the thrombus breaks off and travels in the blood stream (Tortora and Derrickson 2008).

An embolic stroke refers to the blockage of an artery by a travelling particle, or debris, in the arterial bloodstream originating from elsewhere, usually the heart or chest. An embolus is most frequently a thrombus but it can also be a number of other substances including fat, cancer cells or clumps of bacteria. About 15% of embolic strokes occur in people with atrial fibrillation, or heart arrhythmia, that causes the heart chamber to retain blood rather than emptying completely. The blood that remains in the chamber can stagnate and form clots that enter into the arteries connecting the heart and brain (Tortora and Derrickson 2008).

The most common form of thrombotic stroke (large vessel thrombosis) occurs in the brain's larger arteries, usually caused by atherosclerosis. Another form of thrombotic stroke occurs when blood flow is blocked to very small arterial vessels which is known as small vessel disease or lacunar infarction. Lacunar strokes account for about 25% of ischaemic strokes although they can also cause haemorrhagic stroke (Wardlaw 2005). They are caused by cerebral small vessel disease, usually associated with hypertension and result in small infarcts deep within the white matter, basal ganglia or pons often involving multiple sites (Wardlaw 2005).

Cerebral small vessel disease refers to a syndrome of clinical and imaging findings that are thought to result from pathologies in the small blood vessels in the brain; lesions are clinically more insidious, or 'silent'. The syndrome is associated with increasing age, causes stroke and dementia and accounts for about 20% of all strokes worldwide and 25% of ischaemic (or lacunar) strokes. Cognitive impairment, depression and gait problems are often seen with this disease (Shi and Wardlaw 2016).

Haemorrhagic strokes account for about 15% of strokes and present differently to ischaemic stroke. They are characterised by sudden onset headache, vomiting and sometimes loss of consciousness. A blood vessel in the brain ruptures which leads to blood leaking into the surrounding tissue (cerebral haemorrhage) or into the space between the brain and skull (subarachnoid hemorrhage) (Sacco et al. 2013). The expanding haematoma compresses the neurons, which combined with loss of blood supply causes tissue death in the affected area. Additionally, the blood released by the haemorrhage has a directly toxic effect on brain tissue and vasculature (Tortora and Derrickson 2008). The mortality rate is high and those who survive are prone to severe disability; intracerebral haemorrhage has a nearly 40% fatality rate at 30 days (Sacco et al. 2013).

Intracerebral haemorrhage is commonly associated with ageing blood vessels, hypertension (high blood pressure) and atherosclerosis. Congenital arterial vascular malformation can also cause a bleed if the abnormal connection between artery and vein in the brain ruptures. Bleeding from aneurysms on cerebral vessels is a common cause of subarachnoid haemorrhages (Tortora and Derrickson 2008) thus it is essential to differentiate type of stroke because immediate treatment is different. For ischaemic stroke, thrombolysis is used to disperse the clot but this would exacerbate bleeding with a haemorrhagic stroke which may require surgery to remove blood and repair damaged blood vessels (Royal College of Physicians 2016a).

2.2.3: Risk factors and health inequalities

This section considers common risk factors for stroke and trends within different population groups. There are differences in the pattern and prevalence of stroke by gender, ethnicity and social deprivation but the picture is complex with many nuances yet to be understood so the section presents an overview. Key risk factors are summarised in Table 4.

The risk factors for stroke are common to all cardiovascular diseases. Medical conditions include a previous stroke or TIA, coronary heart disease, hypertension, diabetes, chronic kidney disease, peripheral arterial disease and vascular dementia. These are largely caused by atherosclerosis and key risk factors include high blood pressure (hypertension), high cholesterol (hypercholesterolemia) and obesity, which all contribute to the development of atherosclerosis (Leatherman, Sunderland and Airoldi 2008). About 40% of patients with ischaemic stroke have atherosclerotic stenosis, or narrowing of the large intracranial arteries and this is likely to be causative in about 7% of events (Royal College of Physicians 2016a). Many patients have one or more co-morbidities and several risk factors. For example, over half of patients included in national stroke data for April-July 2016 had hypertension, 20% had diabetes, 26% had a previous stroke or TIA and 19% had atrial fibrillation (Royal College of Physicians 2016b).

With regards socio-economic deprivation, people living in relatively poor areas appear to have increased risk, higher mortality and worse functional outcomes compared to those in more affluent areas (Addo et al. 2012). This might be partly explained by increased risk factors, for example, higher rates of smoking that could also to some extent explain widening differences in mortality by social class (Addo et al. 2012). Chen et al. (2015) reviewed a cohort on the South London Stroke Register and reported a significant association between socio-economic deprivation and short- and long-term functional impairment after ischaemic stroke in older people, women and those who did not have pre-stroke comorbidities. However, there were no apparent differences by ethnicity. While access to healthcare was posed as a possible explanation, studies are highly specific to the model of healthcare (Addo et al. 2012) and the interaction between socio-economic status and ethnicity remains unclear (Marshall et al. 2015).

Differences in mortality and morbidity by ethnicity are complex. Possible explanations include socio-economic factors such as income and education, healthcare usage, educational attainment and sickle cell disease in those with African or Caribbean family background (Wang, Rudd and Wolfe 2013). The premature (under 70) mortality rate for stroke in England and Wales is higher among people born outside the UK than those born within it. The difference is highest among men born in Bangladesh for whom the mortality rate is more than three times higher than those born in England and Wales (British

Heart Foundation 2009). It is also much higher for people of Afro-Caribbean backgrounds, who have a higher risk of hypertension. The prevalence of type 2 diabetes for people of Afro-Caribbean and South Asian ethnicity is much higher than in the rest of the population and this contributes to their risk of stroke (British Heart Foundation 2009). The South Asian population (of Indian, Pakistani, Bangladeshi and Sri Lankan origin) is the largest ethnic minority group in the UK and is known to have increased risk of heart disease and stroke compared to the general population. This is associated with higher rates of hypertension, diabetes and hyperlipidaemia (Stroke Association 2017; Banerjee et al. 2010).

The NHS Health Check programme, commenced in 2009, aimed to assess risk factors every five years for people between the ages of 40 and 74 who were not already on a vascular disease register (Department of Health 2013). Although general practitioners (GPs) were incentivised to carry out the health checks, coverage was low in the first four years (21.4%) with big variations between regions and GP practices. Chang et al's (2015) comprehensive analysis of national database records found no differences by gender or socio-economic status but significantly lower coverage in patients from Black and Chinese groups with no clear explanation. They also reported underuse of statins in high-risk groups with potential overuse in lower risk groups (Chang et al. 2015).

Finally, the cumulative risk of a second stroke is substantially increased: 26% within five years and 39% at ten years. The ten-year risk varies considerably possibly due to differences in case-mix and changes in secondary prevention due to the timeframe (1950-2009) of this systematic review and meta-analysis (Mohan et al. 2011). Given such high likelihood of reoccurrence, guidelines for secondary prevention emphasise comprehensive identification and management of risk factors. Key investigations include those for carotid artery stenosis, atrial fibrillation and structural cardiac disease alongside anti-thrombotic treatment, and management of hypertension and raised lipid levels (Royal College of Physicians 2016a).

Clinical guidelines support addressing lifestyle factors, for example smoking cessation, alongside medically driven secondary prevention. Although the evidence is very limited, it would seem likely that addressing the factors that contribute to primary prevention is as important (Royal College of Physicians 2016a). Professionals have a responsibility to provide information and support to assist these changes but it is primarily 'the responsibility of the individual to change his or her own behaviour', which corresponds with the emphasis on self-management (Royal College of Physicians 2016a, p108).

Table 4: Known risk factors for stroke

Non-modifiable risk factors	
Age	Increased risk in over-60s (and increased risk of atherosclerosis); about 25% of strokes occur in people under 65 years.[1]
Sex	More women who have strokes die from them compared with men, generally because they live longer and have their stroke when older. However, stroke is more common in men, compared with women, before the age of 75.[2]
Heredity and ethnicity	Higher risk in Afro-Caribbean and South Asian populations associated with increased prevalence of hypertension and diabetes.[3, 4, 5] In the UK, sickle cell disease mainly affects people with an African or Caribbean family background.[3]
Socio-economic status	Increasing deprivation is associated with increased risk but there are variations and inconsistencies.[6,7,8]
Modifiable behaviours	
Cigarette smoking	Associated with atherosclerosis, smokers have up to three times the risk of stroke and double the risk of recurrent stroke compared to non-smokers, but if they stop smoking the risk is significantly reduced and similar to the level of non-smokers after about 5 years.[1]
Excessive alcohol intake	Regular consumption of a large amount of alcohol is associated with an increased risk of stroke. [1]
Poor diet Hyperlipidaemia Hypercholesterolaemia	Low intake of fruit and vegetable (below 600g per day) increases risk; diets high in saturated fat can raise cholesterol levels; high salt intake can increase blood pressure. Risk factors and treatment of hyperlipidaemia (raised serum levels of lipids in the blood) and hypercholesterolaemia (high cholesterol) are similar. Both are associated with increased risk of atherosclerosis. Risk factors include age (>50 years), family history, hypertension, smoking and poor diet.[1,5]
Physical inactivity/obesity	Being inactive, obese -or both- increases the risk of hypertension, hyperlipidaemia, diabetes and stroke. [1,5]
Medical conditions	
Previous stroke or TIA	About 1 in 4 people will have a second stroke within 5 years[1]; TIA is a precursor of stroke and needs urgent assessment and intervention.[1]

Hypertension (high blood pressure)	A key risk factor for stroke because it weakens the artery walls. It is thought to contribute to nearly half of all strokes in England, Wales and Northern Ireland. A substantial proportion of people have undiagnosed hypertension. It is associated with a four-fold increased risk of stroke. Approximately half of people who have a stroke also have hypertension. Excess salt consumption in the diet is a key contributor.[1,5]
Diabetes mellitus/ hyperglycaemia	Patients with diabetes have a 25% excess risk of stroke. This group often has associated hypertension, hypercholesterolemia and obesity. Effective control of these factors can delay the complications of diabetes that increase the risk of stroke. [5]
Heart and vascular disease	• Atrial fibrillation refers to heart arrhythmias which can allow blood to pool leading to formation of a clot that can travel in the blood stream and lodge in an artery leading to the brain. It often remains undiagnosed and accounts for about 20% of strokes.[1] • Coronary heart disease, dilated cardiomyopathy, previous myocardial infarction and carotid artery disease all increase the risk of stroke.[1] • Peripheral arterial disease refers to atherosclerosis of the arteries outside the brain and heart; it is estimated that 20% of people over 60 are affected; its development is strongly associated with other cardiovascular risk factors.[1] • Cerebral small vessel disease is a common disease in older people and accounts for about 20% of strokes and 45% of dementia.[9]
Hyper-homocysteinaemia	This refers to abnormally high level of homocysteine, an amino acid, in blood plasma; it is associated with an increased risk of a first ever stroke but it is uncertain if it is an independent risk factor for recurrent stroke.[10]
Chronic kidney disease	There is a strong causal association between chronic kidney disease and cardiovascular risk. Patients with kidney disease have more frequent and more severe cardiovascular events and disease.[11]
Obstructive sleep apnoea	Between 30-70% with ischaemic or haemorrhagic stroke have sleep apnoea, depending upon the diagnostic criteria used. Common cardiovascular risk factors (e.g. hypertension, hyperlipidaemia, diabetes) are more prevalent in people with sleep apnoea. The condition itself is an independent risk factor for stroke.[1]

1. *(Royal College of Physicians 2016a)*
2. *(Stroke Association 2017)*

3. *(Wang, Rudd and Wolfe 2013)*

4. *(Banerjee et al. 2010)*

5. *(Leatherman, Sunderland and Airoldi 2008)*

6. *(Chen et al. 2015)*

7. *(Addo et al. 2012)*

8. *(Marshall et al. 2015)*

9. *(Shi and Wardlaw 2016)*

10. *(Møller et al. 2000)*

11. *(Gansevoort et al. 2013)*

2.3: Public health implications: the socio-economic burden of stroke

This section considers the public health implications of stroke globally and nationally. This includes mortality, morbidity and socio-economic costs in terms of health and social care usage and lost productivity. Inequalities in outcomes are briefly considered, both within and between countries.

2.3.1: The international burden of stroke

The age standardised rates of stroke mortality have decreased globally in the last twenty years but the absolute number of people who have a stroke each year, related deaths and the global burden of stroke is increasing with disproportionate effects on low- and middle-income countries (Feigin et al. 2014). In 2010, about 10% of the 52.8 million deaths worldwide were due to stroke. Ischaemic heart disease and stroke collectively killed 12·9 million people in 2010 (one in four deaths worldwide), compared with one in five in 1990; 1·3 million deaths were due to diabetes, a major risk factor for stroke (double the number in 1990). Stroke was ranked the second largest cause of death worldwide in 1990 and 2010, second only to ischaemic heart disease (Lozano et al. 2013). This reflects the general shift in mortality from communicable to non-communicable diseases related to population growth and increased average age of the world's population. In 2010, 75% of deaths worldwide were due to non-communicable diseases but there were wide regional variations and some notable exceptions such as in sub-Saharan Africa where communicable, maternal, neonatal and nutritional causes accounted for 76% of premature mortality in 2010 (Lozano et al. 2013).

If the trend continues, it is estimated that by 2030 there will be almost 12 million stroke deaths, 70 million survivors and more than 200 million disability affected life years lost globally (Feigin et al. 2014). Although the mean age of people with stroke is increasing, the proportion of people with stroke who are less than 65 years is substantial, especially in low- and middle-income countries, where the increasing prevalence of smoking and other risk factors will contribute to the impact of stroke (Lozano et al. 2013). The socio-economic costs include increased health and social care expenditure, lost productivity for younger people unable to resume employment and indirect effects on carers; this exacerbates pre-existing health inequalities within populations and has the greatest ramifications in the poorest countries (World Health Organization 2014).

In summary, the burden of stroke is carried largely by low- and middle-income countries that account for the majority of the global population and have not had the same magnitude of reduction in stroke incidence and improved outcomes as in high-income countries. This is mostly attributable to effective reduction of risk factors and improvement in acute stroke care in high-income countries. In comparison, low- and middle-income countries have variable levels of care, stroke specific units are rarely available and risk factor identification is limited (Marshall et al. 2015).

2.3.2: The national burden of stroke

Mortality from cardiovascular diseases have fallen considerably in the last forty years and age-standardised stroke mortality rates are about one-third of what they were in 1968 (British Heart Foundation 2009). In England, between 2001 and 2010, all age mortality rates from cardiovascular diseases decreased by 36%, with a reduction of 37% for stroke. Over the same period, under 75 mortality rates from all cardiovascular diseases decreased by 40%, with a 42% reduction for stroke (Department of Health 2013). Despite this, cardiovascular disease remains responsible for approximately one-third of deaths each year and this is likely to be exacerbated by increasing prevalence of certain risk factors, particularly obesity and diabetes (Department of Health 2013).

Despite Government targets to reduce the death rate from coronary heart disease, stroke and related diseases in the under 75s by at least two-fifths by 2010 (Department of Health 1999a), stroke was still the third largest cause of death in England when the National Stroke Strategy (Department of Health 2007) was published. Stroke accounted for 11% of deaths and contributed to the difference in life expectancy between the most deprived areas and the population as a whole.

Currently, stroke is the fourth biggest cause of death in the UK but the third biggest in Scotland. It accounts for 7% of all deaths, every year approximately 110,000 people in England have a stroke and 40,173 people died of stroke in the UK in 2015 (Stroke Association 2017). About 20%-30% of people who have a stroke die within a month and one-quarter of strokes occur in people who are less than 65 years old. Stroke is the single largest cause of adult disability with an estimated 300,000 people in England living with moderate to severe stroke related disability (Department of Health 2007). As more people are surviving, there are increasing numbers living with the consequences and almost two-thirds of stroke survivors in England, Wales and Northern Ireland leave hospital with a disability (Stroke Association 2017).

Alongside the personal cost are those to the NHS and economy. It has been estimated that stroke costs about £7 billion per year: £2.8 billion in direct costs to the NHS; £2.4 billion of informal care costs borne by patients' families and £1.8 billion in income lost due to death and disability (Department of Health 2007). However, a slightly more recent estimate suggests total costs of around £9 billion per year of which the total annual direct care cost is estimated to be about 49% of the total, informal care about 27% and indirect costs about 24%. Productivity losses due to death and disability were estimated to be slightly less, at £1.5 billion (Saka, McGuire and Wolfe 2009).

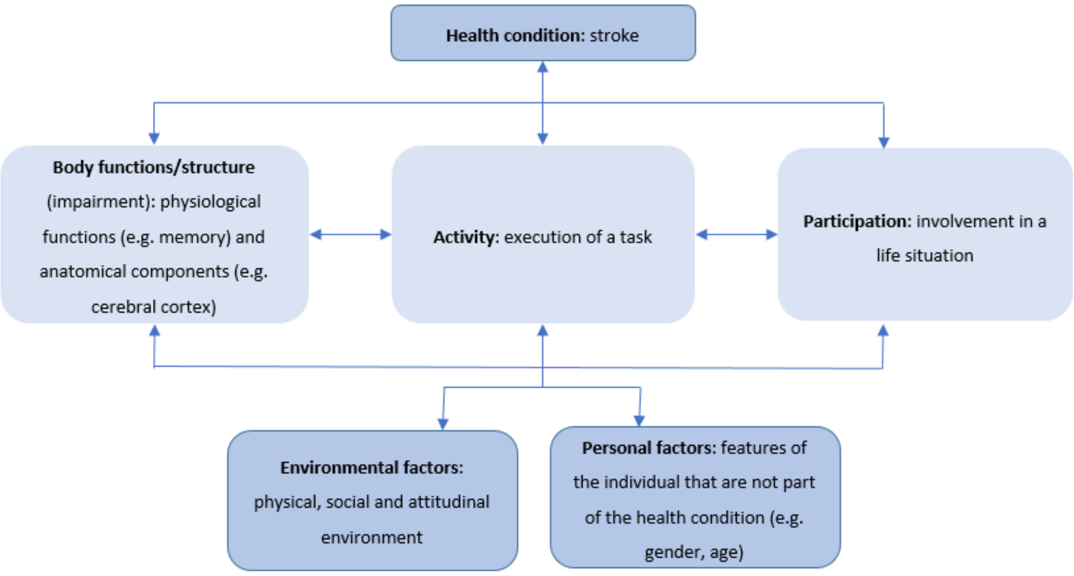
2.4: Stroke as a long-term issue

Having considered the population level effects of stroke, this section explores the impact on the individual. Although stroke is a discrete event the consequences can be long lasting and impairment can be extensive affecting all functional abilities and activities of daily life (Boger, Demain and Latter 2013). As many as two-thirds of stroke patients go on to develop cognitive impairment following stroke and approximately one-third develop dementia (Dawson et al. 2013). However, it can be difficult to differentiate between the direct effects of stroke and the cumulative effects of co-morbidities and ageing (Crichton et al. 2016). There is no standard definition of 'long-term' with the implication that stroke services should be open-ended (Sumathipala et al. 2012), which is endorsed by the imperative of providing reviews 'annually thereafter' (Royal College of Physicians 2012, p128).

2.4.1: A model of disability

The International Classification of Functioning, Disability and Health (ICF) provides a framework to consider how stroke affects the individual within their wider context (World Health Organization 2002) (Figure 2). This biopsychosocial model can be used to assess body structures and functions (impairment), participation in activities, the wider environment and personal factors. The terminology transcends professional boundaries and can be used as a prompt for therapists to address all areas of life including wider issues that can impede rehabilitation. It can be used alongside the International Classification of Disease that provides a framework for the classification by diagnosis of diseases, disorders and other health conditions (World Health Organization 2002).

Figure 2: International Classification of Functioning, Disability and Health



Adapted from World Health Organisation (2002)

2.4.2: Impairment and participation

The effect of stroke on body structure and function corresponds with the area of damage in the brain and there are differences according to left or right hemisphere lesions. The presentation of stroke is varied in terms of function and severity but communication, cognition and mood disorders are common, particularly anxiety and depression, which can have detrimental effects on recovery and relationships (Edmans 2011).

The most common presentation requiring rehabilitation is contralateral hemiparesis: damage to the right motor cortex that results in left-sided hemiparesis (weakness) and vice versa. The disorder involves changes in muscle tone on a continuum from hypotonia (flaccidity) to hypertonia (spasticity) which affects the ability to use the limb in functional activities (Thibaut et al. 2013). For example, lower limb hemiparesis impairs walking while upper limb hemiparesis affects all functional tasks, particularly when the dominant hand is affected.

For the majority of people (97%) the left hemisphere is specialised for learning and using language symbols (Dawson et al. 2013). A language disorder, or aphasia, can affect output (Broca’s or expressive aphasia) and comprehension (Wernicke’s or receptive aphasia) and can be further complicated when the muscles producing speech are affected (dysarthria) (Dawson et al. 2013). Usually people have varying degrees of receptive and expressive problems but severe aphasia, frequently combined with memory impairment, can impede rehabilitation because of difficulty following instructions and lack of carry over between therapy sessions (Edmans 2011).

Apraxia is another common disorder of left hemisphere damage. There are different types of apraxias but they are all disorders of voluntary movement where the mechanism of motor output is intact but the person cannot perform a purposeful activity on command. Apraxia often affects everyday activities such as getting washed and dressed but tends to resolve naturally over time (Edmans 2011).

Right hemisphere disorders are characterised by visual, spatial and perceptual disorders. Up to two-thirds of patients experience visual impairment post-stroke with problems including reduced visual acuity, visual field loss and visuo-perceptual deficits (Dawson et al. 2013). The most common is unilateral spatial neglect which is a failure to respond or orientate to sensory stimuli presented to the contralateral (left) side. Functional effects meant the person might bump into furniture on their left side but it often resolves spontaneously within about three months (Dawson et al. 2013).

Impairment needs to be set against a background of pre-existing health conditions, environmental factors and personal factors that can help or hinder recovery. Table 5 presents a summary of common impairments and the effect on participation.

Table 5: Summary of common stroke sequelae

Function	Common disorders	Examples of effect on participation
Motor	Hemiparesis; reduced balance and/or co-ordination Dysarthria (speech) Dysphagia (swallow) Apraxia	Difficulty transferring on/off chair or bed; need to use walking aid; risk of falls; arm in sling adds to instability. Difficulty producing words so hard to understand. Food has to be pureed; prone to choking on food. Clumsy, difficulty performing tasks on command and may use objects inappropriately, for example putting soap into the mouth.
Sensory	Sensory loss: rarely without motor impairment. Includes hot/cold, pain, touch and pressure.	Unable to detect hot/cold so can burn hand on kettle. Unable to feel the floor underfoot when walking which impedes rehabilitation; increased risk of falls.
Visual, perceptual and spatial	Unilateral spatial neglect Hemianopia: loss of visual field on the same side of both eyes.	Bump into obstacles on affected side. Not allowed to drive; difficulty reading; difficulty negotiating outdoors environment.
Cognitive	Memory Executive functions Expressive/receptive aphasia	Forget to take medication or do exercises. Difficulty planning and organising a hot meal. Unreliable yes/no answer; unable to have a meaningful conversation or express abstract thoughts.
Emotional	Lability (laughing/crying) Anxiety and depression Reduced frustration tolerance levels; increased irritability.	Difficulty controlling emotions and can appear inappropriate. Low mood is common and can impede rehabilitation; often accompanied by high levels of anxiety; may exacerbate pre-existing mood disorder.

(Edmans 2011)

2.4.3: Rehabilitation and long-term management

Stroke rehabilitation can be defined as 'a progressive, dynamic, goal orientated process aimed at enabling a person with impairment to reach their optimal physical, cognitive, emotional, communicative, and social functional level' (Dawson et al. 2013, p4). Rehabilitation consists of many interacting components that make it complex to evaluate because of the difficulty standardising interventions, the need to adapt to local context and the 'length and complexity of the causal chains linking intervention with outcome' (Medical Research Council 2006, p6). It can take place in any setting and the duration and timeframe varies according to factors including the type and severity of impairment, the level of support at home and resource constraints.

Therapy capitalises on the brain's capacity for neural reorganisation, or neuroplasticity, to enhance recovery after stroke. Neuroplasticity after injury occurs by two main processes: firstly, the rerouting and subsequent formation of new connections and secondly, adjacent neurons take over the function of damaged neurons to enhance the effectiveness of existing connections. Repetitive practice is essential to promote neuronal reorganisation in order to 're-learn' a skill, hence the imperative for daily therapy (Edmans 2011).

Rehabilitation is a team approach that should be carried out 24 hours per day, seven days a week with all staff trained in stroke care. Team members include physiotherapists, occupational therapists, speech and language therapists, dieticians and neuropsychologists. Rehabilitation should be based on the best available evidence and clinical guidelines (section 2.7-2.8). A key premise is that patients identify their own goals, which helps motivate them to engage in therapy (Edmans 2011).

Patients having stroke rehabilitation in hospital or in the community are meant to be 'offered at least 45 minutes of each relevant therapy for a minimum of 5 days a week', so long as they benefit and are able to tolerate it (NICE 2010, p16). This target was originally developed through a consensus process and has been much disputed but since national monitoring commenced patients do appear to be receiving more therapy, albeit with wide variations and only 31% of sites providing therapy seven days a week (Royal College of Physicians 2016a). Psychology is particularly limited with only 57% of acute sites nationally having access to clinical psychology and just 6% meeting the key indicator ('at least one whole time equivalent qualified clinical psychologist for every 30 stroke unit beds') (Royal College of Physicians 2016b, p30).

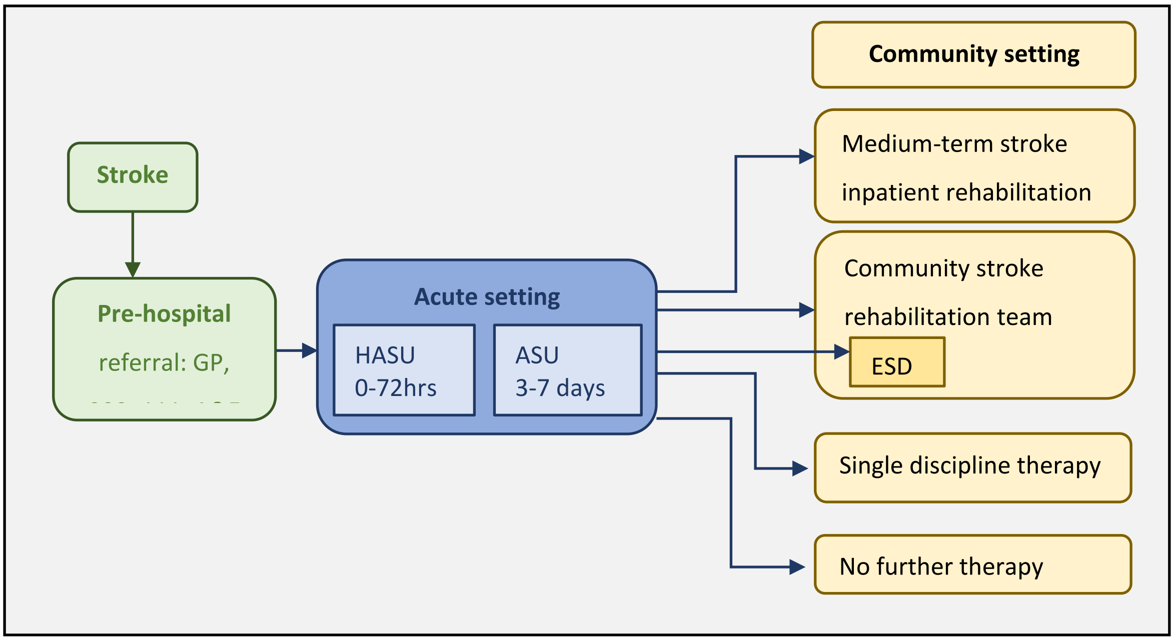
Intensive therapy is important because most gains are made in the first few weeks. Improvement generally continues for six months to a year but then plateaus, although people can make small but significant improvements beyond this period (Edmans 2011). A Cochrane review of therapy-based rehabilitation interventions one-year post-stroke found evidence was inconclusive as to whether any relevant outcomes could be influenced. However, it commented on a dearth of high quality evidence and difficulty comparing different trial designs, interventions and outcomes (Aziz et al. 2008). There is some evidence to suggest that stroke-specific support available in the community can help maximise gains but again the literature is diverse and inconclusive. For example, self-management programmes are popular but are often generic (carried out by those with little stroke training), or unavailable (Stroke Association 2012; Boger, Demain and Latter 2014).

2.5: Stroke services

Historically, stroke services were provided mainly in general and geriatric wards by non-specialists. The National Stroke Strategy was ‘a revolution in stroke care’ and set out an ambitious strategy to develop all aspects of stroke services (Department of Health 2007, p3). The twenty quality markers have driven restructuring over the past ten years and while acute services have advanced rapidly, community provision still has significant gaps in service provision (Royal College of Physicians 2016a).

The National Stroke Strategy (Department of Health 2007) highlighted that not only were the general public largely unaware of the symptoms of stroke or what action to take, many GPs and NHS Direct (an advice line now called NHS 111) failed to recognise stroke as a medical emergency and act accordingly. The Strategy’s first quality marker, ‘raising awareness’, set targets around recognising suspected acute stroke and treating within specific timeframes. For example, thrombolysis had to be provided, when appropriate, within three hours of onset. This lead to the development of hyper-acute stroke units (HASU) for immediate expert treatment and stabilisation. Patients are then transferred to an acute stroke unit (ASU) also staffed by those with specialist skills. Comprehensive assessment determines the next stage of care that comprises further inpatient rehabilitation and/or community stroke services with emphasis on early supported discharge (ESD) and ‘life after stroke’ (Table 7, section 2.7.1). Figure 3 presents an early model of stroke services:

Figure 3: An early model of stroke services

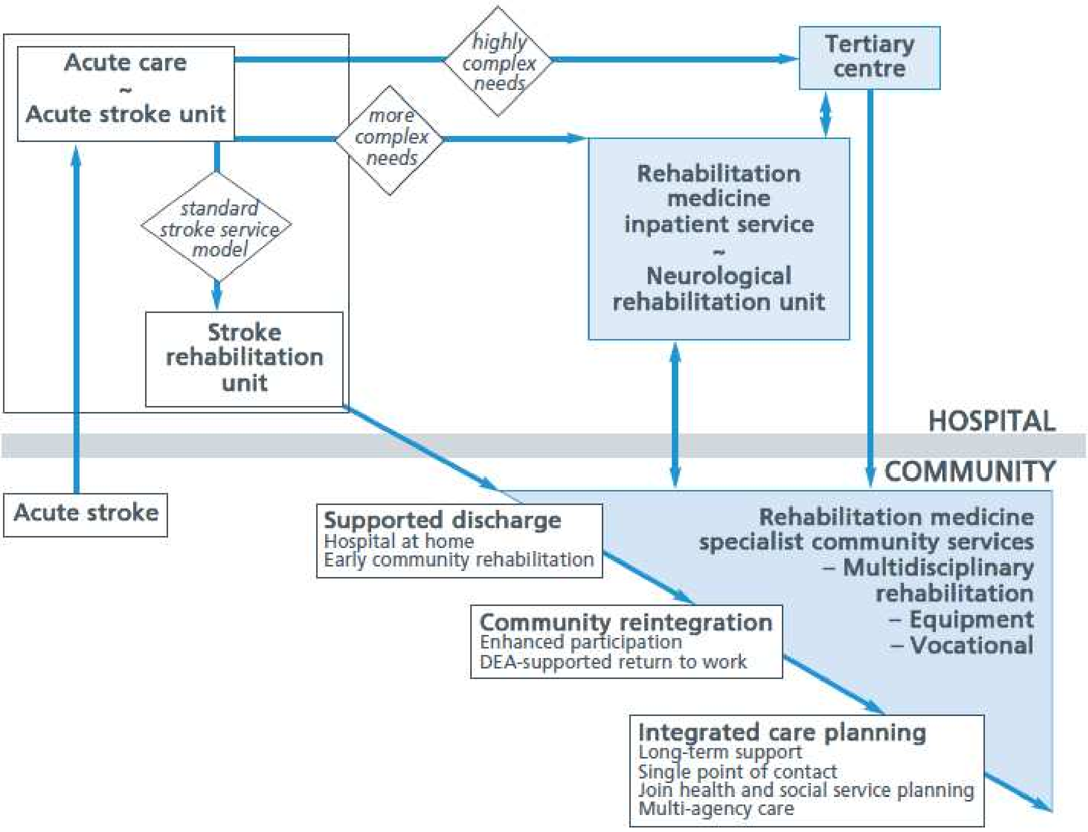


Abbreviations: HASU: Hyper-acute stroke unit; ASU: Acute stroke unit; ESD: early supported discharge.

(Healthcare for London 2009, p10)

The Royal College of Physicians and British Society of Rehabilitation Medicine (2010) published their own care pathway shortly after the above but with a stronger emphasis on long-term outcomes, particularly community integration, supported by integrated care planning (NHS England 2014) (Figure 4).

Figure 4: Clinical pathway for stroke care



(Royal College of Physicians and British Society of Rehabilitation Medicine 2010, p19)

Most local services have adapted the generic care pathway to reflect their local context. All services are required to submit patient level data to the Sentinel Stroke National Audit Programme (SSNAP), which is a national audit of stroke care in England, Wales and Northern Ireland. It aims to improve quality of care by auditing services against evidence-based standards and began collecting data in December 2012 (Royal College of Physicians 2014). It tracks patients from admission to six months' post-admission and publishes national, regional and site-level results. The indicator for the 6MR is the number of eligible patients who receive a review. In addition, a biannual acute organisational audit was launched in 2014 and the first post-acute organisation audit commenced in 2015 (Royal College of Physicians 2015a). The next sub-sections explain the care pathway in more detail.

2.5.1: Inpatient care: hyper-acute (HASUs) and acute stroke units (ASUs)

The aim of creating HASUs was to concentrate specialist care in centres of excellence to ensure rapid response, stabilisation and primary interventions. The National Stroke Strategy (Department of Health 2007) recommended that people with stroke should be immediately transferred from Accident and Emergency to a HASU providing specific assessments and interventions, 24 hours per day, seven days a week and within set timeframes. This included brain imaging, intravenous thrombolysis and the opinion of a stroke consultant specialist.

The national recommendation was that there should be a minimum of 600 stroke patient admissions per year to make a HASU clinically sustainable in terms of expertise and outcomes (Trickey and Hargroves 2015) which meant some smaller units were not viable. For example, stroke services in London and Greater Manchester underwent major reconfigurations in 2010 using different conceptual models to concentrate expertise in larger centres with subsequent reductions in mortality and length of stay (Fulop et al. 2016; Morris et al. 2014).

Acute stroke care follows the hyper-acute phase, usually within 72 hours of admission and provides specialist multi-disciplinary assessment and treatment in a stroke unit where clinicians have the relevant expertise. Minimum standards include input five days per week from physiotherapists, occupational therapists and speech therapists; patient-centred goal-setting; and a multi-disciplinary approach. The guidelines recommended 45 minutes per day for each therapy, where appropriate, which is monitored by SSNAP (Royal College of Physicians 2012). Length of stay varies depending on individual circumstances but is usually under three weeks although a small proportion of patients require longer inpatient care before returning home or being discharged to a care home (Healthcare for London 2009).

2.5.2: Community rehabilitation

The National Stroke Strategy (Department of Health 2007) referred to ‘life after stroke’ which incorporated specialist rehabilitation; a range of community services; opportunities to participate in community activities and return to work. It emphasised that specialised (rather than generic) rehabilitation should bridge the transition from hospital to home. Additionally, health, social care and voluntary services should together provide long-term support including access to advocacy and care navigation. This is still an aspiration for many services and access to vocational rehabilitation and neuropsychology are particularly limited with only 27% of commissioners funding the former and 55% funding the latter (Royal College of Physicians 2016b).

Although the majority (78%) of services commissioned for post-acute stroke care are stroke specific, only one-third of commissioned services provide treatment to patients discharged to care homes (Royal College of Physicians 2015a). Most services are provided by acute and community NHS Trusts with about one-fifth provided by the private and voluntary sector. Joint health and social care commissioning for post-acute services is still only available in 37% of areas (Royal College of Physicians 2015a) but it was not possible to obtain a map of areas (despite contacting SSNAP's advice line).

2.5.2.1: Early supported discharge

ESD teams provide intensive home-based multidisciplinary rehabilitation for those with mild to moderate stroke for up to six weeks and about one-third of patients meet the criteria. The emphasis is on equitable intensity of therapy compared with inpatient care whilst increasing independence at home with family support (Department of Health 2007). Langhorne et al.'s (2005) influential meta-analysis found that hospital stay was eight days shorter for those assigned to ESD compared to standard care and there were improvements in activities of daily living scales and patient satisfaction. The savings from early discharge outweighed the cost of the service (Langhorne et al. 2005) unless patients were prematurely discharged to inadequate services, which was likely to increase long-term dependency and reduce the immediate savings achieved through a shorter length of stay (Department of Health 2007). An update of the review found that appropriately resourced and co-ordinated multi-disciplinary teams could reduce long-term dependency and length of hospital stay for those with mild to moderate stroke but other benefits were minimal or absent, for example, there were no differences in activities of daily living scores. In addition, costs ranged from a reduction to a modest increase, when compared with usual care (Langhorne and Baylan 2017).

An early survey found that only 37% of areas had access to ESD (Care Quality Commission 2011). In 2016, 81% of audited areas had ESD but with considerable variation across England (88%), Wales (33%) and Northern Ireland (50%) (Royal College of Physicians 2016b). Although SSNAP captures indicators of rehabilitation such as the frequency of therapy sessions (Royal College of Physicians 2015a), there is little data on the actual *quality* of therapy provision.

2.5.2.2: Specialist community rehabilitation teams

Specialist community (stroke) rehabilitation teams are stroke specific services delivered by professionals with stroke expertise within a multi-disciplinary team who visit patients at home. The team caters for patients discharged from acute units or transferred from ESD services. The period of intervention is usually longer at about three months, which allows a focus on longer-term goals (Department of Health 2007).

In 2016, three-quarters of sites audited had access to specialist community rehabilitation teams but figures were varied (England 79%, Wales 17%, Northern Ireland 100%) and less than half visited care homes (Royal College of Physicians 2016a). Therapy is less intensive than ESD but should still be provided regularly, typically twice weekly, although again there is much variation (Royal College of Physicians 2016b).

2.5.2.3: Non-specialist community rehabilitation

Domiciliary services treat people at home but are separate to ESD and community stroke teams. About one-third of services commissioned are not stroke specific and a similar proportion do not visit patients in care homes (Royal College of Physicians 2015a). In some areas patients may be discharged to generic neurological teams where therapists may have limited experience of stroke but do have experience of neurological conditions. The least satisfactory outcome is discharge to an intermediate care team which is aimed at older people with an acute illness; therapists may not have neurological experience and the intensity and duration of therapy is limited (Department of Health 2007).

2.5.2.4: Voluntary services

The Stroke Association is the largest provider of services that run alongside statutory ones in the community. While they are commissioned to provide 6MRs in some areas, many more areas provide stroke specific services including family support workers, exercise groups and aphasia cafes. The organisation also has a strong role lobbying for stroke survivors and funding research but does not work with the Neurological Alliance, a lobby group for those with long-term neurological conditions. Other smaller groups include Different Strokes, the National Aphasia Association and UK Connect.

2.6: Unmet need

The 6MR is based on the premise of unmet need with one seminal study (McKevitt et al. 2011) being cited by clinical guidelines as evidence (Royal College of Physicians 2016a). However, definitions lack clarity and stroke-related need is not always differentiated from pre-existing problems. This section will define need, critique evidence of unmet need and consider why policy makers appear to accept that the 6MR is the best approach to ameliorating it. Although the 6MR focuses on patients’ unmet needs it would be artificial to separate from their carers’ needs so the literature review incorporated both. Appendix 2 summarises all the studies discussed in this section, including those excluded.

2.6.1: Defining unmet need

The ethical approach to managing healthcare needs emphasises the identification of suffering and that everyone should be helped regardless of resources (Acheson 1978). This has been countered by a more pragmatic viewpoint which suggests that need should only be recognised when there is an effective intervention that can be provided at reasonable cost, thus acknowledging resource constraints (Acheson 1978). Healthcare needs are those that can benefit from healthcare (health education, disease prevention, diagnosis, treatment, rehabilitation, end of life care) whereas health needs incorporate wider socio-economic determinants of health (Wright, Williams and Wilkinson 1998). On the one hand, need in healthcare is defined as *capacity to benefit* which refers not only to clinical status but includes wider benefits such as reassurance (Stevens and Gillam 1998). On the other, it relates to an intervention that 'actually alters the prognosis of the disease in some favourable way at reasonable cost' (Matthew 1971, cited in Acheson 1978, p10).

Stroke research often defines need as self-reported or 'felt need' perceived by the individual. It has been suggested that this equates with 'want' and is an inadequate measure of 'real' need, given that it is also limited by knowledge of services (Bradshaw 2013, p3). Felt need becomes expressed need when it translates into demand, or help seeking behaviour and can be at odds with normative need. It is experts who define normative need and it involves value judgements and decisions about the resources that should be dedicated to meeting it and whether or not available interventions are effective. It is therefore likely to change over time (Bradshaw 2013). Table 6 summarises these categories.

Table 6: Bradshaw's four types of social need

Type of need	Definition	Example
Felt need	A need for health perceived by the individual; relates to the subjective experience of feeling unwell and does not necessarily equate with health service use.	The patient feels that their walking could improve.
Expressed need	A patient seeks health care for a felt need. Equates with help seeking behaviour, or demand.	Patient asks GP to refer for physiotherapy.
Normative need	A need for healthcare; relates to a professional's judgement of the patient's health status and may differ between professionals. Normative needs are not	Botox injection for upper limb spasticity post-stroke. The consultant decides whether or not the patient would benefit.

	absolute and depend on several factors including the availability of the treatment.	
Comparative need	Individuals in one area who are receiving an intervention compared to those with similar characteristics in another area who are not receiving it; equates with relative need.	Some patients have access to 6MRs while others do not, depending on where they live and their GP.

(Bradshaw 2013; Lewis et al. 2008)

If the overall purpose of needs assessment in healthcare is to collate information and bring about change that benefits the health of the population, different needs have to be prioritised within the context of finite resources but the utilitarian approach of policymakers can be at odds with the individualistic approach of clinicians (Stevens and Gillam 1998). With regards to stroke, policy development has been led by clinicians, researchers, service users and the Stroke Association, all of whom have a vested interest in promoting stroke services, including the 6MR, and an incentive to prioritise stroke above other neurological conditions.

2.6.2: National evidence of unmet need

Much of the stroke literature treats patients as a homogenous group and fails to differentiate by demographics or other characteristics. Those with communication and/or cognitive impairment are often excluded as are those with co-morbidities or for whom it is not their first stroke and those living in care homes. This section critiques research appertaining to unmet need in the UK; while some differentiate working age versus older adults and by ethnicity, none includes care home residents. The section starts with one study (McKevitt et al. 2011) and two reports (Stroke Association 2012; Care Quality Commission 2011) that have been influential in highlighting unmet need post-stroke and concludes with two less influential but nevertheless informative studies (The NIHR CLAHRC Greater Manchester 2010; Rowe 2013) (appendix 2).

McKevitt et al. (2011) estimated the prevalence of self-reported need amongst community dwelling adults in the UK, one to five years post-stroke. The study has often been cited as evidence of unmet need, including by the fourth edition of the National Clinical Guidelines for Stroke (Royal College of Physicians 2012). The authors recruited 1251 participants from two population based stroke registers and a national register for GPs. The questionnaire was adapted from one for people with traumatic brain injury and included 44 closed questions with one opportunity for open comments. The majority of questions were phrased as ‘I would like more information about xxx’ with a yes/no tick box or ‘since your stroke have you had enough help with xxx’ both of which arguably invite the response ‘no’. The questionnaire is presented as a valid measure of unmet need that correctly operationalises the concept; the number of needs not fully met were calculated by summing the number of times a need was reported as ‘unmet’ or ‘only partially met’.

The analysis is comprehensive and includes differences by ethnicity as the population registers had a higher proportion of people from Black and other ethnic groups than the general practice register (King's College London 2017). Analysis was divided into physical/stroke related problems; information needs; impact on social participation; and other factors associated with unmet need. Over half of respondents (51%) reported no unmet needs and amongst the remainder the median number was three (range 1-13). A wide range of needs was identified with 54% reporting an unmet need for stroke information; 52% reduction or loss of work, significantly more from Black ethnic groups; and 18% loss of income. Ethnicity (treated collectively in the multivariable analysis) and greater severity of disability were associated with more unmet needs.

The authors acknowledged that needs identified by participants may not have been stroke related but considered that this did not negate the findings (McKevitt et al. 2011). However, the findings did not differentiate types of need and whether or not they could be ameliorated or by whom. Also, the grouping of partially met with unmet needs is questionable. For example, a patient might identify memory problems (felt need) and request neuropsychology (expressed need) that a clinician deems appropriate but if there is no local service the need would remain unmet.

Discussing the implications for clinical practice, McKevitt et al. (2011) recommended developing primary care based strategies to assess and meet need and suggested a targeted approach might be appropriate given that half of those surveyed did not report unmet needs. This seems a valid suggestion but was not acknowledged by subsequent national guidelines (Royal College of Physicians 2012; Royal College of Physicians 2016a).

The Stroke Association (2012, p27) took a more emotive tone, highlighting in their survey that patients reported ‘feeling abandoned’ post-discharge. This was also cited by national stroke guidelines (Royal College of Physicians 2012) as evidence of unmet need, alongside McKevitt et al.’s (2011) paper. Areas of concern included access to therapies, support and information, and lack of integrated working between health and social care. Information on the method was limited so it was difficult to ascertain how rigorous the findings were but they resonated with an earlier report that found significant shortcomings in stroke care across England (Care Quality Commission 2011).

The Care Quality Commission (2011) published a comprehensive report shortly before that of the Stroke Association (2012), with a more transparent method that reviewed patient and carer experiences along the care pathway. It highlighted that models of care were now acknowledging the long-term effects of stroke and extending support to several months, if not years, and it identified areas for improvement at all stages of the care pathway. Particularly important were gaps in provision of rehabilitation and psychological support and significant variation in waiting times, availability and frequency. Even when services were available, accessing them could be 'complicated and confusing' with many gaps in support and information post-discharge, especially for people of working age or with communication difficulties (Care Quality Commission 2011, p3). While nearly half of Primary Care Trusts monitored whether people returned home, only 17% monitored long-term outcomes such as return to work. The report emphasised patients and carers should be given more opportunities to 'chose and control' the services they received (Care Quality Commission 2011, p21). For example, only 29% of areas told people that they could ask for a reassessment of their needs after services had withdrawn and many areas did not provide six-week or six-month reviews.

The Greater Manchester Stroke Assessment Tool (GM-SAT) was devised to carry out 6MRs (section 2.9.3). Unmet need was defined as 'a problem that is not being addressed or one that is being addressed but insufficiently (i.e. undermet need)' (NIHR CLAHRC Greater Manchester 2010, p3). The study trained SA workers, on a one-day course, to use the tool after which they carried out 137 reviews across ten sites. On average people presented with three unmet needs (range 0-14) and although half of these were met through provision of information and advice, about 20% of unmet needs required referral to other services and/or advising people to contact their primary care team (The NIHR CLAHRC Greater Manchester 2010).

Finally, a small but comprehensive mixed methods study specific to visual problems post-stroke estimated that 60% of patients had problems at baseline and 20% three months later. A significant proportion of visual problems were not identified or addressed during inpatient care and the care pathway for vision was not routinely used by clinicians, largely due to lack of awareness and limited access to orthoptists (Rowe 2013).

2.6.3: Service evaluations incorporating unmet need in the South East Coast region

Service evaluations were accessed by contacting services within the South East Coast region directly. This generated two evaluations of the 6MR and one evaluation of the Stroke Association's 'life after stroke' services (appendix 2).

The first pilot employed an experienced (Band 7) occupational therapist to carry out reviews, mostly by telephone, over two years (Gedge, France and Jones 2013). Of 283 first reviews offered, 125 were accepted (44%); of 162 second reviews, 32 were accepted (20%) but there was no explanation for the low uptake. A need was only deemed unmet when the required service was unavailable. The results were presented in terms of referrals, the average number of days for each service to offer an appointment and which services were unavailable. Most referrals were made to GPs (n=16), consultants (n=14) and the Stroke Association (n=11). Waiting times varied but were particularly long for intermediate care teams, ophthalmology and care management (128, 125 and 91 days respectively). Unavailable services included neuro-physiotherapy, neuropsychology, community occupational therapy and specialist counselling. Patient evaluation data demonstrated that they found the review helpful.

The second pilot involved over six hundred reviews, both six-month and annual, across two localities in Surrey (2012-13), mainly carried out in clinic by a team of therapists, stroke nurses and a community stroke co-ordinator (Curtis and Gallifent 2014). Take-up of review was 61% in one locality and 36% in the other locality, where there appeared to be more annual reviews. This suggested that yearly reviews had a lower take-up, as with the first pilot (Gedge, France and Jones 2013). Reasons for declining the review included good recovery; other services being involved; and other conditions, notably dementia, taking precedence. In addition, while 75% agreed to being contacted the following year, the remaining 25% did not want follow-up. Similar to McKevitt et al. (2011), this supports the idea that reviews could be targeted. A key benefit of the team approach was that some concerns could be addressed on the spot and therapists were able to review goals and programmes, therefore potentially reducing onwards referrals. About 20% needed referral onto community services including therapies and falls service (Curtis and Gallifent 2014).

Finally, a mixed methods approach was used to evaluate the Stroke Association's 'life after stroke' services (Jenkins, King and Brigden 2012). Although the 6MR was not incorporated, the Stroke Association used the same model in areas where they were commissioned to provide them. In addition, patients were surveyed at baseline, four months and twelve months post-stroke which approximated the six-weeks, six-months and yearly reviews policy recommends (Royal College of Physicians 2012). A key finding was that patients and carers valued personal contact with SA workers: they felt reassured that someone had time to listen, liked the continuity of the same person and appreciated emotional support. Practical benefits included information, signposting and communication groups. Clinicians viewed the service as complementary, filling gaps in statutory services. Unfortunately, there were significant staffing reductions during the study period and patients indicated that they had 'a much wider range of problems' than the service could expect to address (Jenkins, King and Brigden 2012, p18).

2.6.4: Patient perspective on unmet need in the UK

Other than those already discussed, there have been surprisingly few rigorous studies (appendix 2) exploring the patient perspective of unmet need subsequent to the introduction of the National Stroke Strategy (Department of Health 2007).

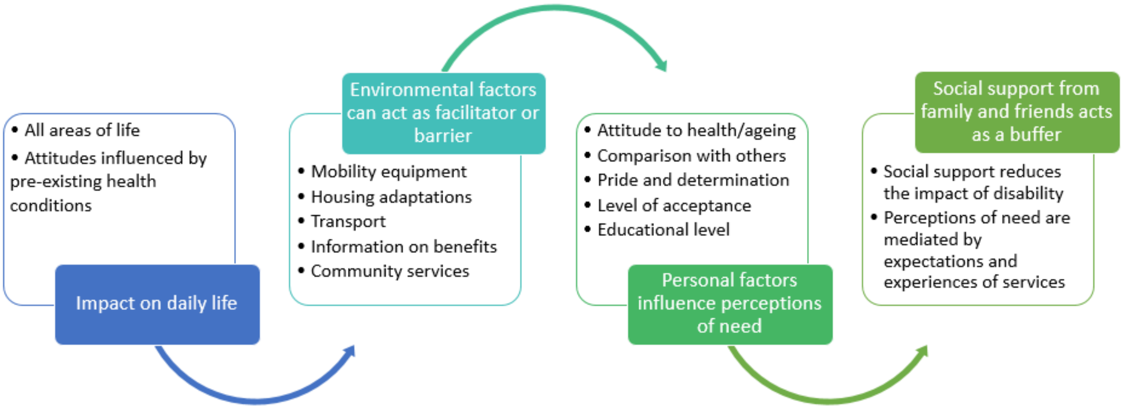
The only study specifically exploring the patient perspective on unmet need one year post-stroke in England interviewed a subset of participants from the evaluation of a tool developed to carry out 6MRs (Shannon, Forster and Hawkins 2016). Ten participants all experienced ongoing impairments or limitations but had not identified these as unmet needs. The meaning of a ‘problem’ varied between respondents and some rejected the term but the reasons for this were not fully explored. The term ‘issue’ was used in preference and while the authors appeared to assume that an issue, or impairment, equated with unmet need, respondents did not. Four themes were proposed to account for this: acceptance of changed circumstances; making comparisons with others; personal attributes, particularly valuing independence; and expectations/experiences of services. It was suggested that because participants’ lives had started to change pre-stroke, some had ‘begun to adjust their expectations, daily lives and perception of what might be considered a problem or unmet need’ (Shannon, Forster and Hawkins 2016, p2003).

Patients’ views about services appeared to influence health-seeking behaviour. Respondents did not identify an issue as an unmet need if they thought that further intervention could not ameliorate it, based on previous experience, which seemed a reasonable assumption. Some did not reframe an issue as an unmet need if they felt others would benefit more than them from treatment, acknowledging the scarcity of resources. Respondents seemed to make decisions based on whether or not ‘treatment was worthwhile or justified’ and this might have made them less likely to report unmet needs (Shannon, Forster and Hawkins 2016, p2004).

Sumathipala (2012) interviewed 35 patients living in South London to explore the impact of stroke on functioning and how needs were perceived in the long-term. Participants were between 1-11 years post-stroke, all but five were over 60 years and most had other long-term conditions. They described a range of impairments that affected all areas of daily functioning including activities of daily living, social participation, mobility, housing, financial support, rehabilitation, information and transport. However, the majority of respondents circumvented these problems by mobilising emotional and practical support from their family and friends that enabled them to reduce the impact of disability and mediate perceived needs. Needs were mapped onto the ICF (World Health Organization 2002) and this demonstrated how a range of environmental and personal factors affected how needs were perceived. For example, some respondents minimised their own disability in comparison to others they regarded as less fortunate while others attributed their problems to ageing, rather than the stroke per se (Sumathipala et al. 2012).

The key concepts from the above studies are summarised in Figure 5.

Figure 5: Patient perspectives on unmet need in the UK

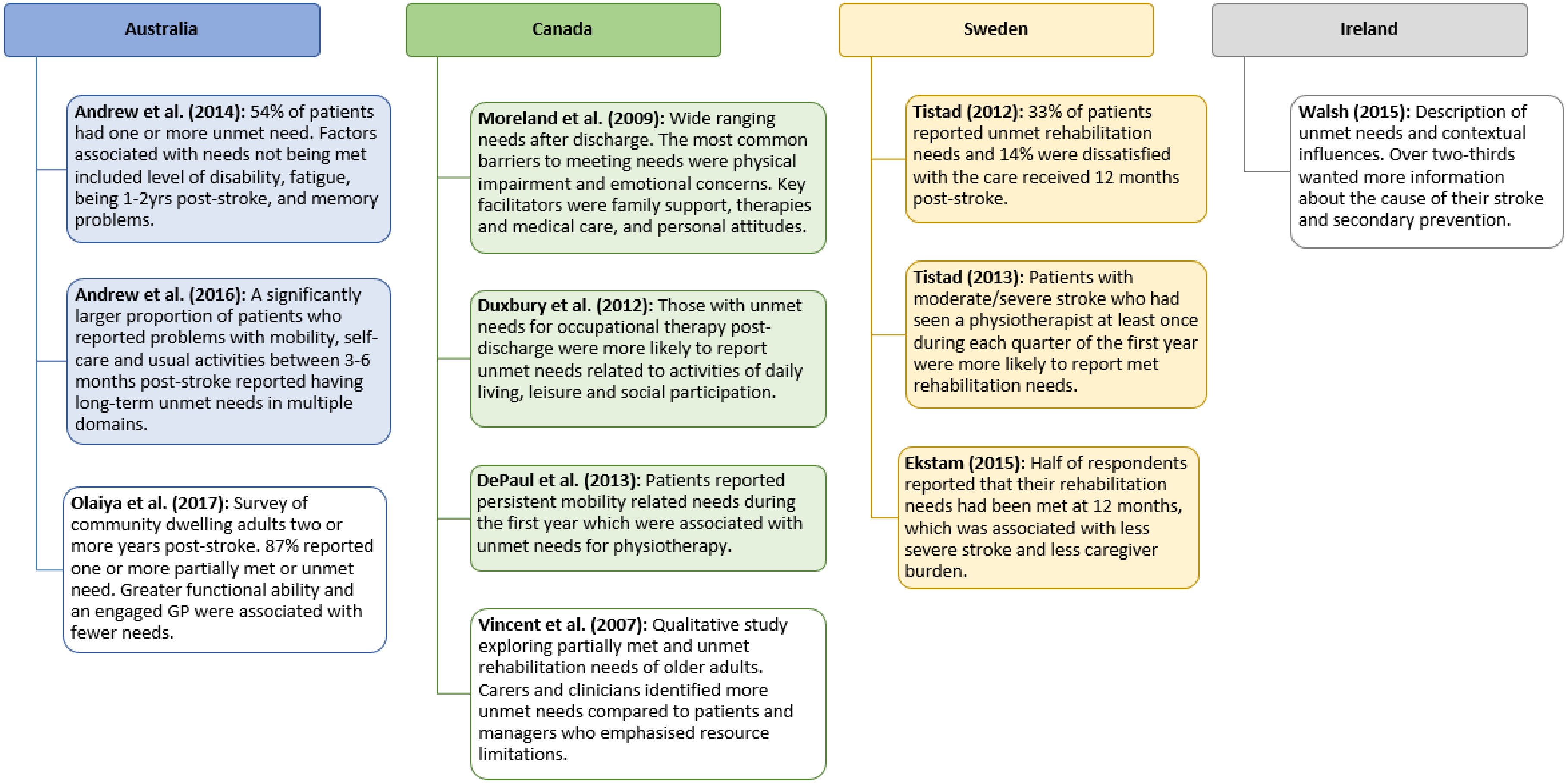


The next section draws on evidence beyond the UK to explore the patient perspective of unmet need.

2.6.5: International evidence of unmet need

These studies were chosen for their relevance and rigorous methods but different parameters make them difficult to synthesise. Figure 6 summarises the key message per study and appendix 2 has further information.

Figure 6: International evidence of unmet need



Australia

Andrew et al. (2014): 54% of patients had one or more unmet need. Factors associated with needs not being met included level of disability, fatigue, being 1-2yrs post-stroke, and memory problems.

Andrew et al. (2016): A significantly larger proportion of patients who reported problems with mobility, self-care and usual activities between 3-6 months post-stroke reported having long-term unmet needs in multiple domains.

Olaiya et al. (2017): Survey of community dwelling adults two or more years post-stroke. 87% reported one or more partially met or unmet need. Greater functional ability and an engaged GP were associated with fewer needs.

Canada

Moreland et al. (2009): Wide ranging needs after discharge. The most common barriers to meeting needs were physical impairment and emotional concerns. Key facilitators were family support, therapies and medical care, and personal attitudes.

Duxbury et al. (2012): Those with unmet needs for occupational therapy post-discharge were more likely to report unmet needs related to activities of daily living, leisure and social participation.

DePaul et al. (2013): Patients reported persistent mobility related needs during the first year which were associated with unmet needs for physiotherapy.

Vincent et al. (2007): Qualitative study exploring partially met and unmet rehabilitation needs of older adults. Carers and clinicians identified more unmet needs compared to patients and managers who emphasised resource limitations.

Sweden

Tistad (2012): 33% of patients reported unmet rehabilitation needs and 14% were dissatisfied with the care received 12 months post-stroke.

Tistad (2013): Patients with moderate/severe stroke who had seen a physiotherapist at least once during each quarter of the first year were more likely to report met rehabilitation needs.

Ekstam (2015): Half of respondents reported that their rehabilitation needs had been met at 12 months, which was associated with less severe stroke and less caregiver burden.

Ireland

Walsh (2015): Description of unmet needs and contextual influences. Over two-thirds wanted more information about the cause of their stroke and secondary prevention.

N.B. Studies sharing data are shaded

Starting with the two Australian studies, Andrew et al. (2014) used an adapted version of McKevitt et al.'s (2011) survey tool to ascertain levels of unmet need. The median time post-stroke was two years but a surprisingly high percentage (84%) reported a health need that was not fully met. Other areas of unmet need included aspects of managing daily life, cognitive and emotional problems, and return to work. Factors associated with needs not being met were greater disability and fatigue; greater disability and being one to two years post-stroke; and greater disability and memory problems. There were many other variables that influenced the extent to which needs were unmet including age, disability level and residential location (Andrew et al. 2014), thus demonstrating the complexity of individual need and the interplay of contextual factors.

The subsequent Australian study (Andrew et al. 2016) investigated attributes of health-related quality of life as predictors for long-term (12+ months) unmet needs. A significantly larger proportion of those who reported problems with mobility, self-care and usual activities between 90-180 days post-stroke reported having long-term unmet needs in multiple domains. Interestingly, those who reported having pain or anxiety/depression in the first six months were less likely to report unmet needs at a median of two years but this may have been due to increased contact with their GP (Andrew et al. 2016). The study concluded that those who reported long-term unmet needs were more likely to have experienced reduced health-related quality of life.

Another Australian study (Olaiya et al. 2017) surveyed predominantly older adults, two or more years after being hospitalised for stroke or TIA. It categorised needs using the ICF and found that the majority (87%) of participants reported one or more unmet needs. As with other studies, including McKevitt et al.'s (2011), this percentage combined 'need not met' with 'need not fully met' and the figures for the former are significantly lower. For example, 41% of respondents reported a need for diet control but only 13% reported this as unmet, while 28% said it was partially met. Factors associated with fewer unmet needs included greater functional ability and reporting that their GP was engaged in co-ordinating their care. Perhaps unsurprisingly, depression was associated with more unmet needs (Olaiya et al. 2017).

The Canadian studies comprised three papers drawing on the same data and one qualitative study. Vincent et al. (2007) used focus groups with patients, carers, clinicians and managers to explore rehabilitation needs of older community dwelling adults. Rehabilitation needs, some partially met, persisted after services had withdrawn, reflecting a mismatch between demand and availability. Follow-up did not sufficiently address adjustment issues or activities of daily living that acted as barriers to social participation. Carers and clinicians identified more unmet needs than patients and managers, perhaps reflecting that neither patients nor managers actually provide care (Vincent et al.

2007). The logical conclusion was that better identification of partially unmet or unmet needs should lead to more effective follow-up for both patient and carer.

Moreland et al.'s (2009) original study followed a cohort of 209 patients from stroke to one year post-discharge, using mixed methods to ascertain need in all domains of the ICF (World Health Organization 2002). Patients were categorised into three groups using the Functional Independence Measure, a more comprehensive outcome measure than those often used such as the Modified Rankin Scale. Results were presented for each category (equating with low, moderate and severe impairment) and collectively. Combining groups, needs after discharge related primarily to physical impairments (35%), education (28%), medical advice (25%) and therapies (21%). Interestingly, one-third of respondents stated that they needed time to recover. The most common barriers were physical impairments and emotional concerns while facilitators included family support, therapies, medical care and personal attitudes. However, results varied widely according to the level of disability reflecting the complexity of need and contextual factors.

Alongside the above were two associated papers determining physiotherapy needs during the first year post-stroke (DePaul, Moreland and deHueck 2013) and occupational therapy needs following discharge (Duxbury et al. 2012). One month after discharge nearly half of patients identified a specific unmet need for physiotherapy with this dropping to 30% at one year. Many needs related to higher-level skills such as participation in sports (DePaul, Moreland and deHueck 2013).

Patients reported a wide variety of unmet needs commensurate with the role of occupational therapy including upper limb function, leisure activities and social participation. However, a small proportion of patients not receiving occupational therapy reported a need for it, whereas over two-thirds reported that they did not need it despite identifying problems that occupational therapy could have addressed (Duxbury et al. 2012). This suggests that patients did not understand its role.

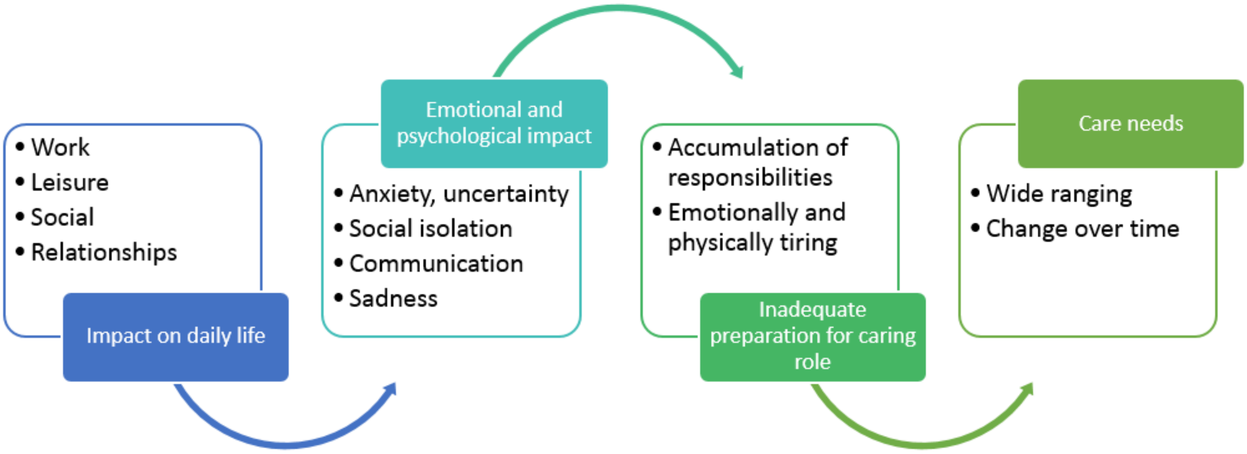
The three Swedish studies considered rehabilitation needs, patient satisfaction and factors that influenced perception of need. Tistad et al. (2012) explored characteristics that contributed to unfulfilled needs for rehabilitation or dissatisfaction with healthcare services at one year. One-third reported unmet needs for rehabilitation but only 14% were dissatisfied with the care they received; personality as well as stroke impact was associated with dissatisfaction. Patients appeared to think that they had the capacity to recover with additional physiotherapy, the implicit suggestion being that therapists disagreed. The subsequent study (Tistad et al. 2013) explored aspects of rehabilitation provision that potentially contributed to needs met for rehabilitation at one year. Patients with moderate to severe stroke who had seen a physiotherapist at least once every three months were more likely to report that their rehabilitation needs had been met. Consequently, the study recommended that for this group of patients, continuity in rehabilitation and/or a reassessment by a multi-disciplinary team six to twelve months after stroke would be beneficial (Tistad et al. 2013). Ekstam et al. (2015) found that met needs were associated with less severe stroke, more coping strategies for solving everyday problems and less carer burden. The conclusion was that patient *and* carer need to be supported with the process of psychological and social adaptation, similar to Andrew et al. (2015), discussed in the next section (2.6.6).

Finally, Walsh et al.'s (2015a) national survey in Ireland also used an adapted version of McKevitt et al.'s (2011) questionnaire. The sample size was smaller and the findings categorised differently, focusing on function rather than the effect on daily life. The proportion of patients reporting no unmet health needs was relatively low (22%) but respondents identified many ongoing problems including falls and problems with fatigue, emotions, memory and concentration. Nearly two-thirds reported negative financial changes with only one-fifth of working age adults returning to work. Interestingly, the authors commented that 'self-reported unmet need is a subjective feeling and could be related to low mood', poor functional outcomes or dissatisfaction with services (Walsh et al. 2015a, p1837), again alluding to the complexity of unmet need.

2.6.6: Carers' perspective on unmet need

While there is a lot of research exploring the impact and burden of caring post-stroke, there have been few robust studies identifying carers' unmet needs in the last decade. To supplement the only UK study (Mackenzie et al. 2007) this section draws on two Canadian studies (Le Dorze and Signori 2010; MacIsaac, Harrison and Godfrey 2010), two Australian (Andrew et al. 2015; Perry and Middleton 2011) and one Swedish (Wallengren, Segesten and Friberg 2010) selected for their applicability to the UK healthcare system. Studies categorised carers' needs, and/or unmet needs, in different ways but all highlighted how they changed over time. Many needs reflected concerns about the stroke survivor but others related specifically to caring and the unavailability of services (Le Dorze and Signori 2010). Figure 7 summarises the key themes across these studies and appendix 2 has further information.

Figure 7: Key themes from research addressing the unmet needs of carers



The studies found that caring affected all aspects of daily life especially the domains of work, leisure, social participation and friendships. The impact was greatest for spouses (Andrew et al. 2015) or carers with multiple caring roles (Perry and Middleton 2011) and was exacerbated when the survivor experienced cognitive and/or communication problems (Andrew et al. 2015). The accumulation of responsibilities and daily tasks for carers was emotionally and physically tiring and often included tasks that had previously been the responsibility of their spouse, such as managing finances. Carers were left with little or no time for their own pursuits, which was a source of sadness (Mackenzie et al. 2007).

The impact of caring increased with the number of reported unmet needs of the survivor (Andrew et al. 2015) and these needs 'significantly predicted burden' (Perry and Middleton 2011, p1890). MacKenzie et al. (2007) found that younger female carers (less than 56 years) and ethnic minority groups experienced particular difficulties. Allied to this was the emotional impact of caring, and associated anxiety and uncertainty (Perry and Middleton 2011).

Although acute distress lessened with time, carers felt the loss of their previous lifestyle, including changes to their relationship and effects on the whole family (Mackenzie et al. 2007). Some were struggling to adjust to their partner's personality changes (Perry and Middleton 2011) while others were frustrated by ongoing communication difficulties. Carers whose spouse had aphasia had to adjust to being unable to discuss concerns as a couple and becoming the sole communicator for both of them (Le Dorze and Signori 2010). In the early stages, carers were focused on their partner's survival and return home but six months on they were starting to think about their own future. Carers sought information related to their own health and wanted to improve their emotional and physical well-being (Wallengren, Segesten and Friberg 2010). However, carers perceived that professionals 'fell short' of preparing them for their new role and described feeling alone (Mackenzie et al. 2007, p119).

MacIssac et al. (2010) highlighted the complexity of becoming a carer, the multi-faceted nature of caring and how needs change as the patient progresses along the care pathway, with patient and carer's needs being interconnected.

Carers expressed the need for more information, advice and support than was available. During the acute phase they focused on factual knowledge about stroke. This developed into a need to understand rehabilitation and their relatives' health status. Carers started to intertwine factual knowledge with understanding and skills, and personal involvement acted as a spur to acquiring knowledge but only when it was directly relevant. For clinicians, this meant they needed to focus on relatives' specific and individual needs instead of providing standard information based on their own expectations (Wallengren, Segesten and Friberg 2010).

In summary, Andrew et al. (2015) emphasised that effective interventions should be directed at patient *and* carer, personalised and responsive to the changing physical, emotional and relationship needs of both partners' overtime. In addition, patient and carer should be able to access a network of services that cut across boundaries between health, social care and the voluntary sector, a common refrain of UK policy (NHS England 2014). Finally, Perry and Middleton (2011, p1899) recommended that patients and carers should have 'regular review and a point of contact for trouble-shooting and reassessment when situations change', somewhat akin to the 6MR.

The rest of this chapter appertains specifically to the 6MR. It starts by considering the policy background and clinical guidelines that have informed service provision, and the extent to which the review is available. It then explores evidence of effectiveness and finishes by describing three tools commonly used to carry out the 6MR.

2.7: Policy background

The imperative for reviewing patients with long-term conditions started more than a decade ago (Department of Health 2005) and has resonated through policy to the present. The term 'need' has been used interchangeably with 'experiences' or 'problems' (Murray et al. 2003a) and the boundary between how it manifests and if/how it can be ameliorated is often blurred. This section tracks policy from when reviews were first mentioned to the present and outlines key policy drivers for the review, summarised in appendix 3. This is followed by a review of clinical guidelines, summarised in appendix 4.

2.7.1: National policy drivers

National policy acknowledged that historically services failed those with long-term conditions because they did not receive adequate support in the community (Department of Health 2001b; Department of Health 2005). Although stroke is an acute event, the long-term consequences are well documented (Jones, Riazi and Norris 2013) and recovery is complex ‘encompassing biomedical, psychological and sociological elements’ (Boger, Demain and Latter 2013, p1415). However, it is only in the last fifteen years that stroke has been regarded as a long-term condition and service provision has tried to adjust accordingly (Jones, Riazi and Norris 2013) with the focus on long-term support. Thus the 6MR is set within a wider policy imperative to support life after stroke through strategies including emotional and practical support, secondary prevention, self-management, a named contact and integrated health and social care planning (Royal College of Physicians 2012).

The National Service Framework for Older People (Department of Health 2001b) highlighted the importance of prevention, early management, rehabilitation and comprehensive long-term support post-stroke. It stated that patients ‘reporting a significant disability at six months should be re-assessed and offered further targeted rehabilitation’, if beneficial, but did not recommend yearly reviews (Department of Health 2001b, p68). Two other recommendations of note were case management, including a named contact, and psychosocial support, both of which are still largely unavailable (Royal College of Physicians 2016a).

The National Service Framework for Long-term Conditions (Department of Health 2005) included stroke and acknowledged that the effects are long-lasting but may change over time. The eleven quality requirements laid the groundwork for later policies with a focus on ‘rehabilitation, adjustment and social integration’, ‘life-long care and support’ (2005, p16) and the needs of carers ‘in their own right’ (2005, p55). To achieve these aspirations it recommended interdisciplinary working, integrated care planning in partnership with patients and ‘regular monitoring and review’ (2005, p20). Reviews could be planned or unplanned according to clinical need and self-assessment. The aspiration was that integrated care would improve care co-ordination between agencies while providing patients with a single point of contact.

The National Stroke Strategy (Department of Health 2007) set out a framework for delivering stroke services over ten years and addressing health inequalities. Prior to this, services in the UK were poor compared to other countries: ‘among the most expensive, with unnecessarily long lengths of stay and high levels of avoidable disability and mortality’ (Department of Health 2007, p11). The Strategy acknowledged that the impact of a stroke was long-term and therefore lifelong services should be available (Department of Health 2007). It identified twenty quality markers that were grouped according to theme, including that of ‘life after stroke’, which incorporated the 6MR (Table 7). Many of the markers relevant to the review process were developed in subsequent policies and since its inception there has been a drive for increased therapy provision, seven-day working and ESD (Royal College of Physicians 2016a).

Table 7: National Stroke Strategy quality markers for ‘life after stroke’

Quality marker	Descriptor
10: High-quality specialist rehabilitation	‘People who have had strokes access high-quality rehabilitation and, with their carer, receive support from stroke-skilled services as soon as possible after they have a stroke, available in hospital, immediately after transfer from hospital and for as long as they need it’ (p36).
11: End-of-life care	‘People who are not likely to recover from their stroke receive care at the end of their lives which takes account of their needs and choices, and is delivered by a workforce with appropriate skills and experience in all care settings’ (p39).
12: Seamless transfer of care	‘A workable, clear discharge plan that has fully involved the individual (and their family where appropriate) and responded to the individual’s particular circumstances and aspirations is developed by health and social care services, together with other services such as transport and housing’ (p41).
13: Long-term care and support	‘A range of services are in place and easily accessible to support the individual long-term needs of individuals and their carers’ (p42).
14: Assessment and review	‘People who have had strokes and their carers, either living at home or in care homes, are offered a review from primary care services of their health and social care status and secondary prevention needs, typically within six weeks of discharge home or to care home and again before six months after leaving hospital. This is followed by an annual health and social care check, which facilitates a clear pathway back to further specialist review, advice, information, support and rehabilitation where required’ (p45).
15: Participation in community life	‘People who have had a stroke, and their carers, are enabled to live a full life in the community’ (p46).
16: Return to work	‘People who have had a stroke and their carers are enabled to participate in paid, supported and voluntary employment’ (p47).

(Department of Health 2007)

The Stroke Improvement Programme was a national drive to accelerate implementation of the National Stroke Strategy during 2010/11. Aims for long-term care included joint health and social care management, timely access to psychological support and six- and twelve-month reviews within a window of five to seven months post-discharge for 6MRs. The ‘multifaceted assessment of need’ was intended to encompass the following (NHS Stroke Improvement Programme 2010, p20):

- Medicines/general health needs
- Ongoing therapy and rehabilitation needs
- Mood, memory, cognitive and psychological status
- Social care needs, carer wellbeing, finances and benefits, driving, travel and transport

The targets for April 2011 were that 85% of patients would receive joint care plans on discharge, 40% would receive psychological support by six months post-stroke, and 95% would be reviewed six months’ post-discharge. In terms of the review, this has not been achieved (section 2.9.1). Improvements in acute care were not matched by those in long-term care and there was much variation in approach to the reviews, ‘a lack of clarity about who should lead them, their objectives, where they are recorded, the role of patients’ GPs in the reviews and how they were implemented’ (National Audit Office 2010, p33).

The window for review changed again when the Clinical Commissioning Groups (CCG) Outcomes Indicator Set for 2014/15 recommended that patients should be re-assessed between 4-8 months after initial admission (NHS England 2013). This sat under Domain 3, helping people to recover from episodes of ill health, of the Government’s Mandate for Change and NHS Outcomes Framework (Department of Health 2014b; Department of Health 2014a). It also recommended that stroke patients should be discharged from hospital with a joint health and social care plan. The subsequent Outcomes Indicator Set for 2015/16 kept the same window for reviews (NHS England 2015) which was adopted in local policy (section 2.7.2).

The Modified Rankin Scale, an outcome measure of arguable reliability (Wilson et al. 2002), was recommended to assess ‘the proportion of stroke patients reporting an improvement in activity/lifestyle’ at six months (Department of Health 2014a, p16). It has been used as an outcome measure for 6MRs and has to be submitted to SSNAP (section 2.5). In addition, the Outcomes Indicator Sets for 2014/15 and 2015/16 (NHS England 2013; NHS England 2015) refer to supporting people to manage their condition and enhancing quality of life for carers; both come under the umbrella of Domain 2, enhancing quality of life for people with long-term conditions and are arguably aims of the 6MR.

Finally, the Cardiovascular Disease Outcomes Strategy (Department of Health 2013) identified nine key actions for commissioners and providers to build on previous policy imperatives. Although not stroke specific, the strategy aspires to improve primary prevention and risk management, reduce health inequalities, and improve services and quality of life for those living with cardiovascular diseases. There is an emphasis on individual responsibility and lifestyle management, albeit with professional support, that accords with stroke-specific policy.

2.7.2: Local policy in the South East Coast region

Strategic Clinical Networks were set up across England in 2013 in response to a policy initiative to re-organise existing clinical networks into twelve geographical areas and four main conditions including cardiovascular disease (NHS Commissioning Board 2012). Twenty eight Stroke Clinical Networks were replaced by Strategic Clinical Networks and stroke was incorporated within cardiovascular disease. The cardiovascular strand of the South East Coast Strategic Clinical Network (SEC SCN) set up a stroke-specific task and finish group to develop local guidelines in consultation with commissioners, providers, service users and carers. This led to local commissioning guidelines for the 6MR based on national policy (Hargroves, French and Trickey 2014). A similar process for ‘life after stroke’ aimed to support commissioners to consider how all aspects of stroke services could ‘enable stroke survivors to re-engage in active citizenship’ and ‘get back to living full and active lives and reintegrating with society as they desire’ (Hargroves and Trickey 2014, p5). In August 2014, eight out of 21 CCGs across the region provided 6MRs.

The guidelines stipulated that it was a review of ‘health and social wellbeing’ and should ‘work with patients and their carers to assess individual patient progress and needs 4-8 months after hospital admission’ (Hargroves, French and Trickey 2014, p23). It recommended using the GM-SAT and itemised the same descriptors as the NHS Stroke Improvement Programme (2010) (listed earlier in this sub-section). Reviews were intended to result in signposting to other services including community and voluntary groups. In addition, locally defined outcomes, or aspirations, were delineated but with no guidance as to how they might be achieved or measured. Table 8 lists the outcomes.

Table 8: Locally defined outcomes for the 6MR

Patient outcomes:
• Greater involvement in identifying and planning to address their ongoing needs • Access to a wide range of information about NHS, voluntary, community and social services that will contribute to achieving stroke related goals • Feeling supported and more confident • Will be less likely to be readmitted to hospital • Will be less likely to have another stroke • Improved health and general well-being • Reduced GP appointments • Reduced dependency
Carer outcomes:
• Support carers improved health and general well-being • Reduced GP appointments • Carers have back-up plans in place
Community outcomes:
• Reduced readmissions • Reduced dependency on social services • Improved health and well-being

(Hargroves, French and Trickey, 2014, p21)

The policy acknowledged that working collaboratively with other stakeholders was required but stopped short of recommending integrated health and social care planning (or any care planning). Instead, a patient-held summary of the review was recommended alongside timely referrals to other agencies (Hargroves, French and Trickey 2014). Who provided reviews was open to interpretation so long as the reviewer was appropriately trained and had access to a stroke team to provide support or guidance when necessary (Hargroves, French and Trickey 2014).

Subsequent guidance concerning 'life after stroke' provided a more comprehensive picture of what follow-up services and opportunities patients might expect. Information and signposting were highlighted alongside psychological care and peer support, return to work or volunteering and access to valued activities. Community based exercise and education schemes were deemed to 'improve physical integration and psychological wellbeing' (Hargroves and Trickey 2014, p59). Approaches to achieving these aspirations included care navigation; joint planning and delivery of health, social care and voluntary provision; person-centred care planning; and sharing information between providers. It recommended that provision of information should 'ideally be co-ordinated through a single point of contact for specialist stroke advice and signposting' and that the role sat within the six-month and annual review team, depending on local circumstances (Hargroves and Trickey 2014, p29).

2.7.3: The changing policy landscape

The Five Year Forward Plan (NHS England 2014) was introduced at the same time as the above local policies and set out an agenda for reorganising healthcare provision. At the core was a mismatch between resources and need, estimated at nearly £30 billion per year by 2020/21. The policy aimed to address demand, efficiency and funding to reduce the deficit. It emphasised prevention, including risk factors associated with stroke, in the context of widening health inequalities. It proposed a small number of 'radical new care delivery options' including 'multispecialty community providers', or 'multi-disciplinary community teams' to integrate health and social care services based around local need (NHS England 2014, p4).

Implementation of the Five Year Forward Plan proposed Sustainability and Transformation Plans as a way of introducing regional planning without formal reorganisation, just three years after the 2012 Health and Social Care Act removed Strategic Health Authorities (Black and Mays 2016). The model was intended to 'break down the boundaries between different types of providers and foster stronger collaboration across services' including local government and the third sector (NHS England and NHS Improvement 2016, p4). NHS organisations were urged to collaborate rather than compete but the purchaser-provider split remained. NHS services across England were divided into 44 geographical regions to promote a place-based approach to planning and delivering health and social care services with a tight timeframe and goals to achieve by 2020 (NHS England and NHS Improvement 2016).

Alongside service restructuring, policy maintained a focus on empowering patients, 'promoting wellbeing and independence' as the 'key outcomes of care'; patients and families as 'experts by experience'; and supporting self-management (NHS England 2014, p12). Thus patients and families are still expected to take responsibility for their care alongside health care professionals.

2.8: Clinical guidelines

This section outlines clinical guidelines relevant to England, Wales and Northern Ireland summarised in appendix 4. The Scottish Intercollegiate Guidelines Network (2010) produced their own guidance which recommended that services should continue to assess patient's needs in the community but makes no reference to a set review process so is not discussed in this section.

2.8.1: Royal College of Physicians guidelines

The fourth edition of the National Clinical Guidelines for Stroke (Royal College of Physicians 2012) recommended reviews at six months post-discharge and annually, based on consensus of the Intercollegiate Stroke Working Party. The guidelines linked the 6MR with therapy input by stating ‘further therapy following 6-month review should only be offered if clear goals are agreed’ (Royal College of Physicians 2012, p126). Presumably, it meant that patient and reviewer should discuss and agree on goals but there is clearly scope for disagreement. The guidelines cited one meta-analysis (Ferrarello et al. 2011) and one randomised control trial (Duncan et al. 2011) that demonstrated improvements in walking and function for people receiving physiotherapy after six months, countering the commonly held belief that patients plateau by this stage (Ferrarello et al. 2011).

Chapter 6, Rehabilitation, briefly mentioned self-management as a means to improve self-efficacy and thus independence but this was alongside equally brief reference to changes in self-identity, self-esteem, self-efficacy and mood (Royal College of Physicians 2012). The recommendation was for psychological interventions despite the shortage of neuro-psychology but this was not linked to the 6MR or goals. Also recommended was a ‘personalised, comprehensive approach’ to secondary prevention that not only incorporated regular reviews of medication and risk factors but also changes in lifestyle factors including ‘smoking, exercise, diet and alcohol’ despite stating there was lack of evidence specific to stroke recurrence and mortality (Royal College of Physicians 2012, p62-3). While recommending ‘at least 150 minutes of moderate intensity, over a week’ (Royal College of Physicians 2012, p63) it did not acknowledge how difficult this can be for stroke survivors to achieve.

The fifth edition of the guidelines (Royal College of Physicians 2016a) has a stronger emphasis on self-management as a component of rehabilitation, goal setting, collaborative care and long-term management. The chapter on long-term management includes a more robust endorsement of lifestyle factors while acknowledging that there is still limited evidence to confirm the level of risk reduction through combined lifestyle improvements.

Further therapy can only be offered if new goals ‘for specific functions and activities can be identified and agreed and the potential for change is likely’ (Royal College of Physicians 2016a, p113). The guidelines cited the same meta-analysis (Ferrarello et al. 2011) as the preceding edition that suggested patients could improve with physiotherapy six months post-stroke. This is compared to a Cochrane review (Aziz et al. 2008) which stated the evidence was inconclusive to support or refute the benefit of therapy one year post-stroke. Given the complexity of factors and the different parameters of the five studies (n=487) included in the Cochrane review it was unsurprising that the results were inconclusive. Despite lack of evidence, the guidelines allowed that some patients may gain from further rehabilitation and should have the opportunity for reassessment at six months. This led to endorsing reviews ‘at six months and one year *after the stroke*, and then annually’ compared to *post-discharge*, as previously (Royal College of Physicians 2016a, p113, my italics).

2.8.2: National Institute for Health and Care Excellence (NICE) guidelines

NICE guidance on stroke, updated in 2016, upheld the recommendation for reviews at six months, twelve months and annually (but not at six weeks) (NICE 2010). The quality statements were cross-referenced with the Outcomes Frameworks for the NHS 2015-16, Adult Social Care 2015-16, and Public Health 2013-16. That carers should have a named point of contact for information was (again) recommended. The rationale for review was that it would enable clinicians to identify ongoing problems and patients and carers to make changes as necessary. The quality standards also recommended access to clinical psychologists with expertise in stroke, regular review of therapy goals and ‘active management’ to return to work, if appropriate (NICE 2010, p29).

More recent guidelines on long-term management post-stroke (NICE 2013, p32) state that the review process ‘should cover participation and community roles to ensure that people’s goals are addressed’ but has been criticised for providing ‘little actual guidance’ to professionals, patients or carers (Drummond and Wade 2014, p526).

While not stroke-specific, guidelines on the transition from inpatient to community care (NICE 2015) emphasised the importance of co-ordination and continuity of care, and recommended that a discharge co-ordinator should agree a plan for ongoing treatment with the community team. Six-month and annual reviews were mentioned in the context of reviewing carers’ training and support needs.

The next section considers the evidence base for the review, different tools devised to carry it out and national availability of the review.

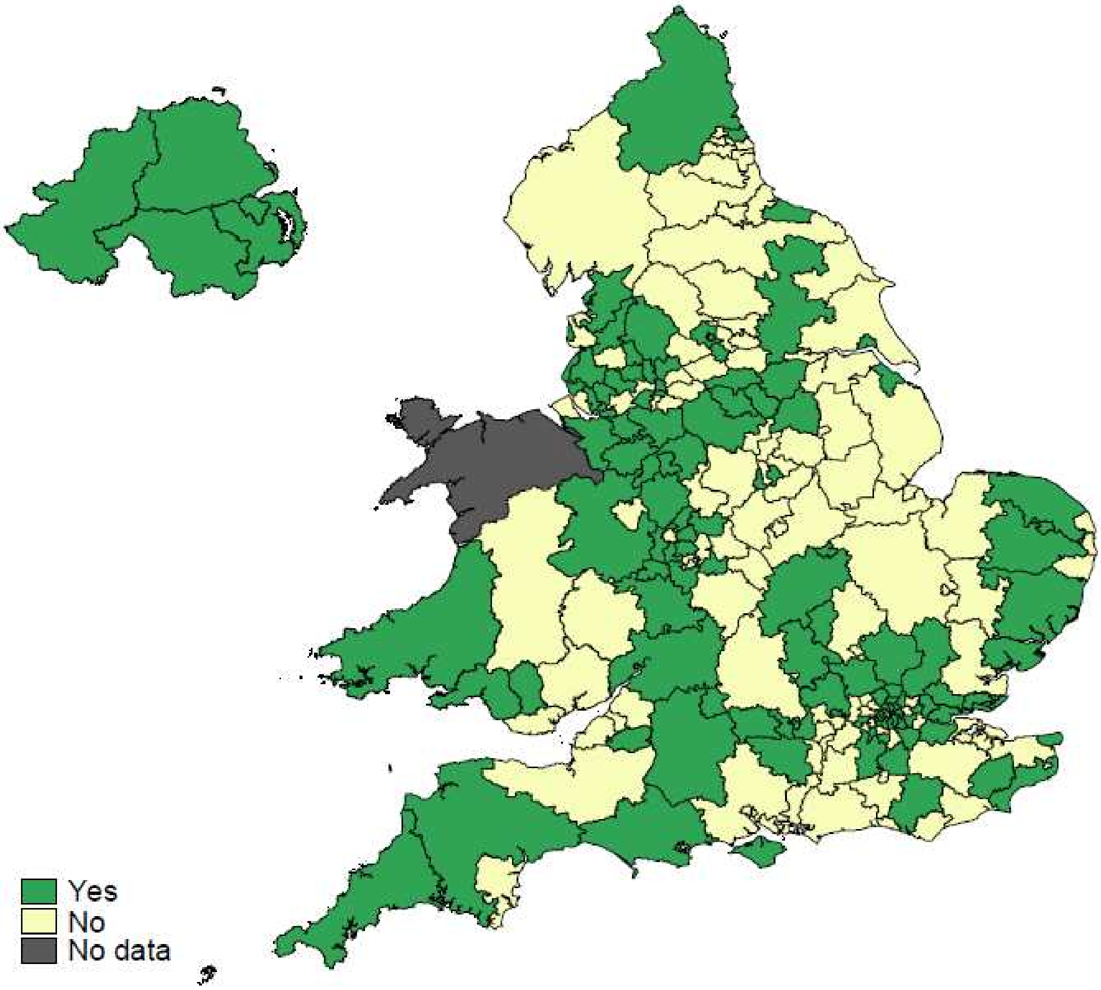
2.9: Availability and evidence base for the review

This section presents evidence of the review’s availability, effectiveness (however that is defined) and different tools used to carry it out.

2.9.1: Availability of the 6MR

The Sentinel Audit (SSNAP, section 2.5) measures who commissions and provides 6MRs and the number of people who receive it out of the eligible population, which is approximately 60,000 patients per year (Royal College of Physicians 2015a). Two hundred and twenty three organisations funded long-term stroke services in England, Wales and Northern Ireland and all but one submitted data, although figures for the 6MR were incomplete (Royal College of Physicians 2015b). Of 139 6MR providers, 40% were acute trusts, 42% community trusts and 12% third sector. Although 6MRs were mandated in England as part of the CCG Outcome Indicator Set (NHS England 2013) only 54% of commissioners audited were supporting it (Figure 8):

Figure 8: Areas commissioning the six-month review



(Royal College of Physicians 2015a, p38)

In the South East Coast region, availability was limited during the study period. In October 2014, eight out of twenty CCGs across the region provided 6MRs and although there has been at least one new service since then, many areas still lack access (appendix 5).

An earlier audit of 6MR provision in England, albeit with a low response rate (36%), identified significantly fewer CCGs commissioning the review than above. It found that 6MR services were operational in just under one-third of CCGs in England with wide variation in coverage within Strategic

Clinical Networks (Walker, Fisher and Fletcher-Smith 2014). Of the 37 services, one-third did not provide 6MRs to *all* stroke patients and this mostly related to their GP practice and whether or not they were already known to community stroke services (Walker, Fisher and Fletcher-Smith 2014). Stroke nurse specialists (SNSs) carried out most reviews, although other reviewers included stroke consultants, therapists, rehabilitation assistants and the Stroke Association. Most reviews took place in patients' homes, taking on average an hour to complete, with 45 minutes of indirect time. A range of issues was covered but spasticity (changes in muscle tone) was the most neglected area. Other issues were service limitations for onwards referrals, particularly psychology and speech and language services (Walker, Fisher and Fletcher-Smith 2014).

An earlier report (Care Quality Commission 2011) highlighted that there was much variation in implementation and a lack of clarity over who was responsible for ensuring that reviews took place. It found that six-week reviews were taking place for about two-thirds of patients, and 44% were due a 6MR but this varied hugely between Primary Care Trusts (replaced by CCGs in 2013). There was little evidence of integrated working between health and social services with only 34% having a framework for joint reviews (Care Quality Commission 2011). The study analysed information packs provided on discharge and noted that while most patients received them, only about one in ten mentioned reviews or the right to ask for reassessment should their needs change. Similarly, the Stroke Association (2012) reported that approximately one-third of respondents reported that they had not been asked if they needed an assessment or review of their needs.

Finally, a cross sectional on-line survey completed by 300 GPs also found much variation in provision, format and outcomes (Goncalves-Bradley et al. 2015). One-third of GPs were aware of recommendations for reviewing stroke patients at regular intervals and just over half provided regular reviews to all patients. However, only half of GPs based the review's contents on clinical guidance. Once needs had been identified they were added to patient records but seldom used to gauge a profile of patients' overall needs and the majority of GPs did not have a protocol to follow-up identified needs. While reviews were fairly comprehensive and mostly included wider issues such as communication, the focus was on medical management. Far fewer paid attention to fatigue, vision, relationship issues, finances/benefits, driving/transport, leisure, exercise and work. While two-thirds of GPs thought the review was of clinical utility, only one-third thought the costs of providing it were offset by its utility (Goncalves-Bradley et al. 2015).

2.9.2: Evidence of effectiveness

This section considers evidence of effectiveness of reviews and presents the few studies that have trialled a similar intervention in the UK, summarised in Table 9.

Nearly ten years preceding the introduction of reviews, Forster and Young (1996) evaluated an intervention consisting of nurse specialist visits over one year post-stroke, with a minimum of six visits in the first six months. There were no significant outcomes for carers but patients with mild disability demonstrated small gains in social outcomes at six and twelve months. However, interviews with a sub-group of participants found that they valued the nurse specialists' sensitivity, empathy and interest combined with expertise and practical help (Dowswell et al. 1997). This personal element resonates with the SA service evaluation, described earlier (Jenkins, King and Brigden 2012) (section 2.6.3).

Over a decade later, Forster et al. (2009) evaluated a structured reassessment of need, at six months, for patient and carer. There were two centres: one reviewed people at home and later discussed them with the hospital-based stroke team, while the other assessed in clinic, with established links to therapy and social care services. Surprisingly, the study did not identify any clinically significant benefits at twelve months and although the intervention group used fewer hospital bed days and less institutional care this was offset by the cost of the intervention. Nevertheless, the intervention group did express greater satisfaction with information provision, which was the most common action, but there was no impact on activities of daily living or carer well-being. Despite the findings of this rigorous study, it does not appear to have informed subsequent policy on the 6MR.

A Cochrane meta-analysis evaluated the impact of a healthcare worker or volunteer whose roles were grouped under the title of 'stroke liaison worker' (Ellis et al. 2010), which would include the remit of SA workers who carry out 6MRs. Sixteen trials were included that provided education and social support (including counselling) as well as liaison between services. The review found no evidence of effectiveness with any of the interventions and noted that they had been developed 'on a practical and intuitive basis' without an understanding of the underlying mechanisms (Ellis et al. 2010, p13). However, the picture was more nuanced and patients and carers did report satisfaction, again reflecting the limits of quantitative outcome measures.

Table 9: Studies evaluating the 6MR or similar interventions in the UK

	Aim	Design	Findings and conclusion
Forster et al. (1996)	To evaluate whether specialist nurse visits enhance social integration and perceived health of patients or alleviate carer stress.	Randomised controlled trial. 240 patients (>60 years) divided into intervention and control group. Stratified by indicators of function pre- and post-stroke. Assessed at baseline, 3, 6 and 12 months. Intervention involved visits from a nurse specialist over 12 months (minimum of 6 visits in the first 6 months).	No significant difference in perceived health, social activities, or stress among carers between groups at any point. A subgroup of patients with mild disability had small improvements in social outcomes at 6 months and 12 months. Many patients made good early physical recovery but later psychological and social adjustment was less successful.
Dowsell, Forster and Hearn (1997)	To assess patient and carers' perspective of the above intervention.	A sub-sample of 30 patients and 15 carers were interviewed within 3 months of completing the above intervention. Half had received visits from the nurse specialist.	Three patients did not recall the visits and one refused but overall the majority felt that they had benefited from the intervention. Less tangible aspects that the quantitative results did not capture but recipients valued was the 'concern, attention, empathy and interest' of nurses combined with professional knowledge and 'responding to particular needs at appropriate times' (p293).
Forster et al. (2009)	To evaluate a structured reassessment for patients and carers at 6 months after a disabling stroke.	Prospective single-blind, randomised controlled trial in two centres. 265 patients split between control and intervention group. The latter received a structured reassessment of need by a stroke nurse.	No difference between groups for the primary outcome measures of patient independence at 12 months and carer stress. Results for secondary outcome measures were similar for both groups. The intervention group used fewer hospital bed days and institutional care but this was offset by the cost of the intervention. The most common action was provision of advice and/or information (67%). No evidence of clinically significant benefits.

Ellis et al. (2010)	To evaluate the impact of healthcare workers or volunteers collectively termed 'stroke liaison workers'.	Systematic review and meta-analysis of randomised controlled trials investigating the impact of a stroke liaison worker versus usual care. Interventions were post-discharge and provided information/advice, social support and liaison with other services.	No overall significant effect for the primary patient outcomes of subjective health status and extended activities of daily living. Similarly, no effect for carer health status. Patients with mild-moderate disability had a significant reduction in disability and death. Despite this, it concluded that there was no evidence of effectiveness for the intervention and no increase in patient or carer satisfaction.
Forster et al. (2015)	To evaluate clinical and cost-effectiveness of a system of longer-term stroke care.	Multi-centre cluster randomised controlled trial of 32 stroke services. 800 patients and 200 carers, split between control and intervention group. The latter received a structured assessment of need that linked to previous problems identified by patient and carer and informed a goal and action planner.	Primary outcome was improved patient psychological well-being at 6 months. Secondary outcomes included functional outcomes for patients, carer outcomes and cost-effectiveness. The study found no statistically significant evidence between the groups for any outcomes. *N.B. Same team as produced the Longer-term Unmet Needs after Stroke tool (section 2.9.3).*

Forster et al. (2015) carried out another trial that compared a new system of care against standard practice with follow-up by postal questionnaires at six and twelve months. The intervention was carried out by stroke care co-ordinators who used structured questions to assess need and had a care plan to be completed after each contact, including setting goals. Co-ordinators used a manual containing evidence-based treatment algorithms and information about national services. Even so, there was no statistically significant difference for any of the outcomes including overall costs. The authors speculated that the measure of psychological well-being was perhaps not sensitive enough to identify changes at six months but a broad range of secondary outcomes also demonstrated no difference. They concluded that the heterogeneity of stroke patients suggests that 'targeted more bespoke interventions' may be required (Forster et al. 2015, p2218).

Overall, there is no robust evidence that reviews lead to any statistically significant improvements and national guidelines (Royal College of Physicians 2012) acknowledged this. However, an evaluation of the GM-SAT (NIHR CLAHRC Greater Manchester 2010) (section 2.6.2 and 2.9.3) cited an earlier report to support the 6MR. This report stated that anecdotal evidence indicated the 6MR had benefits that 'include stroke survivors progressing further than expected in rehabilitation, the avoidance of hospital admission, the modification of risk factors, increased quality of life and compliance with medications' (Healthcare for London 2009, p45) but with no explanation or justification.

Lastly, a Care Quality Commission report (2011) (section 2.6.2) regarded the review process as an opportunity to address difficulties adjusting to life after stroke and to ensure patients accessed relevant support. While the report claimed that early feedback was positive, no evidence was offered to substantiate the benefits that were attributed to the review 'including reducing emergency re-admissions, improving secondary prevention and providing better support for stroke survivors and their carers' (Care Quality Commission 2011, p25).

2.9.3: Different tools for the 6MR

Many services use their own template to carry out the 6MR but there are standardised tools. This section compares three tools of which the GM-SAT is the most established (Table 10).

The GM-SAT (appendix 6) captured a large proportion of the market having been developed with, and endorsed by, the Stroke Association who use it to carry out their 6MRs (The NIHR CLAHRC Greater Manchester 2010). The tool was developed in consultation with professionals and service users and has 38 areas. It includes an algorithm and trigger questions for each area to enable non-clinicians to signpost patients to other services and sources of information (Bamford et al. 2013). The pilot surveyed patients and assessors to glean acceptability and feasibility. It concluded that half of all unmet needs identified (50.4%) could be ameliorated with the provision of information and advice and that patients were mostly concerned with problems that were ‘psychosocial in nature’ (Rothwell et al. 2013, p270). The tool stipulated that it was ‘designed to support professional practice rather than determine it’ and that ‘professional judgement should always take precedence’ over the algorithms (The NIHR CLAHRC Greater Manchester 2010, p14). It was suggested that the tool’s comprehensive nature would enable patients to discuss issues they may not otherwise raise and that it has ‘the potential to significantly improve a patient’s physical, psychological and social outcomes and to optimise their quality of life’ (Bamford et al. 2013, p557). Although the tool claims to be standardised, there is no published data appertaining to reliability or validity.

The Longer-term Unmet Needs after Stroke (LUNS) is a self-completion questionnaire with twenty-two items (appendix 7). It was piloted in England and included patients with long inpatient admissions and communication/cognitive difficulties (LoTS care LUNS study team 2013). It appeared to identify unmet needs concurrent with other standardised measures of health, functional ability and quality of life, which were proxies for validity. Identification of an individual unmet need was ‘consistently associated with poorer health status on the concurrent measures’ (LoTS care LUNS study team 2013, p1026). Questions were worded to ask if there was a need and whether the need was being met. Dichotomous yes/no replies were regarded as a strength because answers were simple and unambiguous. The authors acknowledge that some areas do not map onto the tool but claim the tool would capture such areas in terms of the effect on function. For example, vision is not included but may become apparent in relation to difficulty using transport (LoTS care LUNS study team 2013).

The Post Stroke Checklist (appendix 8) was devised as a brief and easy-to-use tool to facilitate standardised assessment of ongoing need and ‘facilitate referral for appropriate care’ (Philp et al. 2013, pe179). It was developed by the Global Stroke Community Advisory Panel and piloted in England and Singapore. It was deemed to be feasible, given that clinicians could administer it in fifteen minutes or less, and able to identify patients’ needs. It conceded that some areas of concern (muscle weakness, loss of sensation, fatigue, fine motor functions and social behaviour) were not included in the eleven items but were addressed indirectly. The rationale was that it targeted areas with biggest impact on quality of life and that were amenable to treatment (Philp et al. 2013). Patients in the pilot appeared to consider the tool comprehensive but were less confident that identified problems would be addressed (Ward et al. 2014).

Table 10: Tools to support the 6MR

	Greater Manchester Stroke Assessment Tool (GM-SAT)	Longer-term Unmet Needs after Stroke (LUNS) monitoring tool	Post Stroke Checklist (PSC)
Research team	NIHR CLAHRC for Greater Manchester is a collaboration of Greater Manchester NHS Trusts and University of Manchester.	LoTS care LUNS study team, Bradford Institute for Health Research, Bradford Royal Infirmary. The LoTs was a longer-term stroke care research programme consisting of four studies.	Global Stroke Community Advisory Panel. Endorsed by the World Health Organisation.
Definition of unmet need	'A problem that was not being addressed or one that was being addressed, but insufficiently' (Rothwell et al. 2013, p266).	Assessment of needs defined as 'the ability to benefit from health (or social care)' and unmet need as 'expressed needs that are not satisfied by current service provision' (Forster et al. 2014, p77)*.	Unclear. Refers to 'addressing long-term problems and making appropriate treatment referrals' (Ward et al. 2014, p77).
Pilot	Co-ordinators received 1-day training. Piloted with patients (n=137) who did not have cognitive or communication difficulties and were residing in their own home. Patient and assessor questionnaire to assess feasibility and acceptability.	Piloted in England across 40 hospitals. Included patients being discharged home. Two cohorts of patients: the first required a minimum hospital stay of 72 hours; this was increased to 14 days for the second cohort and included those with communication and/or cognitive difficulties. Phase 1 (n=350); phase 2 (n=500).	Piloted in UK (n=42) and Singapore (n=100), patients were 8-60 months post-stroke. Interviews with patients and clinicians. Included patients being discharged to their own home.
Items	38 items which can be summarised as: medical management; risk factors; vision, hearing and communication; diet/weight/swallow; pain; continence; self-care; mobility/falls; cognition; mood/emotions; transport;	22 items which can be summarised as: secondary prevention/diet; medication/blood pressure; pain; mobility/falls; equipment/ adaptations/housing; transport; personal and domestic activities; diet; finances; employment;	11 items: secondary prevention; activities of daily living; mobility; spasticity; pain; incontinence; communication; mood; cognition; life after stroke; and relationship with family.

	activities/employment; finances; carer needs. These areas were informed by the literature and professional and patient consultation. Also includes a self-assessment questionnaire to complete in advance; a mood screen (Abbreviated Wimbledon Self Report Scale); Modified Rankin Scale; a nutrition screening tool; and a report template.	continence; relationships; concentration/mood; leisure/holidays. The areas were refined with stroke patients and carers.	These areas were informed by the ICF (World Health Organization 2002). Delphi methods were used to reach consensus.
Response scale	Dichotomous yes/no. Has aphasia friendly resources.	Dichotomous yes/no	Dichotomous yes/no
Guidance given for questions?	Algorithm for each question with trigger questions.	No, it is a self-completion questionnaire.	Each question states who to refer onto or suggests that whoever is carrying out the assessment observes progress.
Time taken	Average of 74 minutes and 33 minutes of indirect time.	Not stated.	Average 13 minutes (standard deviation 7.6) in UK population. Equated this with feasibility.
Unmet needs identified?	Yes. Mean number of unmet needs was 3 (range 0-14). Most frequent were fatigue, memory/ concentration/ attention, and secondary prevention (non-lifestyle). 50% of needs could be addressed with the provision of information and advice.	Yes. Identification of unmet need was 'consistently associated with poorer outcomes on concurrent measures' (LoTS care LUNS study team 2013, p1020).	Yes. On average 3 per patient (range 0-10). Cognition, mood and life after stroke were the most common.
Reliability/ validity	**Acceptability:** trainers completed a questionnaire (10 questions) and the majority (n=132) were comfortable undertaking the	**Validity**: other tools were used concurrently including Frenchay activities index, general	**Face and content validity**: states that patients 'generally understood and interpreted the items as intended' although there was

	assessment; nearly all felt they had the necessary skills. Over two-thirds of patients completed a short questionnaire and nearly all found the opportunity useful. No data on reliability/validity.	health questionnaire and short-form health related quality of life. **Test-retest reliability**: a second pack (Phase 2) of the tools was posted to patients a week after the first fully completed pack (Phase 1) was received. Between pack 1 and 2, 73% reported no health changes. Individual percentage item agreement was between 78-99%. **Acceptability:** response rates and minimal missing data taken as evidence of acceptability. 69% completed the first pack. Of those, 85% had completed the LUNS questionnaire with 3.5% missing data. This is equated with satisfaction.	discordance between clinician and patients' interpretations of certain items (Ward et al. 2014, p80). **Relevance**: items were 'mostly relevant' to patients (Ward et al. 2014, p80). During concept elicitation some concepts were mentioned that the Post Stroke Checklist did not directly ask about but it claims that they still arose and were indirectly measured. These were muscle weakness, loss of sensation, fatigue, fine motor functions and social behaviour. Headache, dizziness and weight gain were mentioned by one patient. **Clinician satisfaction** 'varied greatly' (Ward et al. 2014, p81) but most found it useful and informative. Overall satisfaction score was 7.7/10. **Patient satisfaction** score was 8.6/10.

(Ward et al. 2014; LoTS care LUNS study team 2013; Rothwell et al. 2013; The NIHR CLAHRC Greater Manchester 2010)

*The first definition is from Wright et al (1998) and the second a direct citation from Heinemann et al. (2002, p1052) both cited in Forster et al. (2014)

2.10: Chapter summary

This chapter outlined key aspects of stroke including risk factors, the sequelae of stroke and the relevance to public health. Although outcomes have improved markedly over the past two decades, stroke is still a major cause of mortality and long-term disability (Royal College of Physicians 2016a). Policy and guidelines have developed to support stroke specific services and now acknowledge that stroke is a long-term condition whereby patients and carers need ongoing support to maximise their health and well-being (Royal College of Physicians 2016a). While the National Stroke Strategy (Department of Health 2007) comes to the end of its ten-year remit, service reconfiguration is ongoing, particularly in the acute sector (Fulop et al. 2016). Less attention has been paid to community services, which largely consist of ESD or community stroke rehabilitation. However, the intensity and duration of therapy is often limited (Royal College of Physicians 2015b) and this appears to contribute to longer-term unmet need.

Overall, there was evidence of unmet need in the UK but it was difficult to compare studies due to different study designs and parameters, omissions in the method sections and different definitions and categorisation of need. In the two service evaluations discussed (Curtis and Gallifent 2014; Gedge, France and Jones 2013) (section 2.6.3), about half to two-thirds of patients accepted a 6MR but take-up rates for the annual review were much lower. While identified needs often involved referrals to other services, this was constrained by service availability. In addition, low expectations may deter patients from identifying a problem as a need (Shannon, Forster and Hawkins 2016). Inadequate provision, explanation and consolidation of information appeared to be a common complaint of patients and carers and perhaps reflected a dissonance between what professionals thought they provided and patients' perception of what they received (Smith, Forster and Young 2009). Overall, there is little evidence that the review process ameliorates need and whilst various assessment tools have been devised there is little evidence that they enhance a client-centred approach or ensure needs are met.

The next chapter presents the underlying methodology that informed the study and the rationale for the case study approach selected to address the research questions.

Chapter 3: Methodology and Method

This chapter is divided into two major sections, methodology and methods. The methodology section focuses on the philosophical approach to the study and seeks to justify why critical realism has been chosen to underpin the choice of case study design. The second section describes the methods for data collection, the role of the researcher and the approach to reliability and validity.

3.1: A methodological approach suited to answering the research question

Traditionally medical research has taken a positivist approach that is coherent with the medical model typified by scientific rationality, the body as a machine, mind/body separation, reductionism and the seeking of universals (Miller and Crabtree 2000, p610). Quantitative research predominates, reinforced by the current emphasis on evidence-based medicine which classifies research according to a hierarchy of evidence where randomised-control trials are regarded as the gold standard (Burns, Rohrich and Chung 2011; Oxford Centre for Evidence-based Medicine 2009). However, high quality evidence does not necessarily translate into strong recommendations (Balshem et al. 2011) as the former, carried out under experimental conditions, does not take account of the multi-faceted nature of health care interventions in a real-world setting including socio-economic, political, cultural and personal dimensions alongside the bio-physical (O'Leary 2005).

The term ‘real world research’ usually refers to applied research, carried out on a small scale, related to change and/or policy and with an element of seeking to evaluate something in an open setting (Robson 2011, p3). The focus is on an issue directly relevant to people’s lives and aims to discover ways of dealing with a problem or better understanding the issue (Robson 2011). It acknowledges that understanding the issue requires appreciation of the context, unlike an experiment which aims to isolate the phenomena in a closed laboratory setting (Yin 2014). The researcher needs ‘to learn the discipline of seeing with three eyes – the biomedical eye, the inward searching eye of reflexivity and a third eye that looks for the multiple, nested contexts that hold and shape the research questions’ (Miller and Crabtree 2000, p611). This includes listening to the patient voice in a way that ‘objective’ biomedical approaches omit (Rose 2014). Arguably, qualitative research can be used to unpack the ‘black box’ of complex interventions (Duncan and Nicol 2004), in this case the review process post-stroke, in a way that quantitative research does not allow.

3.2: Case study design

Case study research is one approach of many to social science investigation. It is the preferred method when ‘how’ or ‘why’ questions are being asked about a particular contemporary phenomenon over which the researcher has little control (Yin 2014). This section will discuss case study design and illustrate why it is best suited to answer the research question.

3.2.1: Key features of case study design and suitability to the research question

Case study design offers a level of flexibility beyond other qualitative approaches (Hyett, Kenny and Dickson-Swift 2014) and takes a ‘holistic’ approach to the study of a social phenomenon in its natural setting which enables ‘thick description’ (Gerring 2007, p49). Case studies require data collection from multiple sources (Yin 2014) and involve the ‘intensive study’ of a case where the purpose is ‘at least in part – to shed light on a larger class of cases’ (Gerring 2007, p20).

Yin (2014), Stake (1995) and Merriam (1998) are regarded as ‘foundational methodologists’ of case study design (Yazan 2015, p134) and their approaches have common characteristics (Table 11) despite differences in definition of the case and approach to design (Yazan 2015). The defining feature is the focus on a case which is the entity of interest that occurs within a specific setting (Yin 2014). The case needs to be bounded or its parameters defined and differentiated from the context, although this is rarely clear-cut (Robson 2011).

Table 11: Characteristics of case study approach

Characteristic
Defining feature is the focus on a particular case studied in its own right.
Concerned with the uniqueness of the case and capturing its entirety.
The case is a bounded system.
It focuses on the ‘how’ and ‘why’ of a particular event or phenomena.
It is not concerned with (statistical) generalisation but may allow theoretical generalisation.
It is empirical in the sense of relying on the collection of evidence.
It uses multiple methods of data collection or evidence.
It focuses on a phenomenon in context typically where the boundary between phenomenon and context is unclear.
It is a strategy or approach, rather than a method.

(Robson 2011, p136; Thomas 2011)

The key strength of a qualitative case study approach is that it allows in-depth study of a complex intervention or situation in the exact socio-political context in which it is carried out (Simons 2009). It does this through exploring multiple perspectives and demonstrating the influence of key actors in order to explain the rationale for what is under investigation. This incorporates exploring the process of change through engaging with the data as it unfolds in an iterative process of induction and deduction, also called retroduction, which involves integrating multiple types of data (Yin 2014) and uncovering underlying mechanisms (Blaikie 2007). These attributes are suited to health services research where the socio-political context is fundamental, interventions are often multi-disciplinary and the patient's perspective often lacks a voice (Peckham and Willmott 2012). At a practical level, case study design is flexible in terms of design, timescale and methods whilst also allowing the researcher to respond to unanticipated problems (Robson 2011).

3.2.2: Yin's case study design

Yin's (2014) approach was selected because it provided detailed practical guidelines on how to carry out all aspects of a case study and explicitly addressed concerns with reliability and validity, helpful for the novice researcher. Secondly, although the approach can be used with any paradigm, much of the approach 'appears to be orientated toward a realist perspective' (Yin 2014, p17), which is compatible with my stance in contrast to Stake (1995) and Merriam's (1998) constructivist epistemology (Yazan 2015).

Yin's definition of case study will be used, which starts by defining the scope (2014, p16):

> *A case study is an empirical inquiry that:*
>
> - *Investigates a contemporary phenomenon (the 'case') in depth and within the real-world context, especially when*
> - *The boundaries between phenomenon and context may not be clearly evident*

The second part of the definition delineates features of a case study on the grounds that the phenomena and context may not be clear cut in a real-world situation (Yin 2014, p17):

> *A case study inquiry*
>
> - *Copes with the technically distinctive situation in which there will be many more variables of interest than data points, and as one result*
> - *Relies on multiple sources of evidence, with data needing to converge in a triangulating fashion and as another result*
> - *Benefits from the prior development of theoretical propositions to guide data collection and analysis.*

‘Data points’ refer to the case, of which there is only one, and ‘variables of interest’ allude to the complexity of the case in its natural setting (Yin 2014). However, the term ‘variable’ with its quantitative connotations is misleading and will not be used here.

The case is defined as (Yin 2014, p237):

> *Usually a concrete entity (e.g. a person, organisations, community, program, process, policy, practice or institution, or an occurrence such as a decision*.

Yin (2014) presents four types of designs which can be summarised as single-case (holistic or embedded) and multiple-case (holistic or embedded). This study uses multiple-case design (section 3.4.2) but the key point is that probability sampling is inappropriate to decide the number of cases. Instead the focus is on the number of ‘case replications’ to inform theory development and to test the strength of rival explanations (Yin 2014, p61). Cases are not sampling units in the way that quantitative research defines them because the number of cases is (intentionally) too small and their choice is not based on random sampling.

The following theoretical propositions were formulated as part of the design phase to guide what data to collect and how to analyse it (Yin 2014):

- Reviews are carried out by different professionals including SNSs, GPs, therapists and SA co-ordinators. Each profession carries its own orientation and priorities, for example, physiotherapists are likely to focus on mobility. The proposition is that the training and orientation of the reviewer will affect the focus of the review.
- The 6MR is essentially an assessment but involves clinical reasoning and decision making. The proposition is that the 6MR constitutes a complex intervention and clinicians (SNSs or therapists) are likely to make different decisions to (non-clinical) SA co-ordinators, which may affect the outcomes.
- At six weeks, patients are mostly still receiving rehabilitation but by six months services have usually withdrawn. The proposition is that needs will vary according to the timing of review.
- The 6MR includes aspects of self-management and secondary prevention but behaviour change is a complex process. The proposition is that self-management and/or secondary prevention may require more than a one-off intervention to lead to behaviour change.
- Different tools are used to carry out the 6MR, including standardised assessments and informal templates. The proposition is that the choice of tool may influence the development of rapport between patient and reviewer.

3.2.3: Criticisms of case study design

The main criticism of case study design is that it is ‘non-scientific’, often carried out without due rigour (Robson 2011) and the published literature demonstrates inconsistent reporting of methodology, study design and paradigmatic approach (Hyett, Kenny and Dickson-Swift 2014). However, this charge could apply to any type of research and fails to distinguish between the approach and how it is carried out: ‘the case study is not a flawed experimental design; it is a fundamentally different research strategy with its own designs’ (Robson 2011, p136). Similarly, the misunderstanding that the method encourages researchers to confirm their own beliefs can be levelled at any approach and if anything, case study contains ‘a greater bias toward falsification of preconceived notions than toward verification’ (Flyvbjerg 2006, p237).

The second criticism is that case studies lack generalisability so cannot contribute to scientific development (Flyvbjerg 2006). Yin (2014) distinguishes between statistical generalisation, where an inference is made about a population based on empirical data collected from a representative sample, and analytic generalisation which consists of a ‘theoretical statement, theory, or theoretical proposition’ which is ‘posed at a conceptual level higher than that of the specific case’ (Yin 2014, p68). The term ‘sample’ is not applicable to case study where a strategically chosen case may add to the generalisability of a case study in the sense that the knowledge generated can contribute to scientific development and refute existing theories. The ‘force of example’ should not be underestimated and the fact that case studies depend on ‘practical (context-dependent) knowledge’ is an asset (Flyvbjerg 2006, p228). Unlike ‘theoretical (context-independent) knowledge’, case studies allow learning through experience in context which is arguably more useful than ‘the vain search for predictive theories and universals’ (Flyvbjerg 2006, p224).

Thirdly, case studies are criticised for unclear comparative potential; especially compared to randomised controlled trials that allow causation to be attributed to an intervention (Bryman 2012). However, unlike randomised controlled trials, case studies enable explanation of *how* and *why* interventions or programmes work and, at the very least, complement quantitative methods (Yin 2014). This focus on how an intervention works in a specific context also contributes to developing robust theory that can be tested and refined, despite the common misunderstanding that case studies are only useful for initial theory generating (Flyvbjerg 2006).

Finally, case study is, in theory, compatible with any paradigm but Yin’s approach has been criticised for lack of epistemological grounding, despite his clearly post-positivist approach (Hyett, Kenny and Dickson-Swift 2014), inclination towards realism (Yin 2014) and arguably positivism (Yazan 2015).

Despite these criticisms, case study design appears congruent with the research question and my stance and will be underpinned by the theoretical approach discussed in the following section.

3.3: Philosophical approach: the realist paradigm

This section will start by discussing the paradigm, or world view, that underpinned the research process. It will then discuss realism, in particular critical realism, and demonstrate why this approach is suited to the research question, to health services research and to case study design. The section will finish with a critique of realism.

3.3.1: A personal standpoint

A paradigm is a set of propositions that makes explicit a philosophical stance and incorporates ontological, epistemological and methodological principles (Lincoln 2010). Paradigms provide a framework to guide decisions and align methodological choices with value systems (Shannon-Baker 2015). A paradigm explains the researcher's standpoint; in particular 'what the researcher thinks counts as knowledge and who can deliver the most valuable slice of this knowledge' (Lincoln 2010, p7). However, the long standing 'paradigm war' perpetuates a simplistic dualist approach between two extremes: positivism (also called objectivism, empiricism, or universalism) and relativism (despite differences, used inter-changeably with constructivism, perspectivism, intepretivism or anti-foundationalism) (Clark, Lissel and Davis 2008). At one extreme are positivists who assert that social science should be treated in the same way as the natural sciences; they favour a quantitative approach that strives for objectivity and context-free generalisation (Johnson and Onwuegbuzie 2004). At the other extreme relativists prefer qualitative research where subjectivity is accepted, multiple realities are acknowledged and context-free generalisations are neither desirable nor possible (Johnson and Onwuegbuzie 2004). Realism arose in response to this dualism and provides a pragmatic middle road which challenges the assumptions of both extremes (Robson 2011). It is not concerned with the positivist's quest for universal laws (nomothetic) or the interpretivist's concern with documenting the unique (idiographic) (Sayer 1992) but it is concerned with understanding and explanation in a real world setting (Robson 2011). As an occupational therapist, realism resonates with my stance that is based on a combination of biomedical training which accords with an objective 'reality', and clinical experience which appreciates the interplay of psycho-social aspects with rehabilitation and recovery. Table 12 summarises the theoretical approach taken for this study.

Table 12: Philosophical underpinning

	Concept	Choice for this study
Philosophical underpinning	A paradigm is a set of propositions, or philosophical stance that explains how the world is perceived. It contains ontological principles concerning the nature of reality and epistemological principles concerning the nature of knowledge.	Critical realism (post-positivist)
	The research strategy or logic of enquiry is concerned with the approach to knowledge generation.	Retroduction
Methodology	Research design and methods to enable us to gain knowledge about the world.	Qualitative
Research design	How to execute the research underpinned by the above constructs.	Case study

(Bryman 2012; Robson 2011)

3.3.2: Introduction to realism

Realism addresses 'how' and 'why' questions and provides an approach to tackle such questions in an open setting (Robson 2011). It has been suggested as the most suitable paradigm for case study where the objective is 'understanding why things are as they are' (Easton 2010, p119) and particularly suited to interdisciplinary (Danermark 2002) and health services (Proctor 1998; Clark, Lissel and Davis 2008) research. Realism is mainly attributed to the British philosopher Roy Bhaskar (Bhaskar 2011; Bhaskar 1978) alongside other key authors including Sayer (Sayer 1992; Sayer 2000) and Archer (Archer et al. 1998).

There are several branches of realism including naïve realism, subtle realism (Hammersley and Atkinson 1995), realist evaluation (Pawson and Tilley 1997) and critical realism (Bhaskar 1978). All branches of realism share certain characteristics (Table 13) and use a theoretical representation of reality to help us understand what we cannot see. A distinctive feature is the belief that the world is independent of our understanding of it and that 'all knowledge is partial, incomplete and fallible' (Maxwell 2012, p5). Realism acknowledges that there can be different yet valid interpretations of a phenomenon based on a particular perspective or outlook (Maxwell 2012). It accepts that knowledge is provisional and has an interpretative element but this should not be conflated with an interpretivist acceptance of multiple realities (Maxwell 2012). It proposes that social phenomena exist in an open system where structures and mechanisms interact at different 'layers' of reality and are in a constant state of flux (Clark, Lissel and Davis 2008). Critical realism arose from Bhaskar's 'transcendental realism' and later 'critical naturalism' and was a challenge to the dominant positivist paradigm (Bhaskar and Lawson 1998).

Table 13: Characteristics of realism.

Characteristic:
There are no facts beyond dispute. Knowledge is a social and historical product. Our knowledge of the world is fallible and theory-laden.
All theories about the world are grounded in a particular perspective and worldview and there can be different valid perspectives on reality.
Science needs to develop theories to explain the real world and to test these theories by rational criteria.
Explanation is concerned with structures and mechanisms rather than phenomena and events and how mechanisms produce events.
A law is the characteristic pattern of activity or tendency of a mechanism. Laws are statements about things that are really happening, the ongoing ways of acting of independently existing things, which may not be expressed at the level of events.
The real world is differentiated and stratified. It consists not only of events but also objects or entities, including structures, which have powers capable of generating events.
Mental and physical entities are equally real, although they are conceptualised by different concepts and frameworks.
Explanation is showing how some event has occurred in a particular case. Events can be explained even when they cannot be predicted.

Adapted from Robson (2011, p31) and Maxwell (2012, p5-8).

3.3.3: Critical realism: key beliefs

Critical realism does not comprise one homogenous theory but comprises different authors proposing various perspectives and developments. However, there are some consistent beliefs which are outlined below, drawing on the early works of Bhaskar (1978) and Sayer (2000; 1992).

3.3.3.1: Critical realism distinguishes between the transitive and intransitive domain

Social phenomena are 'structures, mechanisms and processes' that exist and act independently of humans; this *intransitive* dimension of science remains stable (Bhaskar 1978, p22). However, we can only know the world through socially constructed meanings and this *transitive* dimension is likely to change as theories develop over time (Bhaskar 1978, p22). The distinction between theories (transitive dimension) and what they are about (intransitive dimension) implies ‘that the world should not be conflated with our experience of it’ (Sayer 2000, p11). In other words, critical realism asserts that there is an independent reality ‘out there’ but our knowledge of that reality is socially constructed. This concord with weak social constructionism acknowledges that our description of the world is shaped by language, discourse and ideas but not determined by them (Sayer 2000). Although ‘language is not a transparent, stable medium but opaque and slippery…we can nevertheless develop reliable knowledge of the world and have scientific progress’ (Sayer 2000, p71). This weak social constructionism contrasts with strong social constructionism which accepts that knowledge is shaped by language, ideas and discourses but does not accept that the world operates outside our conception of it (Danermark 2002).

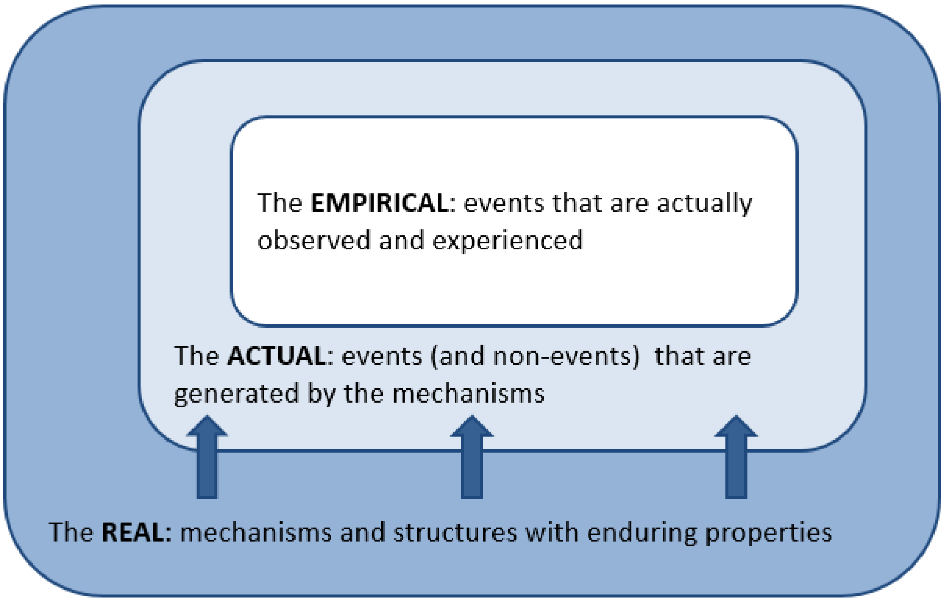
3.3.3.2: Critical realism offers an emergent ontology

Critical realists refer to entities or objects, rather than variables, as used in quantitative research. These objects can be human, social or material such as relationships, organisations and resources and are stratified hierarchically at different levels (atomic, molecular, biological, psychological and social) (Clark, Lissel and Davis 2008). The idea of emergence comes from the concept that the social emergences from the preceding strata but ‘is distinct from and more than, an individual’s cells, biology, or psychology’ and is irreducible (Clark, Lissel and Davis 2008, pE70). Entities have causal powers and liabilities, or ‘ways-of-acting’ that cause or enable something to happen (Sayer 1992, p105). Critical realism argues that the relation between entities can either be necessary or contingent: the former refers to a relation where ‘the existence of one necessarily presupposes the other’, as in doctor and patient; the latter is applicable when it is ‘neither necessary nor impossible that they stand in any particular relation’ (Sayer 1992, p89). This distinction is not related to the importance of the relation, either can be significant or unimportant, and both possess causal powers and liabilities (Sayer 1992). Incidentally, a contingent relation is not the same as context which relates to circumstances, not the relationship between entities (Easton 2010). There are different interpretations of context but this study has defined it as ‘contextual influences that are hypothesised to have triggered the relevant mechanism’ (Wong et al. 2013, p2) and context involves the interplay between structure and agency.

3.3.3.3: Reality is stratified into three domains

Alongside this emergent ontology, Bhaskar (1978) proposed a stratified ontology where mechanisms, events and experiences constitute three overlapping domains of reality: the real, the actual and the empirical (Figure 9).

Figure 9: The three domains of the real



Adapted from Mingers (2004, p94)

The above is simplified but in essence the domain of the empirical is a subset of the domain of the actual, which in turn is a subset of the domain of the real (Table 14). The *real* consists of all of reality, natural or social, and is 'the realm of objects' which possess 'structures and causal powers' that in the transitive dimension we aim to elucidate (Sayer 1992, p11). The *actual* refers to what happens (events) if and when those powers are activated and includes the *empirical* which are events that are observed or experienced.

Table 14: Bhaskar's domains of reality

	Domain of the real	Domain of the actual	Domain of the empirical
Mechanisms	✓		
Events	✓	✓	
Experiences	✓	✓	✓

(Bhaskar 1978, p56)

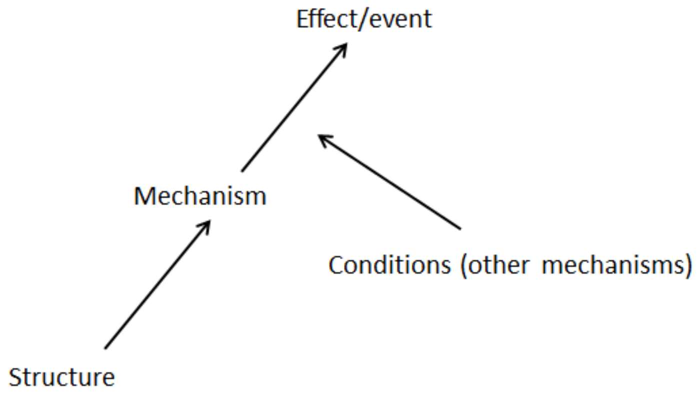
Thus events occur independently of our experiences of them; the latter are socially constructed and comprise the combination of events that 'provide the empirical grounds for causal laws' (Bhaskar 1978, p57). What is important is the complex interaction between a dynamic, open and stratified system where particular structures give rise to certain causal powers referred to as ‘tendencies’, ‘susceptibilities’ or ‘generative mechanisms’ (Bhaskar 1978, p50).

3.3.3.4: Causation is explained in terms of mechanisms

These mechanisms are considered real but are not directly observable: their existence can only be identified by careful testing to determine the contexts in which they do, or do not, operate (Bhaskar 1978). The aim is to uncover mechanisms at the level of the real in order to explain the empirical. Depending on the context, a mechanism may not be ‘fulfilled or actualised’ or may be fulfilled without our perceiving it (Bhaskar 1978, p50). Tendencies at the real level may not be perceived at the actual level because other forces counteract them. For example, a doctor may not display irritation with a patient because he knows he is not supposed to and does not want to risk the approbation of his colleagues. How a mechanism is empirically manifested (or not) is contextually determined so with respect to social phenomena this often relates to, for example, culture, class and gender (Danermark 2002). Thus the same mechanism could produce different outcomes, or different mechanisms may result in the same outcome depending on the context (Sayer 1992).

Events are multi-levelled and involve a number of causal mechanisms ‘all operating simultaneously at multiple levels’ (Elder-Vass 2007, p172). Whilst positivists make connections between observed regularities (A leads to B based on empirical and repeated observations), realists aim to identify tendencies at the ‘real’ level and contend that ‘what causes something to happen has nothing to do with the number of times we have observed it happening’ (Sayer 2000, p14). Causation is explained in terms of ‘identifying causal mechanisms and how they work and discovering if they have been activated and under what conditions’ (Sayer 2000, p14). While ‘conditions’ equate with mechanisms, they also allude to context, but are not as explicit as the context-mechanism-outcome mantra of realist evaluation (Pawson and Tilley 1997). It is unclear why the conceptualisation of causation (Figure 10) omits both context and agency, the latter of which is discussed below.

Figure 10: Critical realist view of causation



(Sayer 2000, p15)

Mechanisms underlie and are responsible for regularities observed in the social world and help us to understand social action (Pawson 2004). However, because the configurations of events are constantly changing this only allows us to explain what configuration was in existence, not to give definite predictions (Robson 2011). This form of logic is referred to as retroductive or abductive reasoning where the aim is to identify mechanisms (Easton 2010) in preference to deduction (moving from theory to observations, usually associated with quantitative research) or induction (moving from observations to theory, usually qualitative research) (Robson 2011). This interpretation was used here but retroductive and abductive reasoning are defined differently and differentiated elsewhere in the literature (Blaikie 2007).

3.3.3.5: Critical realists distinguish between agency and structure

Social structure and human agency are regarded as 'existentially interdependent but essentially distinct' (Bhaskar 2011, p92). There are differences in interpretation of both dimensions but 'the sole and slim agreement is that in *some* sense 'structure' is objective, whilst in *some* sense 'agency' entails subjectivity' (Archer 2003, p2). Structure can be defined as 'sets of internally related objects or practices' (Sayer 1992, p92) and can comprise large social objects such as the division of labour within the NHS or smaller ones such as the doctor-patient relationship.

Agency consists of attributes applicable to people 'such as thinking, deliberating, believing, intending, loving… which are applicable to people but never to social structures or cultural systems' (Archer 2003, p2). Both are real with causal powers that can either promote or hinder action and critical realism seeks to acknowledge this (Bhaskar 2011). Whilst agents 'both influence and are influenced by' social structures they have the capacity to make choices in a way that structures do not, which distinguishes mechanisms at the level of the individual from the social (Porter 2015). In relation to health services research it is important to address the interplay between individual choices, for example, lifestyle choices, and structural factors such as the cost of transport to access community facilities (Clark, Lissel and Davis 2008).

3.3.4: Case study underpinned by critical realism

Case studies can be categorised into three types depending on the research question: descriptive case studies to describe different characteristics of a phenomena in context; exploratory case studies used mostly for theory building; and explanatory ones to investigate causal relationships, usually asking 'how' and 'why' questions, and mainly used for theory testing (Yin 2014). In tandem with a realist paradigm, explanatory case studies aim to elucidate causal mechanisms, or underlying factors, that mediate between cause and effect (Gerring 2007) and aim to understand the relationships between different theoretical components (Baskarada 2014). In other words, both intend 'to peer into the box of causality to locate the intermediate factors lying between some structural cause and its purported effect' (Gerring 2007, p45). Although the main aim of this case study is explanatory, it is necessary to describe and explore before supposing causal explanations.

3.3.5: Realism and health services research

There is a growing body of health related literature using critical realism and realist evaluation, both qualitative and mixed methods, uni- and multi-disciplinary (Duncan and Nicol 2004; Clark, Lissel and Davis 2008; Shannon-Baker 2015; Harwood and Clark 2012; Danermark 2002; Porter 2015). Realist evaluation is particularly popular to evaluate health care interventions as it appears cogent with evidence based practice (Pawson 2006). The focus is identifying context, programme mechanisms and outcomes, or the CMO configuration of an intervention (Pawson and Tilley 1997). How much it shares with critical realism is contentious (Porter 2015) but realist evaluation is criticised for an inadequate distinction between agency and structure; 'lack of robust critical values'; and focus on 'technical solutions' rather than 'ideological' concerns, for example whether suggested solutions promote or inhibit alienating social forms (Porter 2015, p76). For these reasons, realist evaluation was discounted for this study but equally critical realism is not without its detractors.

3.3.6: Critique of critical realism

The paradigm in general could be criticised for confusing terminology and inconsistency of ideas between authors and over time but this is not unique to critical realism or a sufficient reason to reject its tenets. More specifically, an interpretivist/constructivist perspective would criticise it for presupposing that there is a reality ‘out there’ that can be accessed and not appreciating the ‘multiple social constructions of meaning and knowledge’ (Robson 2011, p24). However, realism accepts an interpretative element with multiple perspectives but distinguishes this from multiple realities (Maxwell 2012). An empirical/positivist perspective would criticise the notion of mechanisms that cannot be directly experienced or observed but this approach, suited to natural sciences and seeking universal causal laws (Robson 2011), is not suited to the complexities of social systems.

Realist evaluation attempts to distinguish itself from critical realism through a critique of Bhaskar that concludes the latter ‘is a strategy with no use whatsoever in applied social enquiry’ (Pawson 2013, p71). However, the differences are not so significant and the argument flawed, according to Porter (2015), who considers that the ‘most significant weakness’ in Bhaskar’s paradigm is ‘his extrapolation from experimental physics and chemistry in particular to natural science in general’ (Porter 2015, p68) and his conclusion that natural science experimentation takes place in a closed system while social science inevitably occurs in an open system. Porter (2015) points out that it would be incorrect to assert that in micro-social interactions experimentation is impossible, as social psychologists can attest.

Bhaskar’s insistence on the distinction between human agency and social structure helps with understanding social complexity and the interaction between the individual (influenced or even formed by the social world) and society (Porter 2015). Bhaskar acknowledges that agents ‘have the capacity to think and choose’ (Porter 2015, p77) and while social mechanisms impinge on people’s choices, ‘they are not the mechanisms involved in the making of choices, which reside in the psyches of individuals’ (Porter 2015, p77). However, this dualism could be criticised for insufficient appreciation of the interrelationship of agency and structure. Agents are regarded as having causal powers but it is unclear where these powers come from, what they really are and how they relate to psychological structures, in particular emotion, reasoning and moral choices (Porter 2015).

It is difficult, or even impossible, for any one theory to be entirely satisfactory given the complexity of the case study thus a degree of pragmatism is necessary to allow flexibility in the research process. However, the strengths of critical realism outweigh these criticisms and it appeared best suited to the research question, coherent with the method and the tenets reflect my standpoint.

In summary, the first part of this chapter outlined the methodology. It provided an overview of case study design, its strengths and weaknesses and why it was considered suited to the research question. Realism has been introduced, with the focus on critical realism, which was chosen to underpin this study given Yin’s (2014) weak epistemological stance. The rest of this chapter will present the study design and methods.

3.4: Method

The preceding sections have focused on situating the research and the researcher in terms of the philosophical approach and its coherence with the research question. The rest of this chapter will outline the methods which include determining components of the study design and the approach to data analysis. It draws on Yin's (2014) approach and the DESCARTE model (DESign of CAse Research in healTcarE) which aims to guide decision making and enhance rigour (Carolan, Forbat and Smith 2016).

3.4.1: Planning and preparation

I started planning for the doctorate in 2012. I carried out a literature search, spoke to key stakeholders and experts, and attended meetings arranged by the cardiovascular strand of the SEC SCN (section 2.7.2) for all stakeholders in the region, including patients and carers, involved in stroke care. This included a 'six-month review task and finish group' and a 'life after stroke' group, both of which resulted in commissioning guidance (Hargroves and Trickey 2014; Hargroves, French and Trickey 2014). This helped focus the research question and ensure coherence between the research question, design and paradigm. It took until September 2014 to secure Economic Social Research Council funding and over this time the protocol was revised several times.

Preparation focused on developing the study protocol, gaining ethical approval and ensuring I had the necessary skills (Yin 2014). Most skills, such as being a good listener, apply to all qualitative research but of note is the need to be able to adapt plans as the case study progresses, whilst balancing this against maintaining rigour (Yin 2014). The protocol is an essential tool to increase the reliability of a case study (Yin 2014) and it helped structure and guide the process and identify potential problems.

Finally, I was fortunate to meet a former sociology lecturer who had experienced a stroke some years previously. We discussed his less than positive experience of occupational therapy, which led to discussions about my project. Over time this developed into the role of 'critical friend', or a 'trusted person' who asks provocative questions and provides an alternative lens with which to reflect on decisions, ideas, prejudices and the project overall (Costa and Kallick 1993, p50). This fresh pair of eyes introduced a different perspective and encouraged me to reflect 'more deeply, holistically and honestly' (Loughran and Brubaker 2015, p256).

3.4.2: Design

The design stage focused on identifying the type of case study and defining the case and unit of analysis, together with developing procedures to maintain quality (Yin 2014).

3.4.2.1: A multiple-case design

Evidence from multiple cases is often regarded as more robust compared to a single case design and the analytic benefits ‘may be substantial’ (Yin 2014, p64). In choosing multiple cases it is important to treat them as if they were multiple experiments using replication logic rather than sampling logic (Yin 2014). Each case consists of a ‘whole’ study which is analysed and reported in its own right alongside cross case analysis (Yin 2014). There is no ideal number of cases for a multiple-case design as it depends on several factors including the research question, resources and a trade-off between breadth and depth (Baskarada 2014). However, a greater number of case replications does correspond with greater certainty in the results and allows consideration of rival explanations (Yin 2014).

During the study period just eight of the twenty CCGs in the South East Coast region commissioned 6MRs (Hargroves, French and Trickey 2014). The initial plan was to sample one site from each of the three main regions (Kent, Surrey, Sussex). After further consideration, sites were selected on the basis of their model of review set within the context of local policies and demographics and were thus of theoretical interest. However, it was anticipated that the results would be similar in key aspects (a literal replication) because all services are based on the same local guidance (Hargroves, French and Trickey 2014) and have to submit patient level data to SSNAP (section 2.5). To protect confidentiality, the sites will be referred to by number.

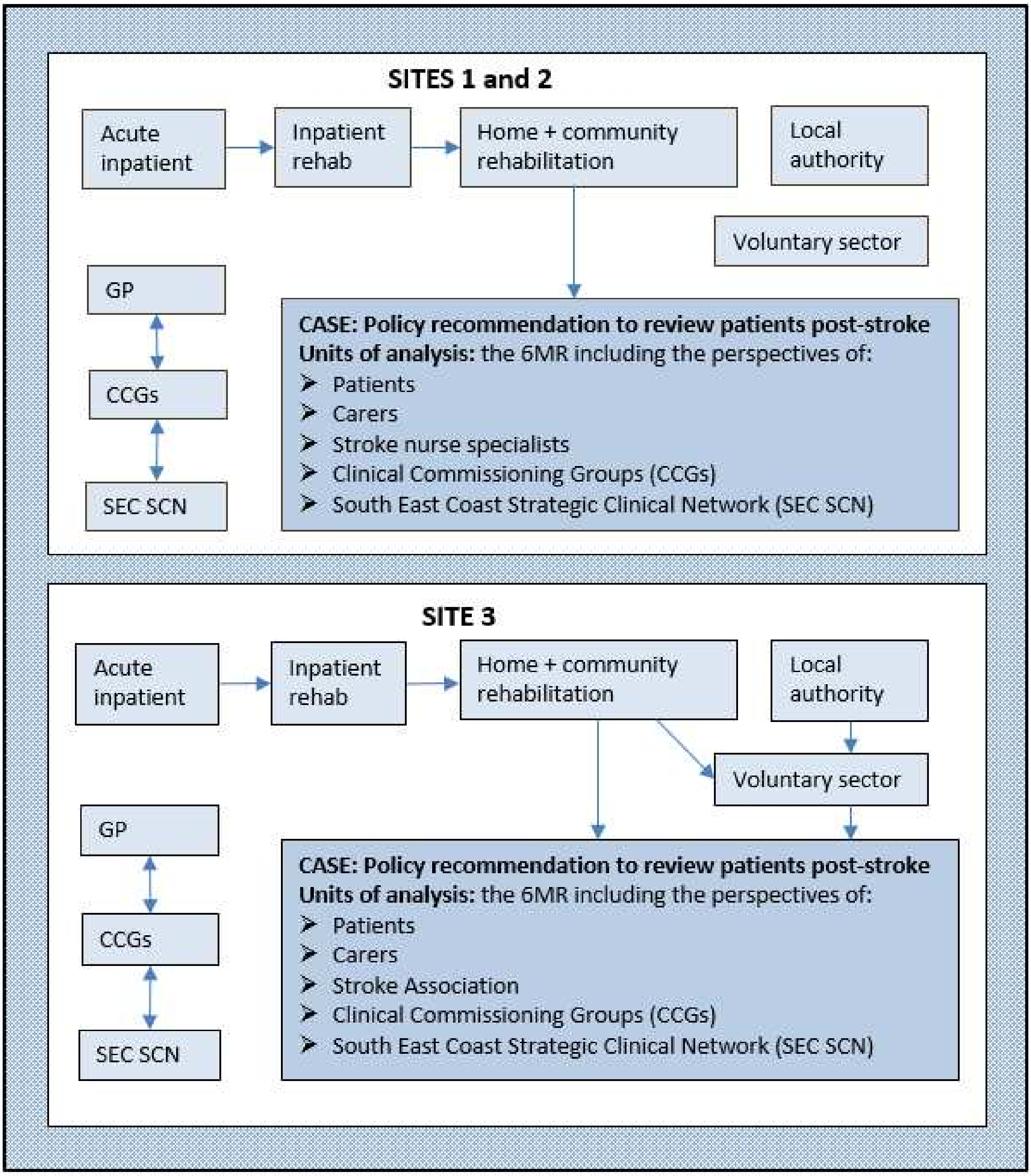
3.4.2.2: The case and unit of analysis

The case is ‘the main subject of study’ and can be a phenomenon or more usually ‘a concrete entity’ (Yin 2014, p237). The case here is a phenomenon, the review process, to ascertain its effectiveness and the mechanisms by which it achieves its outcomes. The process constitutes the review at six weeks, six months and yearly thereafter (Department of Health 2007). However, the six-week review is usually carried out when patients are still receiving community rehabilitation and the yearly review is currently not funded in most areas. Thus the focus, and unit of analysis, is the 6MR when stroke services have largely withdrawn and patients and carers have reported feeling abandoned by statutory services (Stroke Association 2012). The temporal boundaries were from discharge home to shortly after the 6MR, although where possible people were tracked up to one year, to include their annual review.

The parameters of the case were all those directly (patients, carers, SNSs, other clinicians including therapists and SA workers) or indirectly (managers, commissioners) involved in the process. The SEC SCN was included because it had promoted the review process and CCGs were included because they commissioned it. Although social services have a key role in providing long-term support they were not involved in developing or carrying out 6MRs so were not included with the proviso that this decision could be reconsidered. The key population of interest were adults who had experienced a stroke and were entitled to a 6MR, their carers, those who carried out reviews and CCGs who supported it (Figure 11). The term ‘reviewer’ will be used to denote the SNSs and SA co-ordinator who carried out reviews. The term ‘clinician’ refers to professionals, including inpatient ward staff and community therapists.

In site 1, the key reviewers were three SNSs each attached to a community stroke team; site 2 had one SNS, working within a neuro-rehabilitation community service and in site 3, the Stroke Association was contracted to provide 6MRs and employed a ‘co-ordinator’ to do so. Sites are described at the start of Chapter 4.

Figure 11: Multiple-case design



3.4.3: Data collection methods

Case studies draw on multiple sources of evidence to allow triangulation, develop convergent evidence and thus strengthen construct validity (Yin 2014). This section outlines the rationale for which types of data were selected while the next section describes the practicalities and challenges.

3.4.3.1: Interviews

The central tenet of interviews is that they allow access to the participant's point of view in terms of their attitudes and experiences. Critical realism uses interviews, alongside other methods, to elicit the interpretations of participants and to analyse the social contexts within which they act (Smith and Elger 2012). Interviews also enable access to 'richly textured accounts of events, experiences and underlying conditions or processes', or mechanisms, which represent different facets of social reality (Smith and Elger 2012, p14). Realism acknowledges that the validity of information cannot be taken for granted so demands 'critical scrutiny' and understanding of participants 'preoccupations and standpoints' to assist this process of scrutiny (Smith and Elger 2012, p10). This allows anticipation of how information may be biased and reflects the 'investigative and analytically informed orientation' of a critical realist interview (Smith and Elger 2012, p26). Interview techniques that encourage this include keeping an initial focus on specific events; encouraging comparison of events between different settings or episodes; probing for details and implications; querying inconsistencies; challenging accounts where appropriate; testing provisional analyses or theories with participants; and attention to the participant's standpoint (Smith and Elger 2012). Such techniques also contribute to avoiding the potential weaknesses of interviews, in particular courtesy bias and inaccuracies due to poor recall (Yin 2014).

Clearly questions must be within ethical bounds and more invasive ones could cause distress. What was an appropriate level of probing for reviewers and commissioners was different to that for patients/carers and needed careful consideration. The power differential comes into play, for example, a commissioner may regard herself as higher status than a student, whereas 'patients' may feel inhibited by a researcher entering their home. One technique which helped inform the interview guide, was to use a laddered approach whereby questions were divided into three levels and started with the least invasive (Price 2002). Firstly, questions about actions or events were asked which were mainly descriptive, helped set the scene and assured the participant that I was interested in their views. Secondly, questions about knowledge which were more invasive were asked because they might highlight gaps in knowledge (most pertinent to reviewers). Thirdly, the most invasive questions asked were about personal philosophy, or 'beliefs, values and deep-seated feelings' which related to the person's identity (Price 2002, p278).

3.4.3.2: Individual versus joint interviews

Interviews can be defined as ‘an inter-change of views between two persons conversing about a theme of mutual interest’ (Kvale 2007, p2). For reviewers and commissioners it was practical and appropriate to interview individually. For those who have had a stroke, interviews carried out at home were suited to enabling them to fully express themselves in their own time and in a familiar environment, especially if struggling with communication and/or cognitive impairment (Swinburn, Parr and Pound 2007). However, stroke affects not just the patient but also their partner and it was anticipated that many participants would be inter-dependent couples who were likely to feel more comfortable talking together (Morris 2001). Joint interviews also enabled respondents to have a rest in a socially acceptable manner and for the carer to help with communication (Radcliffe, Lowton and Morgan 2013).

Joint interviews have been used extensively in health research and are also called conjoint, couple or dyadic interviews. Criticisms include overlapping definitions; lack of differentiation between approaches to data collection versus analysis; and insufficient exploration of the practical, ethical and methodological implications (Polak and Green 2016). However, joint interviews are particularly suitable when the research question relates to a ‘phenomenon that is empirically a shared one’ (Polak and Green 2016, p1647) and the relationship between participants is socially defined (Morris 2001). In addition, much health literature is constructed from the perspective of either carer or recipient, leading to health services directed at one or other rather than considering their common needs (Torgé 2013). Here, joint interviews denote ‘interviews with two people who have a prior relationship, interviewed at the same time’ while a dyadic approach refers to analysis that ‘utilises the interaction between the participants’ (Polak and Green 2016, p1639).

Joint interviews are a useful hybrid between observing and interviewing (Morris 2001) and can capture each person’s views as well as shared perceptions; in the context of couples managing long-term disability, this can provide insight into how knowledge is constructed and used in practice (Polak and Green 2016). Torge’s (2013) interviews with older couples provided insights into the interaction between participants referred to as ‘we-talk’. Interviewing couples in their own home added to their sense of ‘being a *unit*’ or sense of ‘we-ness’ and the data captured the relational aspects of caregiving within the parameters of their shared history and cultural context (Torgé 2013, p108). Moreover, for the benefit of the researcher, ‘the implicit needs to be made explicit’ which enables insight into tacit assumptions and decision making in a way that individual interview cannot do (Morris 2001, p564).

Clearly, what people say does not equate with what they do but joint interviews may ‘mitigate this weakness’ by providing direct opportunities to observe interactions which allow some analysis of the credibility of accounts of practices (Polak and Green 2016, p1644). This interactive context is one in which the narratives of the participants intersect in three ways: *confirmatory* accounts where participants agree but the shared account may be for the benefit of the researcher; *complementary* accounts where the accumulation of specific details may strengthen the credibility of inferences made about what they do; and *contradictory* accounts where disagreement can provide insights that strengthen inferences about participants' practices (Polak and Green 2016).

The main criticisms of joint interviews are that participants may be less candid; be unwilling to talk about sensitive issues; one may dominate the conversation; and conflict might be underplayed (Torgé 2013). It is possible that only couples with good relationships will participate and that they feel compelled to present a positive front (Morris 2001). Even considering separate interviews implies having secrets which could cause conflict (Polak and Green 2016) but joint interviews run the risk of one partner inadvertently disclosing something to their partner that is potentially harmful (Morris 2001). Offering individual or joint interviews lends a 'small degree of empowerment' (Morris 2001, p556) which was the choice endorsed by the ethics committee (section 3.5).

3.4.3.3: Interview guides

Interviews can be categorised as fully structured, semi-structured and unstructured (Robson 2011). Semi-structured interviews use an interview guide which has a list of topics to be covered and verbal prompts to elicit further information (Kvale 2007). This ensures all topics are covered but allows flexibility, for example, the order and wording of questions can be modified to suit the context (Robson 2011). A carefully constructed guide should avoid bias due to poorly constructed questions (Yin 2014).

The interview guides were developed using the literature and in consultation with the Quality Improvement Lead for Stroke for the SEC SCN. One interview guide was developed for patients and carers with one version for the initial interview and a second version for the follow-up interview (appendix 9a-b). The patient guide evolved to include questions about therapy input and goals because it quickly became apparent that this was a central concern for many respondents and case study research allows such flexibility (Yin 2014). The guide was formatted to suit joint interviews, separate interviews, or interviews with those who did not have a carer. There was a separate interview guide for reviewers, other professionals and commissioners which reflected their perspective (appendix 9c). All interview guides were reviewed by my critical friend (section 3.6). One pilot interview was carried out with a commissioner and another with a service user but neither were included in the data.

3.4.3.4: Observation

Participant observation has its roots in ethnographic research which aims to learn about the diverse perspectives of the study population and understand the interplay between them (Spradley 1980). Participants are observed in their own environment and the researcher tries to learn what life is like as an 'insider' whilst remaining an 'outsider', also termed emic and etic respectively (Spradley 1980). Thus the researcher can check whether people do what they say they do whilst capturing the process and context, including the influence of the physical setting (Mulhall 2003). However, both accounts (what people perceive they do versus what they are observed doing) are valid and 'represent different perspectives on the data' (Mulhall 2003, p308).

The degree of involvement can be categorised (Table 15) but is perhaps better regarded as a continuum. For example, when I first attended a weekly multi-disciplinary meeting on an acute stroke ward I had no involvement and was not even acknowledged but over the weeks moved into the passive category (presence acknowledged, able to make an occasional comment). Observation can also be categorised as *structured* or *unstructured* according to the paradigm. A naturalistic paradigm 'contends that it is impossible to separate researcher from researched' and will employ an unstructured approach in the sense that the researcher will not decide in advance what to observe or the level of participation (Mulhall 2003, p308). Conversely, structured observation aims to maintain an objective distance and stand apart from participants. My level of involvement was determined more pragmatically, for example, given the hierarchical nature of an inpatient setting and confidentiality issues it was not surprising that my involvement was minimal. However, when attending the 'life after stroke' group, I was more involved, for example answering occupational therapy specific questions and making the tea.

Table 15: Types of participation

Degree of involvement	**Type of participation**	**Definition**
High ↓	Complete	The researcher is an ordinary participant within the research setting.
	Active	The researcher seeks ‘to *do* what other people are doing’ and to fully learn the cultural rules of engagement.
	Moderate	The researcher aims to ‘maintain a balance between being an insider and an outsider, between participation and observation’.
Low	Passive	The researcher is present but ‘does not participate or interact with other people to any great extent’; similar to a bystander.
(no involvement)	Nonparticipation	The researcher has no involvement with the people or activities being studied.

(Spradley 1980, p58)

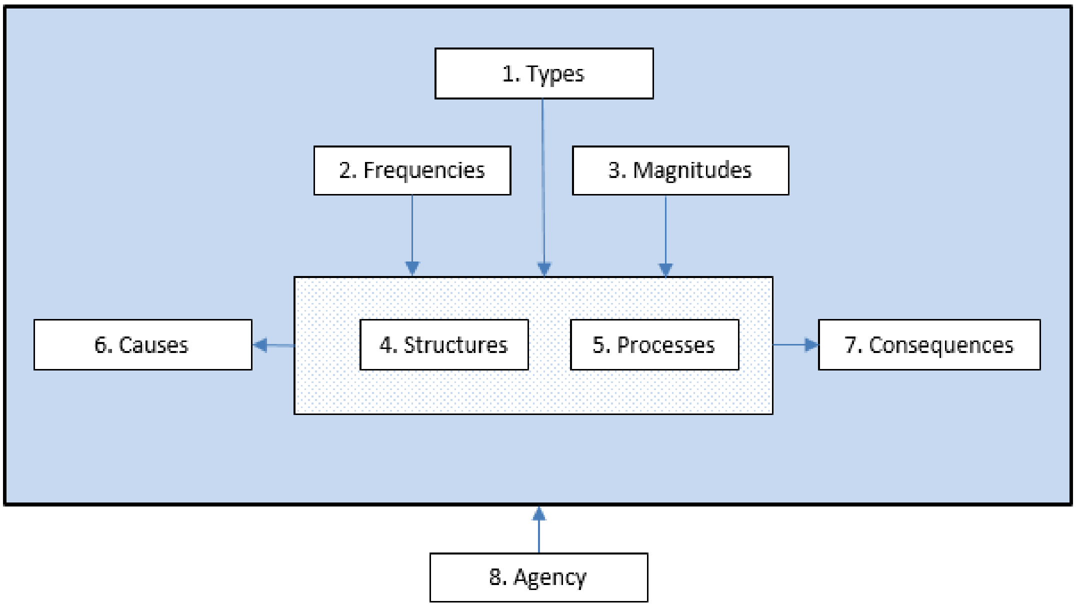
In ethnographic terms every social situation has three primary elements: a *place* or the physical setting; people who are considered *actors* within the setting; and the *activities* that take place (Spradley 1980). I started with broad description and progressed to more focused observations guided by preliminary data analysis (Spradley 1980). My involvement was limited by time and resources but the principles helped guide my observations alongside my occupational therapy background where observation is a core skill.

The disadvantages of observation are the time involved, reliance on memory, its subjective nature and that the researcher’s presence may alter the behaviour of those being observed (Yin 2014; Mulhall 2003). The researcher chooses what to observe, how to filter the information and how to analyse it, which is open to the charge of bias (Mulhall 2003). Although interview data is open to a similar charge the interviewee can, to a certain extent, direct where the interview leads and may influence analysis via member checking (Mulhall 2003).

I used a notebook to capture observations at the time. These were supplemented by fieldnotes straight afterwards and included detailed descriptions of what was observed, analytic notes on what I thought might be occurring and personal reflections (Ritchie et al. 2013), which I typed up later. No confidential patient information was recorded and the data was anonymised.

Emerson et al. (2011, p32) recommends jotting down 'immediate fragments of action and talk', 'concrete sensory details', direct quotes within context and 'emotional expressions' whilst avoiding generalisations or summaries (Emerson, Fretz and Shaw 2011, p32). Obviously it was important to make notes straight away to capture detail and maintain accuracy (Emerson, Fretz and Shaw 2011). I also used questions to help conceptualise what I had observed because understanding events is 'partly contingent' on the questions asked of them (Lofland et al. 2006) (Figure 12). Question 1, type(s), refers to what is being depicted. Frequencies and magnitudes mean how often something is observed and its strength or size; structures and processes ask how something is organised (structured) and how it operates over time (processes); and causes and consequences ask what factors account for the occurrence of something (causes) and what effects something has (consequences). Outside these questions lies human agency which asks 'how people strategize their actions in and toward situations and settings' (Lofland et al. 2006, p144).

Figure 12: Eight basic questions adapted from Lofland (2006, p145)



3.4.3.5: Documentation

The use of documents can help 'corroborate and augment evidence from other sources' (Yin 2014, p107). This includes open access material on the internet as well as documents only available through specific organisations. The main disadvantages of using documents are that they were written for a specific purpose and audience other than that of the case study (Yin 2014); may contain inaccuracies or be incomplete (Patton 2002); and may reflect the bias of the author (Sarantakos 2005). Archival material refers to records such as maps and survey data and need to be treated with caution for similar reasons (Yin 2014). I had asked the SEC SCN Lead for documentation and archival material from 2012 onwards and this included minutes of relevant meetings, commissioning guidance for CCGs and SSNAP data.

3.4.4: Sampling decisions and in/exclusion criteria

This section explains decisions made around the sampling strategy, sample size and approach to data saturation. Sample size and saturation are considered together because they are interrelated.

3.4.4.1: Sampling strategy

Non-probability sampling is used in qualitative research because the aim is not to draw a representative sample from the population of interest but to identify individuals 'who either possess characteristics or live in circumstances relevant to the social phenomenon being studied' (Mays and Pope 1995, p110); in this case adults who had recently experienced a stroke, lived within the case study sites and were entitled to a 6MR. This purposive or criterion based approach to sampling was chosen because it samples participants specifically because they represent the key criterion (Ritchie and Lewis 2003). A secondary aim was to have a degree of diversity 'so that the impact of the characteristic concerned can be explored' (Ritchie and Lewis 2003, p79), or in this case the impact of the 6MR could be 'uncovered', which allowed the development of a patient typology, or 'classification system' (Bazeley 2013, p314). However, the South East Coast region lacks diversity in terms of ethnicity. I wanted to access one site which started a new service part-way through the study and has a more diverse population in terms of ethnicity and socio-economic status. Whilst the community NHS Trust were happy to grant access, unfortunately the Stroke Association declined consent.

Theoretical sampling is a type of non-probability sampling in which the relation between sampling and explanation is 'iterative and theoretically led' (Mays and Pope 1995, p110). Sampling and data collection are guided by developing theory or explanations which may be tested out by gathering more data, strategically sampled, to elucidate or refute the theory. This study used some theoretical sampling at a later stage of data collection to test preliminary findings. For example, I attended one year reviews for certain patients because their response at the 6MR varied from the majority or had some other feature of interest that helped illuminate the process. I also sought out an expert orthoptist because unresolved visual problems were a recurring complaint. This was a pragmatic decision but could be criticised because theoretical sampling is linked with theoretical saturation, both of which are associated with grounded theory. In this context, theoretical saturation refers to the point in data collection when no additional insights emerge and conceptual categories are considered 'saturated' (Corbin and Strauss 2015).

3.4.4.2: Sample size and saturation

Despite saturation's origins in grounded theory, the term is used more generically to mean the point in data collection when no new issues are identified and further data collection yields no new insights (Hennink, Kaiser and Marconi 2017). It tends to be used as a gauge of sample size and stated in advance on research proposals, although it can only be operationalised during data collection (Hennink, Kaiser and Marconi 2017). Although case studies refer to replication logic rather than sample size (Yin 2014), when applying for NHS Ethics and Research Governance approval the emphasis was on providing an exact sample size. The ethics committee I attended demonstrated little understanding that qualitative research aims to enable analytic, rather than statistical, generalisation so that the findings can be generalised at a conceptual level higher than that of the specific case (Yin 2014). A preliminary decision, based on admissions data for each site, was that a total of thirty patients, and their carers, would be feasible. For commissioners, reviewers and other clinicians, there were limited numbers of relevant individuals who were all approached.

A realist approach to sampling describes the sample in terms of the domains of the actual and empirical, expressed as observable categories or features. Sampling 'will always be a construction of something' and the researcher's assumptions need to be made explicit so that the impact on the claims from the research can be considered (Emmel 2013). There are social powers, or generative mechanisms, that 'govern, mediate, and facilitate' the choice of sample to be studied (Emmel 2013, p74). Some of these mechanisms are external and beyond the control of the researcher, such as the NHS Ethics and Governance system. Other weaker mechanisms, or internal powers, such as the researcher's choice of theories also inform judgements made about the sample. The mechanisms that govern the sample are 'dynamic and changeable' so as the research progresses the rationale for why a particular unit is included can be refined through insight gained in the process (Emmel 2013, p74).

Although there are attempts to predetermine sample size this depends on several factors and can be somewhat futile (Morse 2015b). One of the few literature reviews on qualitative sample size found that most literature recommended that sampling should 'continue until "theoretical saturation" (often vaguely defined) occurs' (Guest, Bunce and Johnson 2006, p61). However, most of the literature failed to define or operationalise the concept of saturation. Hennink et al. (2017) offer a useful distinction between *code saturation* and *meaning saturation*: the former refers to 'the point when no additional issues are identified and the codebook begins to stabilise' while the latter is defined as 'the point when we fully understand issues and when no further dimensions, nuances, or insights of issues can be found' (Hennink, Kaiser and Marconi 2017, p594). This latter interpretation was used and ensured that all aspects of the data had been comprehensively explored; less pertinent data was not discarded in case its relevance become apparent later (Morse 2015a). Thus, exact numbers were determined by this view of saturation and paralleled normal practice within qualitative research (Ritchie et al. 2013).

3.4.4.3: Inclusion and exclusion criteria

As already stated, the key population of interest were adults who had experienced a stroke and their carers; reviewers who carried out 6MRs and their managers; and the CCGs who commissioned it. The inclusion criteria were kept as broad as possible to facilitate recruitment.

The main patient inclusion criteria were NHS patients who had had a stroke; were over 18 years (the criteria for adult stroke services); were going to be discharged into the community to their own home or a care home; lived in an area that commissioned 6MRs and had mental capacity. It was anticipated that most people would be retired and living at home with their partner. Those with mild-moderate aphasia and/or cognitive impairment were included if they had mental capacity (as assessed by their consultant) and were able to hold a meaningful discussion. All forms were available in a simplified pictorial version suited to those with aphasia or mild cognitive impairment (The Clinical Research Network 2015).

Patients were excluded if they lacked capacity, or there was any concern that they might. It was anticipated that those who lacked capacity were likely to require nursing home placement and require more intensive services than the review process caters for. Those with severe language and/or cognitive difficulties that precluded a meaningful discussion were excluded, as was anyone who did not speak English (as there was no funding for an interpreter).

Partners, spouses or other relatives may not regard themselves as carers or attach that label to themselves (Morris 2001) so were defined as whoever the patient regarded as their main source of practical and/or emotional support and either lived with the patient or visited regularly. Carers were excluded if the patient did not consent to them taking part.

Commissioners and providers included SNSs and SA staff; those involved with supporting them (mainly service managers); and representatives of CCGs and the SEC SCN.

3.4.5: Recruitment strategy

Once NHS Research Ethics (appendix 10a; section 3.5.1) and governance approval (not included in the appendices to protect confidentiality) had been granted from a specific NHS Trust, or equivalent body, recruitment could commence within that site. This section outlines the process for each category of participant and challenges encountered.

3.4.5.1: Patients and carers

The largest acute stroke unit from each area was selected because they had an established team to provide the 6MR and the largest throughput. Patients were identified and invited to participate in the study when in the acute stroke unit by the local collaborator who was a research nurse, SNS or consultant who had been identified in the research governance process. The patient invitation letter (appendix 11) was provided with a self-addressed envelope but respondents could also contact the researcher by email or telephone. In some instances, the research nurse forwarded the invitation letter with the respondent's contact details and consent to do so.

Recruitment had been calculated on the number of discharges per month over the preceding year but there were significant delays: in site 1 the research nurse did not recruit for two months and then transferred the study to colleagues. I had permission to attend weekly multi-disciplinary meetings and identify potential participants for the colleagues to then invite. Numbers of stroke patients were fewer than predicted and of those who had a stroke the majority were too severe, palliative or had advanced dementia. To supplement, one of the SNSs agreed to include the invitation letter when she mailed appointment letters to the previous month's discharges, which she did for three months. I also submitted a minor amendment to the ethics committee (appendix 10b) so that a consultant and neuropsychologist were able to recruit from two wards in a different hospital within the same site but this resulted in recruiting patients who were already several months post-stroke.

Site 2 had not given permission for me to attend any meetings and the local collaborator did not commence recruitment for over a month. Recruitment was also slower than anticipated for the same reasons as above. To supplement, I attended three rounds (of two sessions each) of a 'life after stroke' group run by the SNS but attendance was much less than anticipated. For the next two rounds of the group the administrator included my invitation letter with their own one.

Site 3 governance approvals took significantly longer due to lack of response from the consultant, several delays with the Stroke Association's processes, and research governance issues. Thus recruitment from this site was delayed by over ten months and recruitment had to be curtailed.

In sites 1 and 2, once patients had returned home I posted the patient and carer information sheet which explained that they were being asked to contribute to one interview once they were home (after the six-week review) and a second one after their 6MR (appendix 12a-c). I telephoned them after a week to answer any questions; if they were willing to take part we arranged the first interview. For site 3, the process was similar but due to delays and logistics patients were only interviewed once, after their 6MR. Formal consent was taken at time of interview (appendix 13a-c).

In sites 1 and 2, a subset of participants were asked after the first interview if I could observe their 6MR; those who had resumed their pre-stroke routines were not asked. In addition, I attended clinics with two reviewers and asked the patient, where appropriate, if I could interview them following their review.

For site 3, the SA co-ordinator asked permission for me to observe their review when she rang to arrange an appointment. She also gained consent for me to contact them in advance to provide the patient invitation sheet and address any questions. I posted the invitation sheet and telephoned the patient one week prior to interview to introduce myself, discuss the study and answer questions.

In terms of who was recruited, it became apparent that those with severe impairment, such that they were being discharged to care homes, were not represented in the sample because it felt unethical to ask them and/or they lacked capacity. Conversely, a few participants with minor stroke were almost back to normal by the first interview thus making follow-up at six months appear inappropriate. These people were followed-up by telephone to check if any problems had arisen and if so were revisited.

3.4.5.2: Reviewers and commissioners

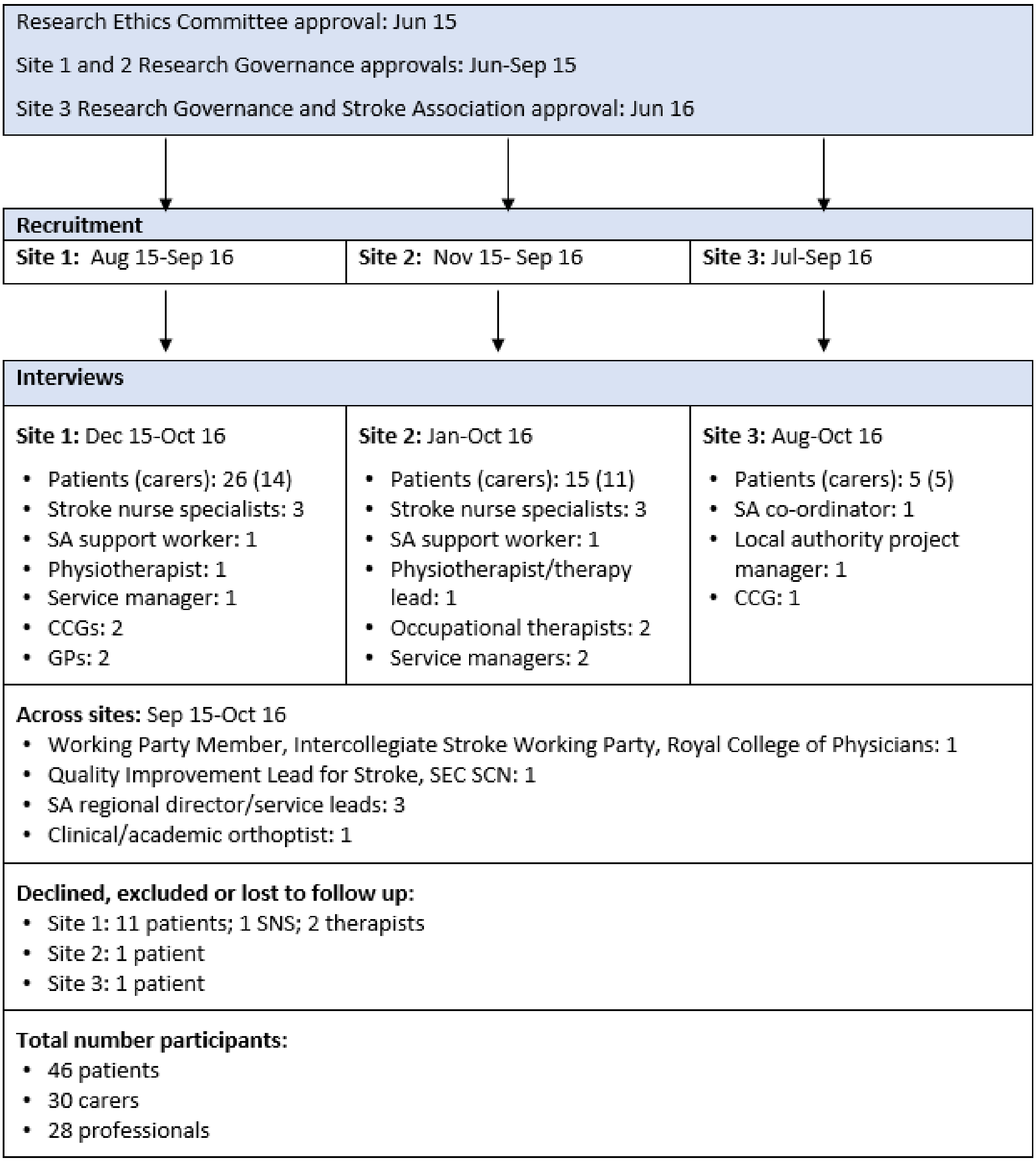
I had already established contact with reviewers so telephoned or emailed to arrange a time for initial interview. The information sheet (appendix 14) was provided in advance by email and reviewed prior to taking formal consent (appendix 15).

CCGs and/or CCG collaboratives that funded the review process in each site were contacted by email using email addresses supplied by the SEC SCN. The email outlined the purpose of the study, had the information sheet and consent form attached (appendix 14-15), and asked their preferred format for interview (face to face, telephone or Skype).

3.4.6: Description of the sample

Overall forty-six patients, thirty carers and twenty-eight professionals were interviewed between December 2015 and October 2016. Appendix 16 provides a summary of who was interviewed per site. More patients were interviewed than planned in order to observe sufficient 6MRs and achieve theoretical saturation. Figure 13 illustrates the recruitment process, including which type of professional was interviewed in each site. Limited information has been provided to maintain confidentiality. A description of each site is provided in the findings (Section 4.2).

Figure 13: Flow diagram of recruitment and sample



Research Ethics Committee approval: Jun 15

Site 1 and 2 Research Governance approvals: Jun-Sep 15

Site 3 Research Governance and Stroke Association approval: Jun 16

Recruitment

Site 1: Aug 15-Sep 16	**Site 2:** Nov 15- Sep 16	**Site 3:** Jul-Sep 16

Interviews

Site 1: Dec 15-Oct 16
- Patients (carers): 26 (14)
- Stroke nurse specialists: 3
- SA support worker: 1
- Physiotherapist: 1
- Service manager: 1
- CCGs: 2
- GPs: 2

Site 2: Jan-Oct 16
- Patients (carers): 15 (11)
- Stroke nurse specialists: 3
- SA support worker: 1
- Physiotherapist/therapy lead: 1
- Occupational therapists: 2
- Service managers: 2

Site 3: Aug-Oct 16
- Patients (carers): 5 (5)
- SA co-ordinator: 1
- Local authority project manager: 1
- CCG: 1

Across sites: Sep 15-Oct 16
- Working Party Member, Intercollegiate Stroke Working Party, Royal College of Physicians: 1
- Quality Improvement Lead for Stroke, SEC SCN: 1
- SA regional director/service leads: 3
- Clinical/academic orthoptist: 1

Declined, excluded or lost to follow up:
- Site 1: 11 patients; 1 SNS; 2 therapists
- Site 2: 1 patient
- Site 3: 1 patient

Total number participants:
- 46 patients
- 30 carers
- 28 professionals

Of the forty-six patients, twenty-seven (59%) were male and nineteen female, with an age range of 28-91 years (Table 16). Twenty-two respondents (48%) had pre-existing long-term conditions including atrial fibrillation, diabetes, renal impairment and arthritis. Eighteen (39%) were less than 65 years old which is relatively high, given that national statistics suggest about one in four strokes occur in working age people (Royal College of Physicians 2012).

Of the eight respondents working pre-stroke, four resumed work during the study period. Most people owned their own homes (n=38, 83%) and were married or co-habiting (n=31, 67%). Three respondents had severe aphasia so interviews captured their carer’s perspective while two had moderate expressive aphasia but could express their views. Appendix 17 provides further information about the age of respondents and their work status.

Table 16: Patient characteristics

	Site 1	Site 2	Site 3
Number of patients	26	15	5
Male (female)	15 (11)	9 (6)	3 (2)
Age range, years	28-88	31-91	67-80
Marital status			
- Married or co-habiting	17[a]	10	4
- Widowed	2	2[b]	1
- Divorced	6	1[c]	0
- Single	1	2	0
Interviewed with carer	14	11	5
Other long-term condition(s)	13	6	3
Working age pre-stroke (<65yrs)	11	6	1
- Unable to work due to other long-term conditions	5	1	1
- Already taken early retirement	2	1	0
- Unable to return to work during study period	3	1	0
- Returned to work during study period	1	3	0
Accommodation			
- Owner occupied house	17	10	4
- Owner occupied flat, bungalow or maisonette	4	2	1
- Private rental	2	2	0
- Council or housing association	2	0	0
- Warden-controlled flat	1	0	0
- Living with parents	0	1	0

[a] Respondent 37’s wife was in a care home so he was interviewed alone.

[b] Respondent 22 lived -and was interviewed with- her daughter.

[c] Respondent 44 lived alone but was interviewed with her daughter

[d] Working age taken as <60 years old for women and <65 years old for men, although one 67 year old man was still working

Finally, Table 17 summarises observations. In site 1, two patients declined a 6MR and three did not receive one despite being many months overdue. In site 2, two people lived in an area where the review was not funded.

Table 17: Summary of observations

	Site 1	Site 2	Site 3
Initial visit	1	0	1
6MRs	10	9	4
1 year reviews	6	NA	NA
Multi-disciplinary meetings, weekly, in the ASU (Oct 15-Feb 16)	10	NA	NA
Team meeting (coding) (Oct 15)	1	NA	NA
'Life after stroke' group (Nov 15-Feb 16)	NA	5	NA

3.4.7: Data collection

This section describes the practicalities of data collection and the challenges encountered (Table 18). The main issues were delays in recruitment and fewer new inpatient admissions per week than had been anticipated.

A case study database was created using the software programme Nvivo 11, a computer assisted qualitative data analysis software tool. It allowed material to be filed according to source, format or content, which meant I could find material relatively easily, keep primary data separate from analysis and maintain an audit trail (Yin 2014). The sequencing of data collection was guided firstly by what appeared logical, for example, interviewing reviewers after observing a 6MR and secondly by practicalities, primarily waiting for research governance approval from each NHS Trust.

Table 18: Sources of evidence and challenges

Method	Source of evidence	Challenges
Interviews	All sites: • Patients and carers • Reviewers • Service managers • Commissioners	• Very slow recruitment as reliant on NHS staff; patients did not meet inclusion criteria; and missing contact details. • Not able to recruit people discharged to care homes as lacked capacity due to communication and/or cognitive impairment. • Some patients had aphasia and/or cognitive impairment so it was difficult to ascertain their views, although carers were able to assist. • Limited access to service managers and their awareness of the 6MR was limited. • Difficult to engage CCGs and find a representative involved with community stroke services. • Stroke Association refused access to a new service so only able to interview one co-ordinator who carried out reviews.
Observation	• All sites: 6MR. • Site 1: multi-disciplinary meetings; coding meeting. • Site 2: 'Life after stroke' groups. • SEC SCN meetings.	• Limited access to SA so only observed four 6MRs and one initial visit. • Difficult to track when 6MRs were due and/or the review was on a day I was unable to attend. Not having an NHS email account meant I could not email names. • Difficult to obtain feedback from SNSs when I was unable to observe a specific 6MR. • Due to recruitment issues some patients had already had their 6MR when we met. • Not allowed access to team meetings in site 2-3. • Three patients did not receive a 6MR and the SNS did not respond to emails/telephone calls (Jan-Oct 16). • Limited opportunity to attend 1-year reviews within the period of data collection.
Documentation and archival records	• SEC SCN website: minutes from meetings; commissioning guidance; SSNAP data. • NHS Trust websites • CCG websites • SA website	• Difficult to access NHS Trust policies and other internal documents including discharge criteria and service overviews. • Stroke Association reluctant to share documentation as 'commercially sensitive' and limited information on website.

3.4.7.1: Interviews with patients and carers

Interviews were carried out in their own home at a time that suited, thereby saving travel time and costs and enabling the interview to take place in a relaxed environment. Prior to commencing the interview I asked participants if they had any further questions before asking them to read and sign the consent form (standard or aphasia friendly) of which they were given a copy. At the end of the interview I asked if they would be willing for me to observe their 6MR.

3.4.7.2: Interviews with commissioners, reviewers and other professionals

One initial face to face interview was carried out with each reviewer in their workplace. Later interviews were more akin to informal discussions to explore findings as they emerged. Written consent was taken before the first interview and verbally thereafter. All commissioners and most other professionals chose telephone interviews.

Interviews were audio-recorded and transcribed verbatim. I transcribed most second interviews but nearly all first interviews were professionally transcribed by an independent transcriber who had signed a confidentiality agreement. Each time I received a transcript I checked it for accuracy against the voice recording. In addition, hand written fieldnotes were used to record observations and ideas during and immediately after each interview and to capture the context of interviews (Emerson, Fretz and Shaw 2011). The notes did not contain any identifiable information and were used after each interview to compile a ‘snapshot’ of each participant’s details and key concerns. The document was a helpful memory aid and used to cross-check information later on.

3.4.7.3: Observation of 6MRs

For a subset of respondents, I attended their 6MR to observe its format, content and the interactions between patient, carer and reviewer. The review took place in a health centre, community hospital or the patient’s home. Participants were aware of this request from the original information sheet and I asked them for permission to observe at the end of the first interview. I telephoned participants the day before their 6MR to check they were still happy for me to observe. I took verbal consent at the start of their review but for the few people who I had not already interviewed, I took written consent before the 6MR commenced.

3.4.7.4: Observation of meetings

I attended relevant meetings which varied according to research governance approval and the meetings held at each site. For site 1 this included weekly multi-disciplinary team meetings and a monthly coding meeting to ensure all strokes had been correctly coded. My focus was on process and the interplay between inpatient and community clinicians. I was refused access to a stroke support group which started mid-way through the data collection period. In site 2, I observed the 'life after stroke' group but logistics prevented attending handover meetings between the inpatient and rehabilitation unit because they were usually by telephone. I attended one meeting between the SNS and a SA worker. I introduced myself at the start of each observation, as recommended by the Ethics Committee, to cover consent issues. In site 3 I was unable to attend any meetings.

3.4.7.5: Observation of 'life after stroke' group

Site 2 ran a 'life after stroke' group that had been instigated by the SNS and covered issues relevant to the 6MR, including secondary prevention. Each running of the group consisted of two sessions of two hours and I attended five sessions. The group was held in a community hospital where patients also attended therapy sessions and their 6MR. Consent was obtained by providing written information in advance (appendix 18), which the administrator posted with their own invitation to attend the group and the dates that I would be present. At the start of each group I was introduced and the group was asked if they had any questions or objections.

3.4.7.6: Documentation

As well as material already collected from the SEC SCN, CCGs were asked for relevant audits, reports or service evaluations that were not publically available but most were not forthcoming. I looked through their websites, and that of the Stroke Association, to find publically accessible information that helped understand local contextual issues. The Stroke Association allowed access to their Key Performance Indicator Framework which summarised the training support workers received.

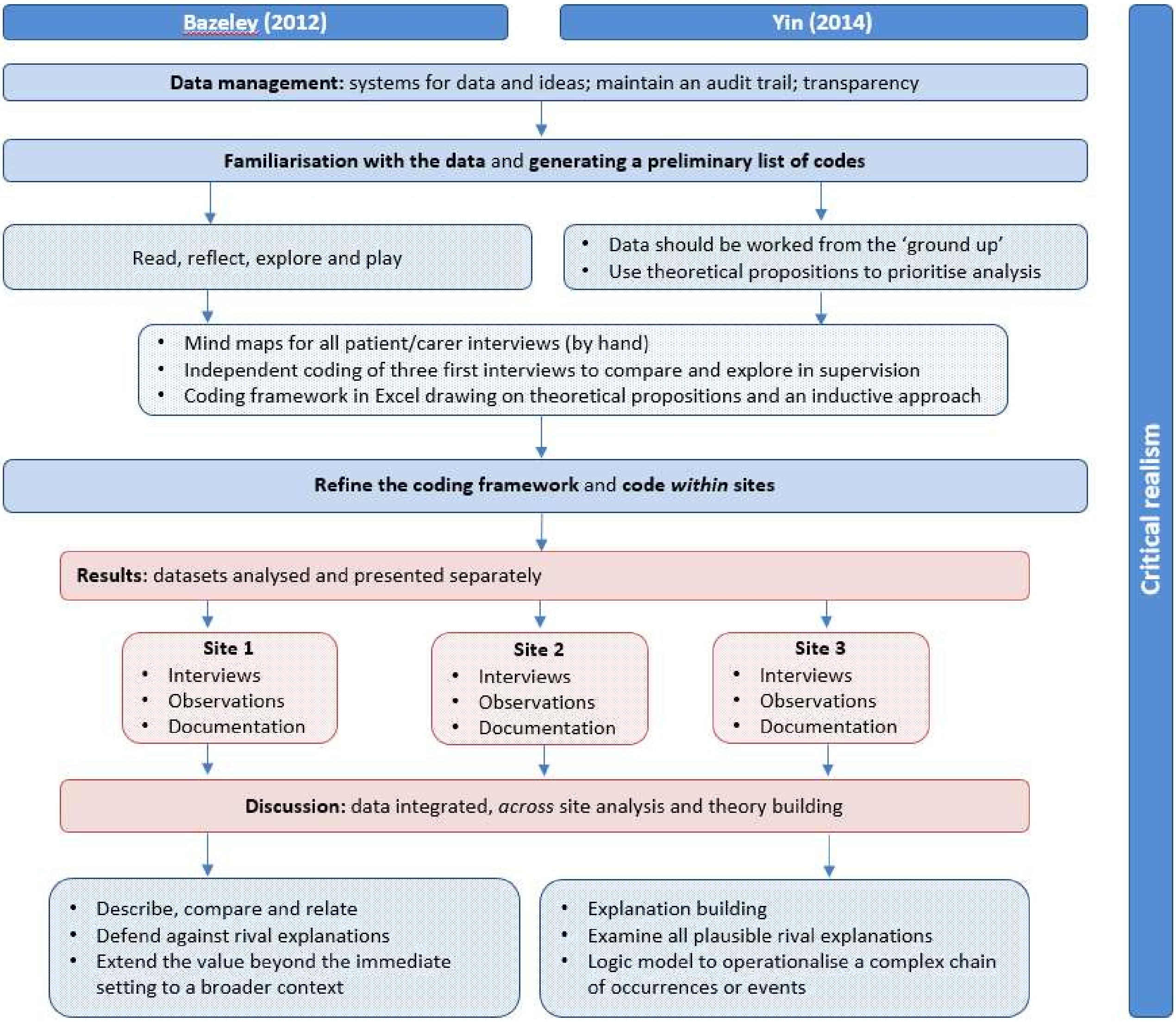
Reviewers were asked to provide information on local policies, the local stroke care pathway and the documentation they used for 6MRs to develop my understanding of local contextual issues and how they worked with other statutory and voluntary organisations.

3.4.8: Data analysis

This section describes the approach to data management, as well as the process and rationale. It is divided into four sections but the process was iterative, not linear. Analysis drew on three approaches selected for a particular strength: thematic analysis was chosen for its clear and succinct account of coding and epistemologically neutral stance (Braun and Clarke 2006); Yin's (2014) case study analysis provided helpful suggestions for theory development; and Bazeley's (2013, p20) comprehensive text provided a model for analysis and theory development which was compatible with 'a pragmatist, critical realist' approach, complemented by a guide to using Nvivo (Bazeley 2010).

Thematic analysis takes a flexible approach that allows for 'identifying, analysing and reporting patterns (themes) within data' and interpreting them (Braun and Clarke 2006, p79). However, ‘identifying themes, at best, falls somewhere in the process between coding and theory development’ and provides insufficient attention to theory building (Bazeley 2013, p191). Yin (2014, p136) recommended four general strategies to inform analysis: firstly, *relying on theoretical propositions* (section 3.2.2) to prioritise analysis because such propositions have informed each stage of the process and have highlighted analytic priorities; secondly, and in contrast to the first strategy, data should be worked *from the ‘ground up’,* using an inductive approach to look for patterns in the data; thirdly, *developing a case description*, or analytical strategy which uses a descriptive framework to organise the data based on the literature review; and lastly, examining all *plausible rival explanations* which works in combination with the previous three strategies. I mapped these steps against those described by Braun and Clarke (2006) and Bazeley (2013) and found most compatibility with the latter, albeit using different language. Figure 14 provides an overview of analysis which is discussed in the following sub-sections.

Figure 14: Overview of data analysis



(Bazeley 2013; Guest 2013; Yin 2014)

3.4.8.1: Data management

Effective data management was a requisite to systematic analysis and maintaining transparency. Nvivo's flexibility allowed me to switch between items (transcripts, codes, memos, annotations), keep track of data and review coding decisions. This ability to go back and forth facilitated the iterative process of analysis (Bazeley 2010). The first step was to import raw data to create an organised and transparent case study database that included all data (compared to what is presented in the thesis), therefore increasing reliability of the entire case study (Yin 2014). Data was categorised according to site, source (interview, observation or documentation) and respondent's role. During analysis I added data such as concept maps and search queries (Table 19). I initially imported audio files but later removed them because they slowed down Nvivo and were easy to access on my computer.

Table 19: Data management using Nvivo 11

Sources in Nvivo		Site 1	Site 2	Site 3
Internal source: folders and sub-folders	**Patients and carers: interviews and observations**			
	• Initial interview	✓	✓	✓
	• Observation of 6MR and/or 1-year review	✓	✓	✓
	• Follow-up interviews	✓	✓	✗
	• Other telephone calls or contact	✓	✓	✓
Internal source	**Reviewers: interviews and observations**			
	• Initial interview	✓	✓	✓
	• Follow-up interviews, discussion or queries	✓	✓	✓
	• Observations of:			
	○ 6MR and/or 1 year reviews	✓	✓	✓
	○ 'Life after stroke' group	✗	✓	✗
	○ Team or other meetings	✓	✓	✗
Internal source	**Therapists or other professionals: interviews only**			
	• Occupational therapists	✗	✓	✗
	• Physiotherapists	✓	✓	✗
	• Orthoptist: x1 expert (not site specific)	NA	NA	NA
Internal source	**Commissioners/managers: interviews only**			
	• Initial interview	✓	✓	✓
	• Follow-up discussion/queries	✓	✓	✓
Internal source	**Documentation**			
	• **Local:** service descriptions, job descriptions/specification, personal correspondence and NHS Trust websites	✓	✓	✓
	• **Regional:** SEC SCN documentation; SA website; SSNAP website (not site specific)	NA	NA	NA
Memos/annotations	• Individually, for specific patients, across all contacts	✓	✓	✓
	• General, across patient/carer transcripts	✓	✓	✓
Queries: text search	• Terms included rehab*, therapy, goals, review, self-manage*. *Within and across sites.*	✓	✓	✓
Maps	• Project map: tried but found unhelpful	✗	✗	✗
	• Concept map: to map themes across sites	✓	✓	✓

3.4.8.2: Familiarisation and generating initial codes

The first step involved familiarisation with the data through ‘immersion’ or repeated reading and rereading of all data and listening to audio-recordings (Braun and Clarke 2006, p78). Some researchers argue that the act of transcribing is part of the analytic process and should be recognised as an interpretative act rather than a mechanical one (Braun and Clarke 2006) but I did not find this and preferred listening to audio-recordings to engage with the data. Preliminary ideas for coding were noted but these were only a starting point to gain perspective on individual data sources and, to a lesser extent, the project as a whole (Bazeley 2013). Annotating transcripts as I read them helped me to reflect and interrogate the data in relation to the research question. I used various methods to record my thoughts and questions including a notebook, commenting on transcripts (by hand and in Nvivo), using post-it notes and summarising key points for each transcript. This was supplemented by discussion with my supervisor and critical friend.

The next step, akin to Bazeley’s (2013) recommendation to ‘explore’ and ‘play’ with data, was to create a mind map for all patient/carer first interviews, some follow-up interviews and observations of the 6MR. This helped generate ideas for initial codes and highlighted common issues. This idea stemmed from an initial attempt at coding in Nvivo where I had not planned my approach and became mired in micro-analysis, or focusing on the minutiae of words/phrases (Bazeley 2013). The mind maps helped me gain an overview of the data, as well as remembering individual circumstances. For each mind map I highlighted key questions and observations with ‘post-it notes’ and highlighter pens which helped me develop a coding framework in the next phase. Mind maps explored individual context and were particularly illuminating where I had used Lofland’s (2006) questions to structure observations of 6MRs (Figure 12).

I had to decide how to analyse joint interviews with patients and carers. Data from joint interviews can either be treated as coming from two people, with two perspectives elicited from one interview, or, as with a dyadic approach, the interaction is considered for what it reveals about the co-construction of knowledge (Polak and Green 2016) and shared meanings created through interaction (Radcliffe, Lowton and Morgan 2013). The latter perspective was used to inform but not dictate analysis.

Having completed the mind maps, I analysed three transcripts by hand, as did my supervisor. We compared codes and explored a recurring metaphor (hospital/home as prison) to facilitate understanding of abstract ideas. The purpose of joint coding was not to ascertain if we would generate similar categories as a measure of validity, which was not a reasonable expectation (Bazeley 2013), but to help me articulate coding decisions and generate initial codes. I also met with my critical friend for the same purpose.

I started to develop a coding framework in an Excel spreadsheet based on the above. Codes were defined as the smallest or most basic unit of analysis (Braun and Clarke 2006) and were deliberately descriptive to avoid jumping to interpretations. I did not use phrases that respondents had used as labels for codes (except in one instance) because they were unique to the individual and could have limited my ability to go beyond the individual to more conceptual terms later on (Bazeley 2013). I then coded the three transcripts that had been previously coded and tried to cross-reference between the transcripts and spreadsheet but this became unwieldy so I reverted to Nvivo, which is described in the next section.

3.4.8.3: Refine the coding framework and coding within sites

Coding provides 'a means of purposefully managing, locating, identifying, sifting, sorting and querying data… designed to stimulate and facilitate analysis' (Bazeley 2013, p125). Nvivo uses parent and sub-nodes to represent a main category and sub-categories and allows a description of each node to be recorded. The benefit over Excel was flexibility: for example, it was easy to re-code or double code exerts, collapse or expand nodes and adjust descriptions of each node.

First level, or initial coding, involved identifying and labelling data and was descriptive. I kept codes as close to the data as possible and did not conceptualise or interpret. Codes maintained the essence and wording of respondents. I soon had too many codes to manage so I grouped them under descriptive topic headings. For example: a parent node of 'inpatient care' was divided into sub-nodes including 'initial experience', 'bad – don't listen' and 'doctors good'. I had one miscellaneous node for exerts that did not fit any category which I reviewed at the end of each transcript and if necessary created a new node (Bazeley 2010). Table 20 gives an example of first level coding.

Table 20: Example of first level coding

	First level code	Example of text
Node	Reactions including loss of confidence	*I do think perhaps the shock of it and the…how much it knocks your confidence and how much you don't understand of what's happened.*
Sub-node	Fear or anxiety re having another stroke	*I didn't go off through the woods and things like I normally did…I'd go around the fields so that I could actually be found; I kept thinking if it happens again.*
Node	Social isolation	*No, I don't feel isolated because you know it's the opposite. I've spoken more, and the neighbours more to me, since my illness than they ever did before.*
Sub-node	Feeling caged or trapped	*They give you a room in [community hospital] and I was - to put it very broadly- I felt I was a prisoner. I was told to stay in my room and not to move out of the room.*

I coded all site 1 initial interviews first because this was the largest group. I continued to refine the coding framework and kept a record of changes by exporting each version into Excel. I coded larger chunks of text than I had originally done and many phrases/sentences were double or triple coded. Using multiple overlapping codes for the same passages of text indicated that the codes had some relationship that needed exploring and helped me refine the coding framework (Bazeley 2013).

Initially, I used the Nvivo function of 'memos' which allowed me to capture ideas, note reminders to review at a later date (Bazeley and Jackson 2013) and maintain an audit trail (Birks, Chapman and Francis 2008). However, I found the function inflexible, particularly having to flick between a memo and the source it related to. Instead, I used memos for reflections related to the project overall but switched to using 'annotations' to record ideas linked to specific sentences or phrases within each data source. This worked well because the function allowed me to highlight phrases in the transcript and view comments displayed as footnotes. Some interviews were particularly hard to code because they contained so much information and memos were invaluable to track coding decisions later on. I found the annotations and memos helped me retain ideas *within* and *across* transcripts and sites. This fostered reflexivity and helped me interrogate the data and my own interpretations.

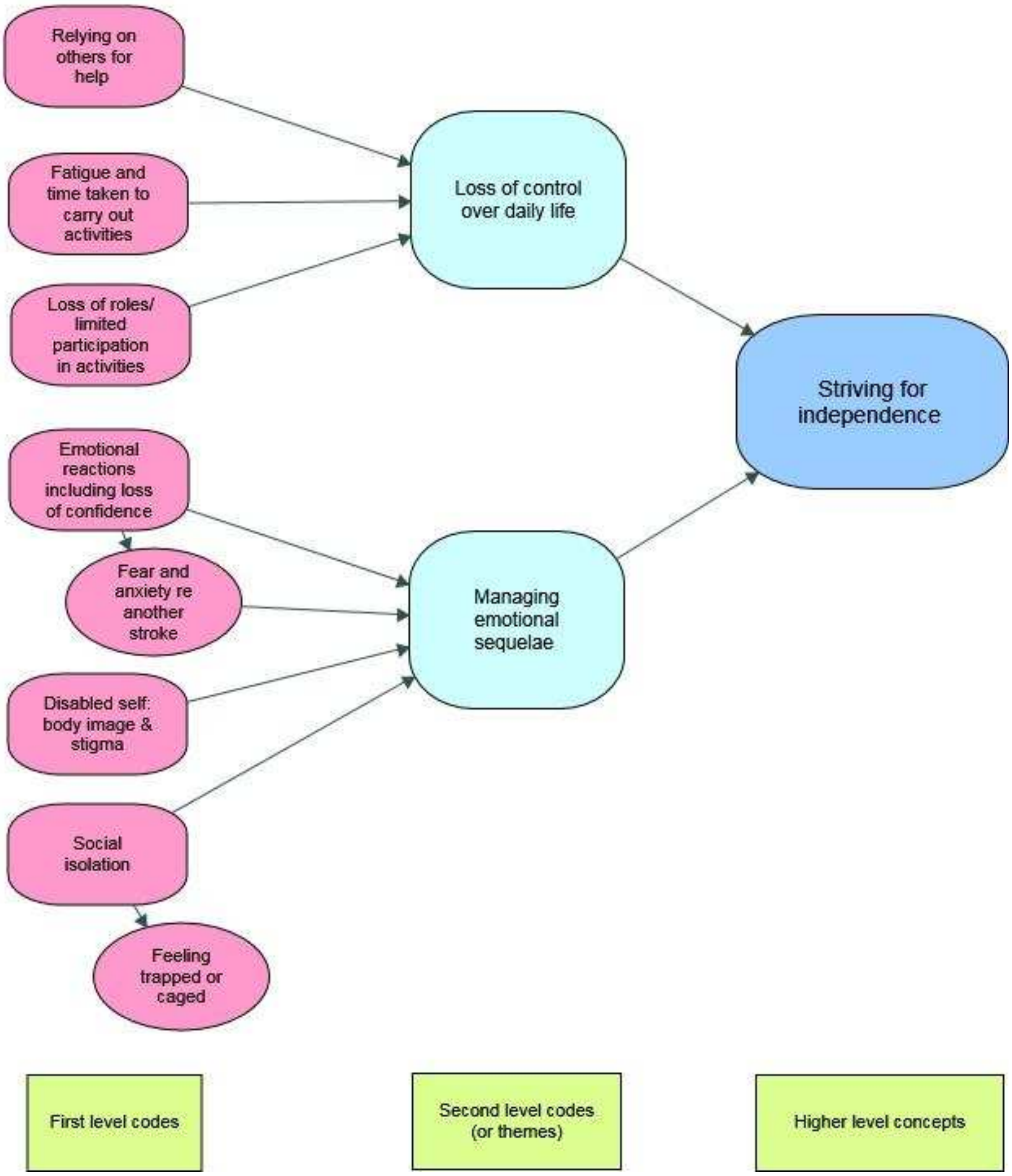
Once I had coded all site 1 initial interviews in chronological order I coded those for site 2 and 3, also in chronological order which took several weeks. I kept refining my coding framework until I was sure that codes did not overlap and I could justify their inclusion. I used my original mind maps and post-it notes comments to ensure I was happy that the framework reflected all elements of the data. To help manage the data it was also important to focus on the most significant aspects of the case study relating to the original objectives (Bazeley 2013). For example, I decided not to focus on specific deficits (such as sensory impairment) because it was not directly relevant to the 6MR. However, the composite effects of impairment on function were included because that is an area the 6MR should address.

I continued to code patient and carer observations, second interviews and further contact or telephone calls by site and in chronological order before moving onto reviewers and other professionals, SA staff and commissioners/managers. Table 19 reflects the order of analysis. I then coded observations of meetings and groups and finally documentation and archival material. Documents were summarised in terms of what was relevant to the research question (Sarantakos 2005), namely the purpose, outcomes and mechanisms of the review process. To aid rigour, original wording was retained and each quote could be traced back to its origins (Ritchie et al. 2013). Material of questionable relevance was not initially dismissed in case its relevance became apparent later on. Handwritten fieldnotes could not be imported into Nvivo but much of the material had been captured in notes that were typed-up after each contact and imported into Nvivo. Instead, fieldnotes were read and useful exerts coded by hand and cross referenced with transcripts.

Demographic information was held separately, in part to protect confidentiality but also because I had organised it in Excel during data collection and saw no advantage to repeating in Nvivo. I recorded information that was relevant to the research question and likely to be useful during analysis (Bazeley 2013). A one-page summary of patients became an invaluable tool to remember each person's key circumstances. By now I could remember the name that went with the patient number, hence I was loathe to replace with pseudonyms in the results section.

The next phase, or second level coding, involved a similar process but in relation to the whole data set to consider whether the codes, or themes if using Braun and Clarke's (2006) terminology, accurately reflected the whole dataset. Some codes were collapsed and the process of considering more interpretative aspects commenced. For example, comments about doctors being good and nurses bad developed into a theme around trust and expertise. This higher level coding overlapped with the next phase of comparing across sites. Figure 15 gives an example of developing higher level codes.

Figure 15: An example of coding



N.B. This is not an exhaustive list but an example extracted from Nvivo

3.4.8.3 Integrating the dataset

I looked for relationships and conceptual categories across sites with multiple sources of data and multiple perspectives. I compared the data for patient interviews across sites but, despite considering various aspects of the patient journey, was unable to find any significant differences. I looked for inconsistencies and gaps in understanding *within* each site and then *across* sites. I compared individual cases to find out why some people found the 6MR helpful while others did not and then reviewed the transcripts to check each patient's circumstances, for example, whether they were housebound or independent pre-stroke. I started to group respondents, initially by attitudes to self-management, but realised this was only one aspect. I re-reviewed each transcript to explore perceptions of inpatient care and rehabilitation and regrouped according to respondents' views and characteristics.

The next stage involved cross-referencing patient and carer views about the 6MR with what the reviewer had commented and my own observations. Where I had not observed the review, I still had access to patient, carer and the reviewer's perspective. Where possible I also compared with what therapists said about particular patients, or from my observations at team meetings. For example, one respondent gave a positive account of his medical care while therapists were highly critical of perceived medical oversights.

I tried to establish at what point along the care pathway patients formed their views and if/when they changed them. For example, there were instances where patients reported predominantly negative experiences but really appreciated a particular community therapist. I tried to visualise how themes were interrelated using pen and paper diagrams and concept maps in Nvivo. Those presented in the results chapter were reached after many attempts.

I expected divergent findings by the nature of the study design so it was important to have a strategy for managing apparent inconsistencies in the data. In the initial stages of analysis, I retained all evidence, even if contradictory, so that I could address all plausible rival interpretations (Yin 2014). I explored 'deviant' or 'extreme' cases to understand apparent anomalies in the data and sought further 'confirming or disconfirming evidence' to understand underlying mechanisms and adjust analysis accordingly (Bazeley 2010, p432). This process was assisted by discussion with my supervisor and critical friend and reflecting on the analysis over several months.

3.4.8.4: Theory building

Yin recommends five analytic techniques, of which two were relevant: explanation building and logic models. Firstly, explanation building is a type of pattern-matching relevant to explanatory case studies. The latter involves comparing a pattern found in the data with predictions made prior to data collection; if the patterns are congruent this strengthens credibility (or validity, section 3.4.9.1).

Explanation building is a type of pattern matching with the goal of explaining the phenomena by identifying how or why something happened, or the underlying mechanisms. It involves a series of iterations to test an initial theoretical statement, compare an initial case against the statement, revise the statement and keep repeating as necessary. However, this approach lends itself to criticism of researcher bias (Yin 2014) so was used with caution.

Secondly, a programme level logic model, which is a visual representation of the theory of how a programme works and attends to contextual conditions (Hawe 2015). I was testing the 'theory' or logic behind the 6MR against the data. The model intended to capture the complexity of the review by depicting key aspects including simultaneous causal strands where two or more pathways are needed for the intervention to succeed; alternative causal strands where a mechanism may work differently in different contexts; and unintended consequences (Hawe 2015). While logic models and programme theory are 'essentially similar concepts' (Rogers and Weiss 2007, p63), Weiss differentiates between implementation theory and programme theory (Rogers and Weiss 2007). The former focuses on how a programme is carried out with the assumption that if it is carried out correctly the desired outcomes will be achieved, whereas the latter considers 'the *mechanisms* that intervene between the delivery of program service and the occurrence of outcomes of interest' (Rogers and Weiss 2007, p72). The mechanism of change was not the activities of the 6MR per se 'but the response that the activities generate' (Rogers and Weiss 2007, p72).

Integration occurs when different data sources and analysis are combined 'in such a way as to become interdependent in reaching a common theoretical or research goal, thereby producing findings that are greater than the sum of the parts' (Bazeley 2010, p432). The intention was to extrapolate findings from my dataset to develop a theoretical understanding that could be extended to a broader context (Bazeley 2013).

3.4.9: Enhancing rigour

Qualitative research has traditionally eschewed the terms reliability and validity because they reflect a rationalistic paradigm (Guba and Lincoln 1982). Instead, qualitative research arguably aspires to the concept of trustworthiness reflected in the criterion of credibility, transferability, dependability and confirmability (Guba and Lincoln 1982). Although there are benefits in using terminology consistent with that of the larger social science community (Morse 2015b) the constructs do not sit comfortably with this study. However, there are common approaches to achieving rigour, or trustworthiness that are discussed in the next section.

3.4.9.1: Credibility (internal or construct validity)

This concept questions the 'verisimilitude between the data of an inquiry and the phenomena those data represent' and aims to ascertain if the researcher's analysis and interpretations are 'credible (believable)' (Guba and Lincoln 1982, p246). Prolonged engagement and persistent observation are required and involve 'lengthy and intensive contact with the phenomena (or respondents)' (Schwandt, Lincoln and Guba 2007, p18) to overcome any effect of the researcher's presence, test for biases of researcher and researched and allow time to identify relevant characteristics of the context and phenomena (Guba and Lincoln 1982).

Yin (2014) suggests there are four types of triangulation that can boost validity: *investigator* triangulation among different researchers; *theory* triangulation of perspectives relating to the same dataset; triangulation of methods, rather confusingly termed *methodological* triangulation; and *data* triangulation, or using different sources of data. Much of the literature appertains to data triangulation which has been criticised as a test of validity (Moran-Ellis et al. 2006). The process involves looking for 'patterns of convergence to develop or corroborate an overall interpretation' which is controversial as a genuine test of validity but is better employed as a way of guaranteeing comprehensiveness and encouraging reflexive data analysis (Mays and Pope 2000, p51). Although my fieldwork was limited, I was able to use multiple sources of evidence which were selected because they had complementary strengths and different weaknesses so were likely to generate 'stronger outcomes, that is, better supported by evidence, or more generalizable, or both' (Bazeley 2012, p816).

Explanation building and using logic models both contribute to credibility, as described above. Other strategies used were negative case analysis, or analysing instances that did not appear to fit with the majority (Morse 2015b), mostly in respect of the patient typology; peer debriefing, or discussing emergent theories with 'a disinterested professional', in this case my supervisor, to assist with maintaining integrity (Guba and Lincoln 1982, p247); and establishing a chain of evidence (Yin 2014).

Member checking, which involves asking participants to review their transcripts and/or analyses to confirm accuracy (Guba and Lincoln 1982), was avoided because it is based on the misplaced 'assumption of a fixed truth or reality', whereas participants may change their mind or disagree with the researcher's interpretation (Angen 2000, p383). In addition, it is neither practical, particularly for busy clinicians, nor recommended (Morse 2015b).

3.4.9.2: Transferability (external validity/generalisability)

Generalisation involves 'making an inference about the unobserved based on the observed' (Polit and Beck 2010, p1451). Naturalistic inquiry recognises that 'human behaviour is time and context-bound' and therefore aims to 'establish plausible inferences' rather than unequivocal generalisations

(Schwandt, Lincoln and Guba 2007, p17). With case study design, transferability is addressed in the design stage by using multiple-case studies and replication logic (Yin 2014) (section 3.4.2.1). This provides some assurance that the results will be 'more broadly applicable' and allow understanding of the processes involved and how they are affected by local context (Bazeley 2013, p411), which resonates with this study's methodological approach.

Thick description, or providing a detailed narrative about the context, allows the reader to 'make judgments about the degree of fit or similarity' should they wish to apply the findings elsewhere (Schwandt, Lincoln and Guba 2007, p19). It is arguable how much description will suffice (Schwandt, Lincoln and Guba 2007) but I had to adopt a pragmatic approach given time and resource constraints. Thick description is dependent on prolonged engagement and persistent observation both of which are required to build trust with participants so 'more will be revealed' and 'the data will be more valid' (Morse, 2015, p3) or authentic. This relates to having an appropriate sample size to maximise the diversity of information collected (Guba and Lincoln 1982) and the interpretation of saturation (section 3.4.4.2).

3.4.9.3: Dependability (reliability)

Reliability, or dependability, refers to 'demonstrating that the operations of a study … can be repeated with the same results' (Yin 2014, p46). Although qualitative study design is flexible and thus precludes exact replication, an audit trail should delineate all steps and decisions (Guba and Lincoln 1982). The steps I took to ensure this have already been described and included thorough documentation of all procedures, referring to the protocol, and maintaining an accurate, organised database (Yin 2014).

3.4.9.4: Confirmability (objectivity)

The 'onus of objectivity' refers to the 'confirmability of the data' rather than that of the researcher (Guba and Lincoln 1982, p247). Three strategies are recommended: data triangulation, as already described; reflexivity; and a confirmability audit, a counterpart to the dependability audit in which the auditor verifies that each finding can be appropriately traced back through analysis to the original data, and that interpretations of data are 'reasonable and meaningful' (Guba and Lincoln 1982, p248). I treated the confirmability and dependability audit as one audit trail that would allow an outsider to follow all stages of the process.

Interestingly, Yin (2014, p112) makes little mention of reflexivity other than noting 'the mutual and subtle influence' between interviewer and interviewee. However, reflexivity is an important tool to improve the 'integrity and trustworthiness' of qualitative data by engaging in 'an explicit, self-aware meta-analysis' of the research process that is comprehensively documented and open to scrutiny (Finlay 2002, p531). Thus reflexive (as opposed to reflective) analysis involves a continual process of evaluating the research method, process and outcomes in order to scrutinise subjective elements including our own impact and that of interpersonal dynamics (Finlay 2002). This adds to trustworthiness, or rigour, through the process of not only questioning ‘what I know and how I know it’ but also recognising how knowledge is ‘co-constituted’ or constructed between researcher, participants and their interrelationships (Finlay 2002, p531). Although this stems from a constructivist paradigm, the principles are still relevant to a critical realist approach that acknowledges multiple perspectives and wants to ‘hear these different voices’ (Finlay 2002, p543) whilst synthesizing the evidence at a higher theoretical level and maintaining vigilance for researcher bias. As a former occupational therapist, it was important to maintain a neutral stance and resist the temptation to comment particularly in multi-disciplinary meetings where I often wanted to.

3.5: Ethical considerations

Potential to cause harm is difficult to predict and ‘often quite subtle’ with qualitative research and whilst the ethics process intends to safeguard participants, it comes from a biomedical paradigm that is ill matched to that of qualitative research (Guillemin and Gillam 2004, p272). Therefore it was important to consider not only ‘procedural ethics’, which involved seeking approval from the NHS Ethics Committee, but also ‘ethics in practice’ or the ‘everyday’ ethical issues that arise when conducting research (Guillemin and Gillam 2004, p263).

3.5.1: Procedural ethics

Ethical approval was applied for through the Integrated Research Application System (IRAS). Approval was received from NRES Committee London-Surrey Borders in June 2015 (Rec Reference 15/LO/0808 (appendix 10a). I then applied for research governance approval with each NHS Trust of which there were two acute, two community and one joint acute and community trust.

In terms of risk management, it was important to demonstrate to the ethics committee that I had considered the potential for distress when discussing participants’ experiences and had strategies to manage unforeseen circumstances, including medical issues that required follow-up or concerns related to safeguarding or bad practice. In practice, when I had concerns about a patient I contacted the reviewer with the patient and/or carer’s consent.

In terms of confidentiality, I had to comply with the University of Kent and NHS data protection policies with specific reference to patient identifiable data. For example, each respondent was allocated a code as they entered the study and by which they were known throughout, all transcribed data was anonymised, and the code sheet linking name to number was kept separate from all other study materials and password protected. Table 21 explains the codes used to identify participants.

Table 21: Explanation of codes used to identify participants

Identifier	Refers to:
CS1, R18, F, 87yrs:	Case study (or site) 1, respondent 18, female, 87 years old.
CS1, R9, M, 79yrs:	Case study 1, respondent 9, male, 79 years old
CS2, C3:	Case study 2, the carer of respondent 3
CS2, M2:	Case study 2, the second manager interviewed
CS1, GP1:	Case study 1, the first GP interviewed
CS1, CCG3:	Case study 1, a commissioner within a CCG
CS1, SNS1:	Case study 1, a SNS
CS3, SA3:	Case study 3, a SA co-ordinator
CS2, OT2:	Case study 2, an occupational therapist
CS2, PT2:	Case study 2, a physiotherapist

N.B. Those not prefixed by CS1-3 are not site specific, for example, Or1 refers to an orthoptist.

I am also bound by my professional code of conduct as an occupational therapist registered with the Health Care Professions Council (Health Care Professions Council 2013). Although these stipulate standards of proficiency that are applicable to research as well as clinical practice they are generic and of questionable relevance to research (Guillemin and Gillam 2004).

The practicalities of asking participants for consent have already been outlined but from an ethical perspective it was important to ensure that they understood exactly what they were consenting to and how the information would be used. Aphasia friendly information sheets and consent forms were used where appropriate and I reviewed the information sheet with respondents, prior to taking formal consent.

3.5.2: Ethics in practice

Unlike the bureaucratic process above, ethics in practice considers ‘ethically important moments’ when there is the potential for harming the participant if the researcher mismanages a difficult situation (Guillemin and Gillam 2004, p265). It involves acknowledging and being sensitive to the ‘micro-ethical dimensions’ of research and being prepared to respond appropriately when necessary

(Guillemin and Gillam 2004, p278). With this project, patients were particularly vulnerable given the nature of their situation. It was important to be sensitive to verbal and non-verbal cues that might have indicated distress, fatigue or in the context of dyad interviews, conflict between patient and carer. Thus ‘ethical competence’ refers to the researcher’s ability to think through ethical dilemmas and respond appropriately to avoid harmful ethical ramifications (Guillemin and Gillam 2004, p269). I telephoned participants before sending the patient information sheet to ensure they were expecting it; to make the first appointment; on the day before interview; and in the gap between interviews. This helped establish and maintain rapport such that participants appeared to feel comfortable with me and able to, for example, ask for a break mid-interview or reschedule an appointment at the last minute, usually due to fatigue.

3.6: Patient and Public Involvement

The public includes anyone who uses services, their carers and professionals. Public and patient involvement can be defined as ‘public involvement in research as research being carried out ‘with’ or ‘by’ members of the public rather than ‘to’, ‘about’ or ‘for’ them’ (Hayes, Buckland and Tarpey 2012, p6). It is a ‘subjective and socially constructed’ process that is difficult to evaluate (Barber et al. 2012, p229) but a requisite of many funders of healthcare research. There is a moral imperative to include the public, not only because it is regarded as a mechanism to produce ‘better’ research (Oliver et al. 2008) but because it reflects ‘democratic aspirations of accountability and transparency’ (Barber et al. 2012, p230). Despite the resource implications, I was keen to include service users to improve the design and as an ethical choice based on inclusive practice.

I started by approaching the Stroke Association as the major advocate for this client group. I discussed my ideas with one Regional Head of Operations in a London borough (Jan-Feb 2013) who gave positive feedback on the research question based on his experience and that of a service user group based in the same area. I also discussed the protocol with another more local Regional Head of Operations (Feb-Mar 14), with who I remained in contact.

Early in 2013 I consulted with three branches of Different Strokes, a voluntary group run by and for people of working age who have had a stroke. Those I spoke to felt that they had experienced inadequate long-term support from statutory services and felt left to manage on their own. As there was no group local to my area I subsequently attended three sessions of the local branch of Connect (March-April 2013), a support group for people with aphasia, and was able to discuss the project and request feedback. Most members were retired and had their stroke several years ago. They were in favour of any input that remediated the social isolation they had experienced once statutory services withdrew. I had further email contact with a younger stroke survivor because his experiences and perspective differed to that of older members. I intended to discuss preliminary findings with Different Strokes and Connect but four years later the service users I was in touch with had moved on.

I attended meetings of the SEC SCN 'six-month review task and finish group' (Mar-Apr 2014) and spoke to three of the patient representatives who attended the meetings to canvas their views. All had experience of stroke and were involved in producing guidelines for the 6MR so were able to provide helpful feedback.

Finally, I have benefited from the advice of my critical friend who I first discussed the project with in 2013. He provided insight from the service user perspective as well as drawing on his sociology background. In the early stages, he commented on a draft protocol, patient information sheets and topic guides. Since then we have met to discuss the results and discussion, an informal process that helped me reflect and progress to the next stage.

3.7: Chapter summary

This chapter has presented and critiqued the methodology and methods used for the study. The methodology used critical realism to underpin a multiple-case study design. The case was defined as the review process and the unit of analysis as the 6MR. The three sites were chosen for their different model of review. Data collection described the use of multiple sources including interviews, observation and documentation. Respondents included all those involved with the review process. Overall, forty-six patients, thirty carers and twenty-eight professionals were interviewed. Of the patients, nearly half had other long-term conditions and over one-third were less than 65 years old. Most people lived with their partner or spouse in their own home. Data analysis drew on three approaches (Bazeley 2012; Braun and Clarke 2006; Yin 2014) to explain the process, mechanisms and outcomes under different conditions. The chapter concluded with a discussion around issues of trustworthiness, ethics, and patient and public involvement.

The next chapter describes the case study sites and explores respondents' perspectives on the journey from hospital to 6MR. This includes the initial response to having a stroke, inpatient experiences, the transition home and community rehabilitation.

Chapter 4: Findings - organisation of stroke services and the patient journey from stroke to 6MR

4.1: Introduction

This chapter starts with a description of each case study site. It then explores patients' and carers' responses to the stroke, its impact on daily life and how they made sense of the stroke within the context of pre-existing concerns; including other long-term conditions and complex social circumstances. This leads onto a discussion about respondents' experiences of stroke services along the care pathway and until their 6MR and how this influenced their response. The last section presents a typology which classifies reactions to the review, based on the data.

4.2: Organisation of stroke services in the case study sites

This section describes each site in terms of demographics, the stroke care pathway and the review process. The South East Coast region compromises Kent, Surrey and Sussex and approximately 1.76% of the population registered with a GP have had a stroke or TIA, although this ranges from 1.27%-2.56% (at the level of CCGs). Based on 2013 data from GPs, there were 81,000 people registered with a GP as having had either a stroke or TIA and 6009 patients are discharged annually after experiencing a stroke (Hargroves and Trickey 2014). The prevalence of hypertension in the South East is very slightly higher than the England prevalence (13.8%), while levels of obesity are very slightly lower than the national prevalence of 9.5% and the picture for diabetes mellitus and smoking is mixed (Primary Care Domain, NHS Digital 2016).

The three case study sites were within the South East Coast region and all had better than average outcomes for premature death from stroke with rates between 11-12.4 per 100,000, compared to the range across England from 7.7 to 28.2 per 100,000. All sites were within relatively less deprived areas based on the index of multiple deprivation, had urban and rural areas and lacked ethnic diversity (Public Health England 2016a; Public Health England 2016b; Public Health England 2016c). Table 22 summarises key indicators for the case study sites.

Table 22: Key indicators for sites situated within the South East Coast Strategic Clinical Network

Case study site:	1	2	3	England value
Local authority ranking (out of 149)	44	22	27	NA
Population	1,524,719	1,168,809	544,064	NA
Life expectancy at birth (years) Male Female	 79.8 83.5	 81.5 84.5	 80.1 84	 79.5 83.1
Under 75 cardiovascular mortality rate (heart disease and stroke) per 100,000**,** 2013-15	66.5	55.8	58.9	74.6
Stroke prevalence: percentage of patients with stroke or TIA, as recorded on GP registers as a proportion of total list size, all ages, 2015/16.	1.8	1.6	2.4	1.7
Age standardised rate of mortality from stroke per 100,000 before the age of 75, England, 2013-15	12.4	11.0	11.7	13.6
Smoking related deaths per 100,000, 2013-15, aged 35+	280.9	221.4	252.2	283.5
Socioeconomic decile (1 most deprived to 10 least deprived)	7	10	7	NA

(Public Health England 2016b; Public Health England 2016c; Public Health England 2016a)

4.2.1: Case study 1

The acute NHS trust was undergoing review during the study period. Patients were recruited from the two acute stroke units from which SNSs received most referrals. There were three pathways for those requiring ongoing rehabilitation: further inpatient treatment in a community hospital; ESD for intensive rehabilitation at home; or a community stroke team for less intensive therapy, also at home. Alongside this, the hospital was running a pilot that divided patients into one of three pathways for discharge but the criteria were unclear, did not fit with the stroke care-pathway and appeared to cause confusion during multi-disciplinary meetings. This pathway included intermediate care and 'reablement' for generic rehabilitation.

Three SNSs were employed by the community NHS Trust and based in three community teams, each covering a different geographical area. The Trust's community stroke service specification focused on overall requirements and only mentioned that SNSs should be part of the team. Their job description was broad but did specify provision of six-week, six-month and yearly reviews; requirements included signposting, onwards referrals, medication review, health promotion, education, support, guidance and secondary prevention. This allowed some creativity:

> *When I started my post…our job description was very broad and it was never… streamlined to tell us what exactly it involves, because we have sort of evolved around the changes… there are no policies or protocols… we have taken the Stroke Strategy as our backbone* (SNS4)

Since then the window for the 6MR had widened to 4-8 months post-stroke (Hargroves, French and Trickey 2014). The SNSs had different ways of trying to ensure patients were seen within this window, for example, one SNS started sorting referrals at four months to give herself time to arrange a review. Six-week reviews were not carried out routinely due to time constraints but yearly reviews were provided.

SNSs were vigilant in trying to ensure all eligible patients were referred for 6MR. SNSs had access to the inpatient database, usually attended the ASU's weekly multi-disciplinary team meeting and liaised with the community team. Even so, some patients were omitted, often when they were transferred to a neuro-rehabilitation rather than stroke unit.

SNSs had differing degrees of contact with consultants, community therapists and other specialist nurses but there were no formal links with GPs or community pharmacists. The SNSs had recently started a stroke support group but had limited patient attendance.

One SNS had monthly meetings with a consultant in order to check the preceding month's discharges had been correctly coded. The SNS followed-up any patients whose stroke had been miscoded, usually as a TIA. The consultant did not routinely review patients at six weeks because he trusted the SNS to highlight those needing follow-up and he carried out her requests to, for example, instigate investigations or referrals. The other SNSs did not have formal or regular contact with consultants who generally reviewed all patients post-discharge.

Mostly SNSs saw patients according to when their 6MR was due but there were variations. If therapists requested an early visit, for example to address continence issues, they would do so. One SNS had a systematic approach because her waiting list was so long and prioritised those who had not been reviewed by the consultant soon after discharge:

> *If they're people that have somehow missed out their six-week appointment with the consultant or if the consultant's waiting time is so long that they have not had a review for at least three months or so then I will prioritise them* (SNS4)

To a certain extent SNSs prioritised according to information gleaned during multi-disciplinary meetings. If patients were deemed vulnerable or high need they were likely to be reviewed sooner. This was supplemented by telephoning patients to assess need directly. Two SNSs saw patients at home and one held clinics in community facilities, such as health centres.

All used their own proforma developed before local guidelines endorsed the GM-SAT (Hargroves, French and Trickey 2014). Each patient had a community health and social care (paper) file that was used to document interventions and included templates of various standardised assessments.

Alongside statutory provision, the Stroke Association was commissioned to provide services across the region. They supplied information packs for inpatients, had family and carer support workers, communication workers and various groups such as aphasia cafés. There were no formal links between SNSs and SA workers but they did have contact with each other on occasion.

4.2.2: Case study 2

This site's acute services were also undergoing review during the study period. Patients were recruited from the ASU with the largest throughput and from which the SNS received the majority of referrals. The options for further rehabilitation were similar to case study 1: inpatient treatment in a community hospital; ESD at home; or the community stroke team. The care pathway also allowed single discipline outpatient therapy but this was seldom appropriate. The ASU employed their own SNS to carry out six-week reviews in hospital. She was allowed only twenty minutes per patient so concentrated on medication and blood pressure. She and the consultant decided who should be reviewed post-discharge:

> *If when I'm seeing them I think there is still something very medical outstanding and they need to see a doctor, then I will call them back for another appointment but that rarely happens. But, generally, on discharge from hospital, we decide which clinic the patient should go in, whether that's a consultant clinic or whether that's a nurse follow-up clinic, depending on their needs* (SNS6)

The acute SNS sent the community one a register of all patients discharged in the preceding month. The community SNS also attended meetings on the stroke ward but had found it difficult to develop good working relationships with her acute colleague and the consultant, so communication was limited.

Other stroke units also discharged patients to the areas that the community SNS covered but referrals appeared more ad hoc and so she spent considerable time following-up. The SNS had access to patients' discharge reports and other information on the inpatient and GP database.

Stroke and neurological community services were based in a purpose built unit opposite a community hospital which had four beds allocated to stroke patients. The community SNS carried out 6MRs in the purpose built unit, using the GM-SAT. However she was not commissioned to carry out six-week or yearly reviews. She sat within the community team alongside three other nurse specialists, two for

Parkinson's disease and one for multiple sclerosis. The stroke SNS’s role was split between ESD and 6MRs so she met some patients prior to review, in the former role.

An administrator kept a register of patients and invited them for their 6MR in chronological order. She also invited them to attend a ‘life after stroke’ group that the SNS had initiated to supplement the 6MR. The first two-hour session was a presentation about stroke including aetiology, risk factors and secondary prevention. The second session had presentations from a dietician, physiotherapist and occupational therapist. The Stroke Association worker attended occasionally and she appeared to have a good working relationship with the SNS; each referred patients to the other, when appropriate. The SA provided similar services as described in case study 1.

The community SNS was employed by a social enterprise, created when several Primary Care Trusts were amalgamated and needed to separate provider from commissioning roles. The co-ownership model meant that staff owned the organisation and everybody who had worked there for over a year was given full voting rights. Shareholders did not profit from the dividends which were reinvested back into clinical services or their social enterprise arm which supported local charities. The service covered a population of 290,000 and delivered a range of inpatient and outpatient nursing and therapy services for adults, children and families. Services were provided at home, in community settings and within four community hospitals. The main contractors were CCGs, ASUs for therapy services and the county council.

4.2.3: Case study 3

The Stroke Association first piloted 6MRs in 2010 and started providing them in this area in 2013, under a three-year contract. They were commissioned by the local authority and three CCGs, split 50:50, to carry out 6MRs but not six-week or yearly ones. The contract was renewed until March 2017 and again subsequent to this. Before this the SA provided services similar to those in sites 1 and 2 but the community stroke team carried out reviews.

The Stroke Association used the same local guidance for the 6MR (Hargroves, French and Trickey 2014) as the other sites. The GM-SAT was used to carry out reviews and the SA co-ordinator had attended a one-day training course on using it. Similarly to the other sites, she sent a short report to the GP and copied it to patients. Support staff and co-ordinators did not need a professional qualification but the organisation had its own key performance indicator framework and training programme.

Patients were recruited from the ASU from which the SA co-ordinator received most referrals. She had recently started spending a half-day per week on the acute ward so that patients and carers could meet her but the take-up had been limited. Standard SA information packs were provided to all patients. Similar to the other sites, those requiring rehabilitation post-discharge were referred to ESD or the community stroke team.

The Stroke Association shared offices with another charity (although this changed during the study period) and two other SA workers who organised various activities including a new singing group. The co-ordinator visited patients at home, usually two per day, leaving her the afternoon to complete paperwork and input SSNAP data (as the SNSs also had to do).

The SA co-ordinator received referrals in the form of patients' discharge notification letters which she collected from a box on the hospital ward but she had doubts about the efficiency of this:

> *I always feel we don't get 100% especially on the weekend…we keep harping on about getting these discharge notices and [patient] phone numbers and it doesn't seem to improve. Who knows how many we're getting. There must be people we're missing* (SA3)

The Stroke Association co-ordinator had a good working relationship with the community stroke team and attended their team meetings fortnightly to receive referrals and discuss patients' needs:

> *The community stroke rehab team are really good, I work really well with them, I find them really helpful… they'll tell me if there is something I need to know about those people if they're still ongoing or if they've finished with them* (SA3)

All patients were sent an introductory letter from the SA co-ordinator and could request a visit in advance of the 6MR. Similarly, therapists sometimes asked the co-ordinator to visit patients for a specific reason. During my fieldwork, patients referred by the community stroke team all wanted exercise referral schemes. Therapists could have referred directly but by asking the co-ordinator to visit, patients could access the whole service.

However, irrespective of each site's organisation of stroke services there were commonalities in the patient experience from stroke to 6MR which will now be explored.

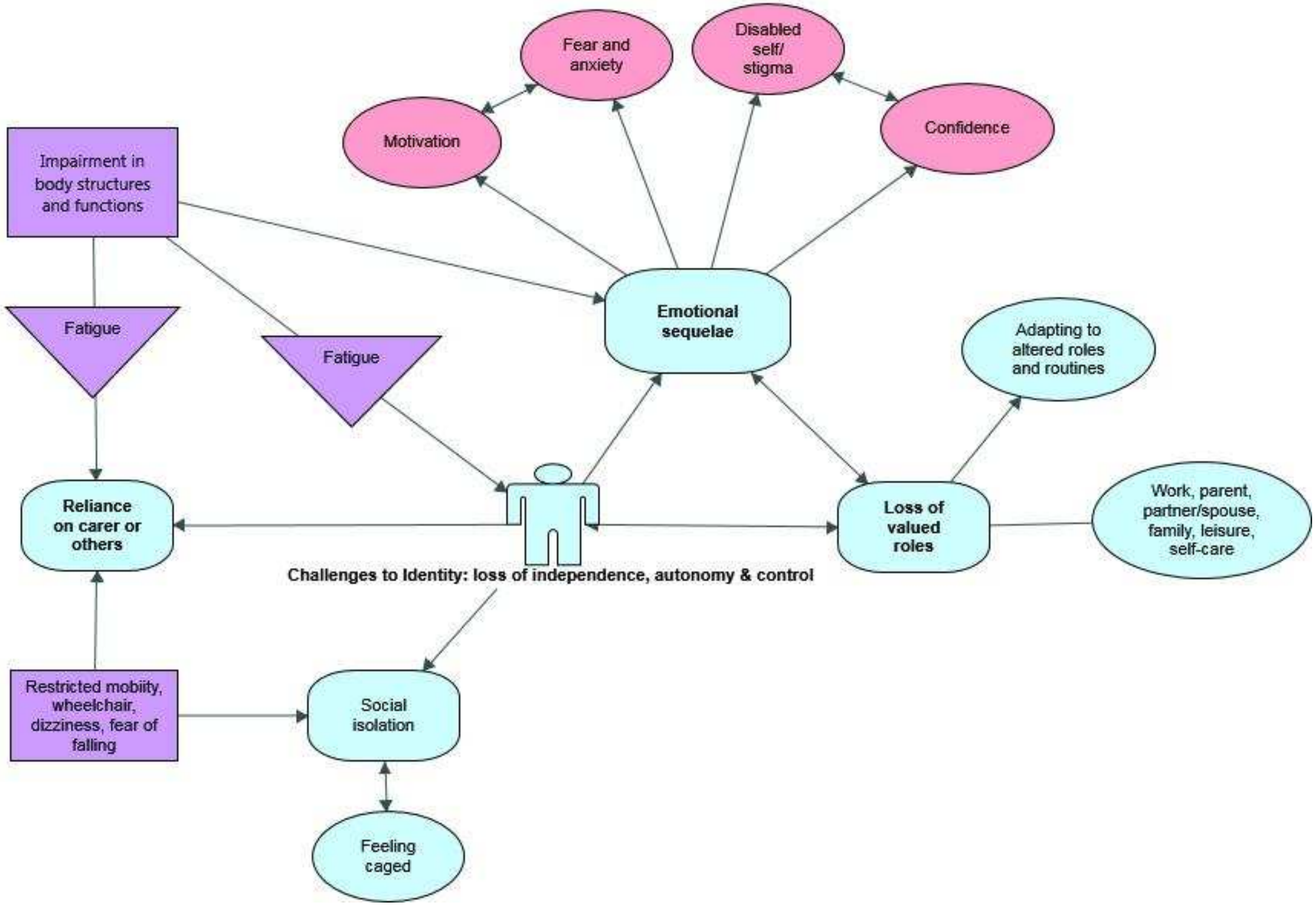
4.3: Patients' and carers' responses to stroke

This section considers the impact of stroke on the individual and their carer. It explores how respondents reframed their stroke against a background of other significant issues. The reviewer's perspective is briefly considered with respect to managing stroke sequelae versus other issues.

4.3.1: Impact of stroke on daily life

Respondents reported a wide variety of physical, sensory, cognitive and psychological sequelae post-stroke. When initially interviewed after discharge, residual impairment was common and for the majority was exacerbated by a pervasive sense of fatigue. At six months, although most symptoms had improved or resolved for those with mild to moderate stroke, many were still limited by fatigue and it compounded the difficulties of those with severe residual impairments, mostly hemiparesis and aphasia. Figure 16 summarises the impact on daily life and emotional sequelae.

Figure 16: Impact of stroke on daily life



The overall impact of the stroke on daily life was a strong feature of the patient narrative. At the time of the 6MR, residual impairments, intensified by fatigue, restricted respondents’ ability to participate in valued activities and regain independence:

> *I sleep an awful lot, it’s as much as I can do to get out of bed in the morning and get dressed and sometimes I’m not down here until half past ten or eleven. I go to bed fairly early* (CS1, R18, F, 87yrs)
>
> *I find it so hard being stuck in because I can only walk the dog and then I'm exhausted and I have to do that with a wheeler* (CS2, R4, F, 85yrs)

This enforced reliance on others emphasised a sense of dependence, particularly for younger respondents:

> *It's affected everything, because as full-time worker and full-time mum, doing the school run, driving them to school, everything, I can't do that anymore…my whole life has come to a standstill… it really bothers me to have someone to do something for me and to let go of my independence* (CS1, R13, F, 37yrs)
>
> *Before she was ill, she's always been in control… She was being in control of the house and the children and everything, and everybody would just do exactly as they were told* (CS1, C2)

This lack of control contributed to frustration and changed the balance of responsibilities between couples as they tried to adjust to changed circumstances:

> *I think because you're so longing to get home you don't realise how frustrated you're going to get because you can't potter… It's because I've only got one hand. If I had two hands I wouldn't complain. I mean my husband is a wonderful carer but he does things differently to me and sometimes does things that I wouldn't necessarily do, so in that way it was frustrating. You have to learn to give up so much… … I find it difficult, the sort of the balance changed totally* (CS1, R12, F, 69yrs)

Not all respondents struggled to accept limitations as other long-term conditions had already imposed restrictions. For example, respondent 14 had already stopped playing golf and doing woodwork due to co-morbidities and his day was organised around taking medication two hours after meals. The stroke had exacerbated pre-existing fatigue but he had adjusted his routine to include a daily walk with his wife and an afternoon rest:

> *Because I feel more tired, less active, it hasn't hit me as much as I thought it would. I thought I'd be very frustrated not being able to get on and do all the things I like doing but it hasn't been quite as bad because I just haven't got the energy… so it hasn't got too frustrating* (CS1, R14, M, 85yrs)

There were other instances of a positive reframing of the impact. Respondent 10 had been unable to work for several years due to numerous illnesses and resultant anxiety and depression:

> *It's kind of stopped me kind of worrying and thinking about my future, like what am I going to do to get some more income, because I really don't feel like I'm capable of work now, because I used to work in IT and that was quite a stressful job* (CS2, R10, M, 55yrs)

While some accepted their new situation, others fought against it. Alongside reduced independence, reliance on others and limited ability to engage in valued activities was the effect on identity. Many people defined themselves by their work, even if they were not working pre-stroke, and mourned the loss of their work lives:

> *That's really like the worst thing, to be honest, not doing what I normally do* (CS1, R24, F, 34yrs)

This linked with sensitivity to other people's reaction to their disability, although comments related to this were fewer than I had expected. Respondents acknowledged that they may have been misinterpreting other's reactions and questioned whether or not they perceived themselves as disabled:

> *I went to Tesco with my husband… and ASDA as well. I haven't done that because I felt like I had people staring at me -which obviously they might not- and with ASDA especially because it's closer to my work, the thought of meeting people from work…. them seeing me that way, but I had to conquer the fear, so I went… … I said to my husband I'm not disabled to get a disabled badge, but when we got out and we're parking I said, well if I had it, it'd be easier to park… so why don't I get it to make things easy for myself* (CS1, R13, F, 37yrs)

Alongside other's perceived reactions to their disability was the desire to regain a sense of 'normal' and do things to their usual standard:

> *Normal is getting up, going to work, coming home* (CS1, R2, F, 50yrs)

Many people reported good social support but even so felt isolated, trapped at home and for those who drove pre-stroke, robbed of part of their identity. They mourned this loss of freedom and imposed reliance on others:

> *I feel as if I'm in a cage. People have been good, but I hate asking* (CS1, R1, F, 77yrs)
>
> *So we can't go out, we're in a shell, all like ourselves, by ourselves* (CS1, R9, M, 79yrs)

Two patients later purchased a mobility scooter and both were delighted with the difference this made to their daily life and sense of isolation. Both were able to go to the shops and one was able to visit a friend who also had a stroke and was housebound.

Some respondents capitalised on local support to counter potential social isolation. Of note were a couple (respondent 36 and his wife) who had moved from overseas, to a city and then to a rural location in preparation for retirement. Both were commuting to work when he suffered a catastrophic stroke, resulting in severe hemiparesis and aphasia. His wife gave up work to care for him and both their families were overseas:

> *We were new to the village. But the village have been fantastic. They've been like a family. They just knock on the door. Have a glass of wine. Come over. What do you want us to do? … Every weekend we see someone in the village and somebody offers something or other… A really brilliant support system, and another reason to be thankful to be not living in [city]* (CS1, C36)

Similarly, respondent 15 had taken early retirement to care for his mother but had also planned to travel overseas and run marathons. Now he was unable to drive and lived in a semi-rural area with few buses. His mother had dementia so conversation was limited but he appreciated getting to know his neighbours:

> *I don't feel isolated because you know it's the opposite. I've spoken more, and the neighbours more to me since my illness than they ever did before* (CS1, R15, M, 57yrs)

A number of respondents experienced anxiety about having another stroke. Whilst anxiety lessened over time for some respondents, others were afraid of losing further independence and previous experience influenced their response:

> *My mother had haemorrhagic strokes… I know these are slightly different and I have medication, so hopefully I don't have another one. If I did, and I do not need a psychologist or any treatment for depression because I'm not depressed, I would not want to come through it… If it was going to leave me some incontinent slug in a bed… No way, and I've been trying to think how I can get this written down. I know you could do a living will* (CS1, R12, F, 69yrs)

Anxiety was common to both partners and in part related to an unclear prognosis that they had expected the consultant to address. This concern about the prognosis was not always a source of anxiety but a straightforward need for answers, often well before the 6MR was due:

> *There's this niggle about whether I should be saying to somebody, look, I still get these sort of funny things round my head. Or my eyes suddenly went funny. Does this matter? … I wouldn't call that a great anxiety thing because I'm getting on with my life* (CS2, R40, F, 76yrs)

> *I would have liked more contact with the medical profession just for reassurance, as any slight symptoms in the first six months made me feel anxious that it would happen again* (CS2, R11, F, 63yrs)

Enmeshed with loss of independence and changed circumstances were emotional sequelae that still resonated several weeks or months later. The initial shock and difficulty comprehending what had happened so unexpectedly was common with, but not limited to, younger respondents:

> *I can't get that in my head. I'm 28 years old, fit and healthy, there has to be a reason for this to happen. It can't - it don't just happen for no reason at all* (CS1, R34, M, 28yrs)

> *I was in denial, I said, "It can't be a stroke, not at 31. It's what old people get"* (CS2, R8, M, 31yrs)

The shock, ongoing impairment and reduced autonomy had a detrimental impact on confidence. Some expected to recover more quickly than they did, while others were affected by low mood, mood swings and/or lack of motivation:

> *It's just the nightmare of having had a stroke and getting used to everything… I feel tired, bit depressed now. I thought I was really going for it before but it suddenly hit me* (CS1, R21, F, 67yrs)

> *I've lost this spark of enthusiasm and energy that I've always had… It's so feeble though not to have fully recovered by now…. … at 87 you don't have all that much time to be patient* (CS1, R18, F, 87yrs)

4.3.2: Re-framing in the context of complex life issues and long-term conditions

The above section considered the impact of stroke on identity, roles and independence. This section considers how people reframed the impact against a background of other significant issues they were currently dealing with. The section also considers how clinicians approached the 6MR when stroke was one of many issues.

4.3.2.1: Respondents' perspective

Alongside the impact of stroke on daily life were emotional sequelae including shock, loss of confidence, anxiety concerning another stroke, or conversely, relief that they had survived. There was no apparent difference in approach to reframing depending on impact or severity of stroke but those with pre-existing long-term conditions did make comparisons:

> *I had a stroke, and yes it was very frightening, but it's not been my major health problem… the stroke is just one episode of many others* (CS2, R3, M, 76yrs)

It was notable how many people referred to luck - that they had not been affected more severely - and made explicit comparisons with others, particularly those they had seen in hospital. Even those who had experienced severe sequelae were grateful that the outcome was not worse:

> *The neurosurgeon said, "I have to perform this operation or [girlfriend] won't survive. There's a significant risk of disability". Considering what she's been through you know that's sort of how we look at it positively it's just incredible that she's up on her feet… … we're so grateful for that* (CS1, C24)

> *I realise how lucky I was… when I've seen other people's strokes* (CS1, R30, M, 73yrs)

This 'luck' also related to family support and not being alone:

> *Some of these elderly people… they might even have a husband or a wife but sometimes, you know, they're a similar age to them and could be disabled themselves. So, you know, it's not an awful lot of use to them. But some people have got nobody at all and how do they cope? … … I've been so fortunate. My neighbours have been so good… … I'm fortunate in as much as I've still got my voice. And I can still think* (CS1, R41, F, 63yrs)

Only one person expressed a sense of injustice. While she had largely recovered from the stroke it was against a background of other long-term conditions including a history of anxiety, depression and an eating disorder. She was also negative about rehabilitation and did not engage with self-management:

> *The strokes just made it worse. I just think, "Why me? Why's it happened to me?"* (CS1, R2, F, 50yrs)

While referring to luck, many respondents demonstrated that they (and their carers) had learnt to accept their circumstances:

> *I think in that way we've sort of accepted it, haven't we?* (CS1, R14, M, 85yrs)
>
> *We're us; this is where we are; we're coping, its okay* (CS2, C7)

This acceptance was associated with a fatalistic approach:

> *I'm bit of a realist, if it's going to happen it's going to happen… there's nothing I can do* (CS2, R23, M, 61yrs)
>
> *There's nothing that can be done about it except put up with it* (CS1, R18, F, 87yrs)

Alongside this acceptance there was often stoicism, resilience and determination to improve. For example, respondent 20 had been divorced, lost his business and become homeless. He referred to a TIA, although he actually had a stroke but recovered very well:

> *I've set myself a target to sort of like rebuild my life… If you've gone through a TIA and you can actually basically go through anything really and you think you know your back's hurting, that's irrelevant now… … My whole outlook has changed definitely, yeah, with a passion* (CS1, R20, M, 51)

Respondent 28 had recovered well and was determined to continue her own rehabilitation once services withdrew:

> *I think it's just the struggle yourself of thinking, "Oh I want to go to the toilet. I know it's going to take me half an hour", but you've got to live with that… I think it was just determination really, just getting on with-- if I thought, well I'll try, if I can't do it I can't do it* (CS1, R28, F, 66yrs)

Some respondents also maintained a positive attitude but felt that their body needed time to heal and were not as driven but still adopted a proactive approach to rehabilitation:

> *I believe my body is quietly sorting itself out… The body's recovering… everything in our life is good. Oh that's a bit of a nuisance I'm sitting here talking like this, but we're happy* (CS2, R29, M, 91yrs)

Others also accepted their situation but alluded to hope:

> *We've acclimatised I guess… you can't do anything about it, just hope that something's going to improve* (CS1, R12, F, 69yrs)

Only one person made clear that she felt her life had finished. She was very clear that she was not clinically depressed and would not commit suicide, as a close relative had previously done so but nonetheless she referred to Dignitas. Later, when she bought a mobility scooter and was able to visit friends she appeared more positive but maintained the same view:

> *If I'm honest and I said to you, but don't think I'm depressed, if I'd got £10,000 I'd go to Switzerland… Because it's made my life so… I don't like saying that, but I think its right that if you feel you've finished your life you should have the… choice* (CS2, R4, F, 85yrs)

Respondents were not specifically asked about coping strategies but the use of humour appeared common, particularly between couples:

> *We laugh a lot because you have to, no point in crying* (CS1, R12, F, 69yrs)

Striving to resume valued activities was prominent. Respondent 10 was particularly impressive because having experienced significant long-term illness he was resuming activities he had previously enjoyed (running and cycling) and gradually increased his endurance:

> *I don't just sit alone thinking 'what do I do now?' I'm always doing something… … even when I was having chemotherapy I was running… I think that helps in a way because it keeps you focused on trying to do your own thing* (CS2, P10, M, 55yrs)

He was the only respondent to explicitly state that he avoided people worse off than himself, which deterred him from continuing to attend a balance class where other patients were less able:

> *I don't really want to hear how bad other people have been. Because I want to hear from people who are fit and well and doing their normal routine* (CS2, P10, M, 55yrs)

Other respondents hinted at avoiding those who were less able but did not state this explicitly, possibly because they thought it socially unacceptable to do so.

4.3.2.2: Reviewers' perspective

In most cases, reviewers had some awareness of the complexity of social and medical problems but focused on the stroke and avoided engaging in issues to do with social circumstances or other long-term conditions, which they expected the GP to manage:

> *Sometimes if there is a problem that the patient did not feel was managed then I would advise the patient or be their advocate with the GP, but I don't feel that I should interfere in their management when I don't have possession of all the facts. I tend to concentrate on nursing issues such as continence, hydration, nutrition, pressure relief etcetera. I do feel that the GP must have overall responsibility for their patients* (CS1, SNS1)

Two respondents had long-term conditions which took precedence (R34, cardiology; R24, renal) and were both being seen by the relevant consultant. The SNS questioned how valuable a review would be, given the complexity of their medical histories and other specialities involved.

In Site 2, the SNS was one of four condition specific nurses based in the same unit and able to access each other's notes on the internal database. For example, the SNS was aware that respondent 5 had been seen by the Parkinson's disease nurse shortly before his 6MR so did not stray into her territory. However, the couple did not find the review particularly helpful or informative because they were already actively managing their situation, for example, they had found out about a local group for people with aphasia.

This couple's joint approach to managing daily life leads to the next sub-section which considers the carer's role.

4.3.3: Social networks and the burden of caring

The role of the carer in supporting the person who had a stroke was particularly important for those with aphasia and/or cognitive impairment. They had to negotiate the system, manage unforeseen problems and re-establish a daily routine. Many patients expressed gratitude for their partner's support, some expressed concern at being a burden and only two people (R2 and R41) complained that their family lacked understanding. The carer as advocate mostly related to inpatient experiences and the transition home, which is explored later.

References to the burden of caring and the effect on their relationship were not universal; more common were couples working together to remediate the impact of stroke for both of them. Respondent 36**,** as previously mentioned, had experienced a major stroke set in the context of having re-married, moved country and moved home. His wife was remarkably resilient and sorted out several problems that services had not sufficiently addressed, such as incontinence. She had developed strategies to maintain a positive outlook:

> *This is just another chapter and another challenge. That's the positive way we look at this… … I am trying to give myself some time. So I've got yoga and I've got meditation classes. And I teach the piano… I need to have a life as well* (CS1, C36)

There were comments about lack of support for the carer and/or that the carer had a worse time:

> *People don't think about the carer because they're thinking about the person who's ill* (CS2, R8, M, 31yrs)

Equally, patients worried about being a burden:

> *My wife has been very, very stressed over it all… but she won't admit it so she's not seeking help. So things have been difficult between us* (CS2, R3, M, 76yrs)

Carers were often sanguine about the negatives of caring:

> *Yeah, it does get tough sometimes if he starts hollering an shouting an swearing an everything, that gets on my nerves… But then I just think to meself well it's not him, you know… he's not really like that and hopefully he will get a bit better* (CS1, C38)

However, some admitted that they became tired and frustrated:

> *He spends all day in the house, I feel angry, I feel frustrated* (CS1, C26)

Practical support encompassed a multitude of activities including: using equipment such as hoists; developing exercise programmes; using on-line computer programmes for cognitive, speech and visuo-perceptual re-training; and transport to appointments. Respondent 22's daughter had given up her job and moved in with her mother to look after her. She had taught herself about her mother's condition, learned to use complex equipment and was working on her mother's mobility and communication long after services had withdrawn. She and the family had co-ordinated her mother's care and had each taken on a role in order to circumvent gaps in services and maximise her mother's dignity. For example, she referred to her sister-in-law as a 'personal assistant' who did all the telephone calls and arranging appointments. This daughter did not regard caring as a burden and had taken on the language of caring (my bold):

> ***I commode you*** *before the carers come usually, so it's a bit in private for Mum… … that's* ***a Molift****… we* ***practice to stand for transfers****, but that chair's a bit low… you're buying a new chair, which is electric,* ***tilts in space*** *and everything* (CS2, C22)

The next section considers how the impact of stroke on daily life was influenced by experiences along the care pathway leading up to the 6MR.

4.4: Patients' experience of the care pathway

This section explores the journey from stroke to 6MR including inpatient experiences, discharge and the transition home. Most respondents appeared to separate their experiences of the ambulance service and Accident and Emergency from the point at which they were admitted to stroke services.

Two respondents had adverse encounters at this stage but were still able to isolate them from that of stroke services. Early experiences are not discussed because they did not appear to influence perceptions of the 6MR.

The first interview was timed to take place shortly after respondents should have had a six-week review and the second interview straight after their 6MR. The inpatient experience resonated strongly through all interviews irrespective of the severity of stroke, perceived quality of care and whether the respondent was of working age or retired. Discussions of inpatient experiences often led to concerns around discharge, waiting for community services to commence and coping once they had withdrawn, usually before their 6MR. These points, or ‘hotspots’, in the care pathway appeared to be when respondents, including carers, felt particularly vulnerable and/or unsupported. The hotspots triggered anxiety but were also important milestones in the journey towards recovery and for a few respondents the 6MR represented a marker of their progress.

4.4.1: Inpatient experiences

How inpatient experiences affected respondents’ attitudes to their 6MR, within the context of their overall care, was difficult to ascertain except where experiences were perceived in very negative terms and led to patients declining review. Respondent 33 declined on the grounds that it would not contribute to her care because she had regular appointments with stroke and renal consultants and did not think the SNS could add anything. Respondent 32 was angry about perceived poor inpatient care and declined the review on the grounds that he had done everything himself and would continue to do so.

There was a wide variety of inpatient experiences. Case study 1 allowed me to observe weekly multi-disciplinary team meetings and where patients were discussed who I later interviewed, I was able to compare accounts. Staff rarely acknowledged my presence in meetings and certainly did not appear to change their behaviour because of it. There were frequent discussions around delayed discharges due to lack of social care, mental capacity, family issues, palliative care, nutrition and therapy. These reflected complex decision making processes between clinicians coming from different professional backgrounds and with contrasting opinions. Occasionally patients or carers commented on these differences of opinion but mostly they appeared unaware. More often, respondents commented that they felt excluded from decision making but again, this was not universal. These respondents are referring to the same unit:

> *I was just kept out of the loop all the time. I didn’t know what was happening to me. And they used to go off and have their meetings… and nobody ever seemed to come to talk to me. And I had to one day*

> *kick up a real fuss and I got myself in a real state over it to get somebody to come and tell me what was happening* (CS1, R41, F, 63yrs)

> *They tried to involve me in every step. I think they came to my house as well to see if I needed something… I liked the way they involved me in it as well* (CS1, R13, F, 37yrs)

Patients had very different perceptions of the quality of care they received. These differences existed within and across case studies and there was no discernible pattern. For example, the same rehabilitation unit was deemed 'soul destroying' and 'fantastic' (CS1, R9, M, 79yrs and R1, F, 77yrs respectively). Such inconsistencies appeared to relate to the respondent's outlook which was also reflected in their response to the 6MR. Where care did appear compromised, it appeared to stem from staff shortages and system constraints, lack of communication and rushed discharge. This left respondents feeling disempowered and some carers had to advocate forcefully to find out relevant information. One respondent described how he wanted to know if or when he would be transferred to a rehabilitation unit but staff would not commit:

> *I hadn't been told anything. I hadn't been told whether or not I was going, but we went and found out ourselves, as it were, or [wife] did, and we… waited and waited and waited to see if they would ever inform us… it just went on and on* (CS2, R31, M, 63yrs)

Examples of poor care were countered by examples of excellent care, a seamless service and dedicated staff:

> *The staff were all fantastic, all of them, and there's a lot of-- the names and the faces I'll always remember because they were just so fantastic at that time* (CS2, C8)

Perceptions of care also related to therapy. Accounts of physiotherapy were mostly positive but there were surprisingly few comments about speech therapy and little sense that occupational therapy contributed to recovery. Respondents were often unclear what the purpose of occupational therapy was and attributed interventions, such as home visits, to other clinicians. This may have been due to prioritising information:

> *They don't specifically know necessarily what OTs do and although we explain it there is certainly an overload of information… in the early days and weeks… people tend to take in what's really important to them at the time* (CS2, OT2)

Respondents were always keen for more physiotherapy than was available. They reported receiving less therapy than the guidelines recommend (Royal College of Physicians 2016a) and while fatigue sometimes accounted for short sessions, lack of staffing appeared to account for low frequency.

Respondents noticed that therapy appeared to dwindle prior to discharge and disliked having no therapy over the weekend, which felt like wasted time:

> *I feel that I had so much wasted time. I used to sit in my room five, six hours a day, and Saturdays and Sunday. I felt, me being what I am, I wanted to get on* (CS1, R9, M, 79yrs)

Linked to frequency was the observation that respondents did not know in advance when to expect therapy because some units did not use or keep to individual timetables. This made it difficult to plan visitors and manage fatigue, thus impeding self-management, a key goal of therapy and arguably the 6MR.

Respondent 33, who had had numerous admissions, commented on the formulaic nature of inpatient occupational therapy but acknowledged it was system-led and discharge orientated and compared it to the physiotherapist's more relaxed approach:

> *As long as you can do the loo test and make a cup of tea test… last time I said I wouldn't do any of it. I just want to come in and get stable… the physio was great… he'd take me down for a cup of coffee just to get me out of the ward… their hands are tied* (CS1, R33, F, 56yrs)

Finally, the environment was identified as an important contextual factor. Night-time noise and lighting impeded patients' sleep, leaving them tired and less receptive to therapy. Respondents also mentioned disturbances which they understood might not be avoidable but still caused irritation:

> *People have got to rest; it's the only way to get better… it's too noisy and you've got to turn the lights out so people can sleep* (CS1, R15, M, 57yrs)
>
> *The nurses were absolutely lovely, but at night… you are stressed, you're worried… and the last think you want is not to be able to get a good night's sleep… there were nurses, and I mean literally banging and crashing around… "How was your holiday? What did you do last night?"* (CS2, R11, F, 63yrs)

In summary, the inpatient experience resonated throughout respondents' accounts of their experiences leading up to the 6MR and it was apparent how formative these experiences had been. This is explored further in section 4.5 while the next section considers the transition home.

4.4.2: Discharge home

Perceptions of discharge were mixed from efficient to disorganised and rushed. Those on the ESD pathway who received a home visit within two days of discharge found this allayed anxiety but many respondents experienced delays waiting for follow-up services and felt unsupported during this gap. Those in site 2 were invited for a six-week review with a SNS based in the ASU but it did not appear to ameliorate their concerns which appeared related to the brevity of the appointment (20 minutes) and its purely medical focus. For example, respondent 40 (CS2, F, 76yrs) stated that while inpatient care was good, post-discharge ‘it was a bit like falling off a cliff’. The timing of her 6MR did not coincide with when she needed support, even though she was independent and had recovered well.

Complaints about discharge included lack of notification and preparation, disagreements between staff, equipment delays and medication mismanagement. This added to the shock of suddenly being home after the protected ward environment. Some respondents stated that they did not feel sufficiently prepared by therapists to manage independently once home:

> *I suddenly thought, Christ, I’m here on my own. What am I going to do? I can’t even get out to the toilet… I’d never walked anywhere on my own… I was frightened… in hospital, they’re taking your blood pressure… And suddenly, you’re out here, on your own. And nothing.* (CS1, R41, F, 63yrs)

Respondent 43 (CS3, F, 80yrs) appeared to have had a rushed discharge, which the couple attributed to clinicians needing to clear the wards before the Easter weekend. Her husband had queried the discharge plans but she came home anyway, unable to get in and out of bed without maximum assistance. The community stroke team were meant to start straight away but had not been informed of the discharge, resulting in a nine-day delay. In the interim, they called the ambulance several times during the night because they could not cope.

After the initial discharge, some couples found it hard to adjust while others were relieved to be home. Respondent 5 had aphasia and his wife had not anticipated the difficulties of adjusting:

> *I wasn't anxious. I was probably blind… I was so relieved when he learned to walk because I thought now I can cope with him. Now I can cope with everything. So I was just so relieved that he was going to come home to me that it didn't occur to me to be anxious* (CS2, C5)

Respondent 17 (CS2, F, 68yrs) was sent home without the correct medications over a Bank Holiday. The GP noticed discrepancies with the discharge summary, visited them at home and liaised with a community pharmacist. Respondent 29 (CS2, M, 91yrs) also had medication issues due to an illegible handwritten script and tablets he was unable to swallow. Remedying this took the combined efforts of their daughter (a nurse), ward staff and the GP.

Although guidelines recommended that patients should ‘know who to contact if difficulties arise’ (Royal College of Physicians 2012, p27), this was not always the case and appeared to reflect a gap in communication between hospital and community which caused confusion:

> *It’s just very confusing because there's not one person that you can go to, to organise anything… there should be one person who's sort of in control… I thought it might be [patient]'s GP, but no, not really because he's kind of part of the chain of information but not the driving force* (CS1, C18)

Although most respondents received a letter informing them about their 6MR, with contact details, few respondents initiated contact and none identified the reviewer as a ‘link person’. Some respondents’ expectations of follow-up were based on what inpatient staff had told them but there appeared to be a disparity with what was delivered. This exacerbated the sense of disempowerment some respondents experienced as inpatients:

> *There's such a gap between what goes on in hospital and what goes on in the community. I think what the hospital think you need just isn't carried out once you get home. It's too separate…suddenly you're just plonked with a whole new set of rules, whole new set of people, whole new set of time constraints, and it was a shock… I couldn't cope with… a stream of faceless people* (CS1, R33, F, 56yrs)

After the immediate transition home many respondents expected their consultant or GP to contact them. GPs rarely did so and only with regard to specific problems. While some respondents found their GP supportive, others complained that they were not even aware of their condition. The GP perspective was that patient expectations were too high given the size of their caseloads (CS1, GP1).

There were instances of efficient discharge but also many examples of delays with follow-up appointments and misplaced referrals. Some respondents were assertive and chased appointments, some asked their GP and others simply waited:

> *I went to my GP and she was brilliant. She chased it all up and then as soon as she started chasing up I had letters coming through the door left right and centre. I didn't know I had to chase up* (CS1, R34, M, 28yrs)

> *I had to phone to follow-up because no one actually followed up and we were a bit concerned that after a stroke surely somebody should follow-up… to co-ordinate what should be happening* (CS1, C18)

The discharge process marked the transition from inpatient to home-based care. While many respondents had a reasonably smooth discharge it was still a ‘hotspot’ where many felt particularly vulnerable, especially while waiting for rehabilitation to commence.

4.4.3: Community rehabilitation

Most respondents were eager for therapy to commence post-discharge and devised their own strategies while waiting:

> *Well it’s a long time to wait before they came round [a few weeks], I wanted to get moving because the physio was so good in hospital… but then when you come home there’s nothing and if you’re the sort that wouldn’t enquire about things you’d just be left on your own whereas I wanted to just get going and build on what I was doing in the hospital* (CS3, R44, F, 79yrs)

The converse to long waits for therapy was an excess of poorly co-ordinated visits from community teams, which left patients feeling overwhelmed and exacerbated their fatigue. Some carers acted as advocates and tried to manage visits:

> *It was hopeless and because of the fatigue associated with stroke [wife] was absolutely wiped out… it would be better if they had a central diary… they were trying to… be helpful but it was all coming at us left right and centre and we got fed up… we've got the carers coming in; we've got a cleaner comes in. We've got all sorts of things going on, plus hospital appointments, GP coming in as well, and you just sort of end up being bewildered by it* (CS2, C17)

Therapy could only continue as long as there were achievable goals that the patient took responsibility for but there appeared to be a mismatch in expectations between patients and therapists. For example, respondent 29 attended balance classes and wanted to continue beyond the two sets of five sessions that therapists were allowed to prescribe. The rationale was that patients needed to move onto community exercise schemes and this was part of acceptance and self-management but the respondent did not understand this and did not accept limitations to his recovery:

> *It was exactly around this whole adjustment issue… even though he has done very well in our eyes, he is not back to normal, and they just want therapy for ever* (CT2, PT2 referring to R29)

> *You get discharged after five classes whether you're well or not… I wasn't better* (CT2, R29, M, 91yrs)

Patients had to move on to community facilities because there were limits to what therapy could achieve and caseloads were large. While new goals could be identified, there were other ways to meet them that also encouraged community integration. One interesting observation was that goals helped manage expectations by encouraging patients to reflect on how far they had come:

> *They often forget how impaired they were in the first place and that they have made achievements but they just remember where they were before it happened* (CS2, OT2)

When asked about self-management, therapists regarded this as part of their role but acknowledged that 'we don't have time to do it' (CS2, OT2). They offered a narrow interpretation of self-management which consisted of signposting patients to other services and encouraging them to do their exercises. Although clinicians supported self-management in principle, limited time meant that rather than a continuous process it appeared to be largely deferred to the 6MR.

Another key gap was return to work for younger respondents who were not at that stage until after the community team had withdrawn. Those who resumed work did so without professional support:

> *The needs for people who are my age are different, a lot different… I shouldn't be sitting indoors doing nothing… We need to be able to try and get back at it as soon as we can* (CS1, R34, M, 28yrs)

Lastly, some respondents, mainly those with severe disability complained that community rehabilitation withdrew too early. This appeared driven by goals and whilst therapists maintained that patients had plateaued, respondents disagreed:

> *I felt they had a timeframe and then they had to leave you on your own to get on with it… it's when you need them the most they are not there for you* (CS1, R13, F, 37yrs)

This left a gap where the patient did not feel equipped to manage everyday life but had no ongoing form of support and their 6MR was not due for several months. In site 3, the SA co-ordinator tried to time visits with when therapy withdrew so that she could provide reassurance but in other areas co-ordination between therapists and reviewers was not apparent. In addition, respondents had a longer-term outlook than community therapists who appeared to withdraw services when respondents felt they could still improve. Some respondents drew on previous experience and that of family or friends to develop their own strategies, while others resorted to private physiotherapy. For younger people, motivation was financial:

> *He's gone back to work… I still think that it's too much but financially… he didn't have a choice but also he needed to do something to motivate himself… he was just on the sofa, eating and not doing anything* (CS2, C8)

While community rehabilitation was highly valued, delays waiting for it to start, and not being kept informed of when it would commence, exacerbated anxieties around the transition home. Many respondents wanted more therapy than was available. Similarly, they wanted more information and advice once home; this is explored in the next section.

4.4.4: The importance of information and education

The need for ongoing support linked with the need for information and education along the whole care pathway. While information was provided during the inpatient phase, respondents expressed difficulty absorbing it because they felt overwhelmed, staff were rushed and the environment chaotic. Timing was important and patients could only absorb what was immediately relevant:

> *You're in a bubble… you tend to [say]… "Yes, that's fine." But you don't really take it in* (CS2, R29, M, 91yrs)

Alongside feeling overwhelmed, a few respondents (and carers) did not know what to ask because they had no prior knowledge of stroke and did not know what to expect:

> *Your mind, apart from being blown apart by the stroke anyway, you don't think of what you need to ask… because (a) we don't know what's necessary, and (b) we don't know what to expect anyway, and you rely on the professionals to do whatever they think should be done and can be done* (CS1, C35)

The couple quoted above trusted professional expertise but not all did. Some respondents remained vigilant and identified instances of incorrect medication and even misdiagnoses. For example, respondent 17's husband (CS2) spotted that she had been prescribed an additional anti-depressant and been incorrectly labelled as having dementia.

In site 3, the SA co-ordinator provided standard information packs and her contact details, although many respondents had already received the former during their inpatient stay. While some found the pack helpful, others had not opened it, had deferred to their carer to read it or felt it was too generic to be of use, especially younger respondents. Standard packs were evidently provided to ensure recipients were aware of the full range of available services.

When asked what information respondents would have liked, or liked more of, there were two main areas. Firstly, what was going to happen in terms of their immediate treatment, transfers to other units and discharge home. For example, respondent 36's wife commented on the transfer from acute to rehabilitation unit:

> *We didn't know where we were going, what was going to be next, that, oh my god, they're already going to move you somewhere else* (CS1, C36)

Secondly, respondents wanted more information about aetiology, prognosis and secondary prevention. They had many questions about diet, exercise and fatigue. While the 6MR would later address these concerns, this need was unmet in the preceding months and respondents would have benefited from earlier input:

> *That [information] was fairly zero, actually! ... I would have liked more information about how to prevent another stroke and also… any alarm signals* (CS2, R40, F, 76yrs)

Some respondents had follow-up appointments with the stroke consultant where these queries were addressed. Others felt the appointment was rushed and/or forgot their intended questions. Often these were picked up at the 6MR because respondents had more time to consider, reflect and clarify information.

In site 2, the ASU used a 'personal stroke plan' which was a booklet all patients were meant to receive on admission and aimed to help them navigate the care pathway. It included a list of who was involved in their care, therapy goals, personal risk factors and general information. However, few people found it helpful and many did not remember receiving it or had lost it. The majority of booklets had not been completed while others had been completed without discussion and/or contained errors:

> *It has a value. I just think that there's so much paperwork on all pathways… people have care plans in their homes from social services… then they've got bits and pieces from us… it ends up being A N Other* (CS2, PT2)

> *We couldn't make head nor tail of it but it had some addresses in the back that were probably useful… We were given it by the hospital and they said we've got to take it everywhere but nobody ever asked for it… I couldn't understand why we had been given it if it was to put data in, but nobody asked for it* (CS2, C5)

Respondents in site 2 found the 'life after stroke' group helpful to varying degrees. The timing of the group in relation to their 6MR was very varied but it appeared to act as an additional point at which respondents could seek reassurance. Most appreciated was one-to-one time with the SNS or dietician to discuss specific concerns. Because this interaction was not structured, like the 6MR, it enabled respondents to lead the conversation.

Those who did not find the group helpful either had aphasia or were dissatisfied with service provision overall:

> *I didn't think it helped at all… apart from say having your blood pressure taken, I don't think it told us really anything that either wasn't common sense… or hadn't been mentioned before* (CS2, C31)

> *There was two or three things… but then a lot of it was see, was no point at all* (CS2, R5, M, 72yrs)

Many people used the internet but acknowledged potential drawbacks. As well as general information about stroke it was used to access clinical trials, equipment (for example, a mirror box for upper limb rehabilitation) and mobile telephone applications ('apps') for memory retraining. Some people resorted to the internet because they felt the information they had received was insufficient or too medicalised while others wanted to supplement what they had been told:

> *I like to research myself because… when I go to my GP the language they speak is sort of like you can't understand half a word they say* (CS1, R20, M, 51yrs)

> *I try to acquire knowledge elsewhere, so I take what they [therapists] tell me and what I learn online as well and use it* (CS1, R13, F, 37yrs)

In summary, respondents had specific and ongoing needs for information, education and advice that generic information did not satisfy. Some respondents used other sources to supplement their knowledge. The next section illustrates how these needs, and the patient experience overall, informed the response to negotiating the care pathway.

4.5: Approaches to negotiating the care pathway from stroke to 6MR

Analysis indicated that, broadly, patients responded to rehabilitation and therapy in three ways. Firstly, many respondents had an active orientation to recovery and were determined to improve their functional abilities, established good relationships with therapists and clinicians on the ward and were interested in self-management. Secondly, a smaller number were still proactive but took their own approach to rehabilitation and self-management at odds with, and to a certain extent in conflict with, that of therapists and clinicians. Thirdly, a small group adopted a passive orientation to rehabilitation and did not appear interested in self-managing their condition or addressing lifestyle factors.

4.5.1: Respondent type 1: proactive and self-managing

This group of respondents demonstrated motivation, resilience and determination with engaging in therapy. They continued their own rehabilitation once statutory services had withdrawn, which reflected their drive for autonomy and regaining lost skills. Being home was an important factor in regaining independence, compared to the inpatient environment where they had little control over daily life. Those who could afford to employed private physiotherapists or personal trainers whilst others stated they would have done so if they had the means. Respondents used pre-existing activities to further their recovery, for example yoga and swimming, and/or sought out new activities such as exercise classes:

> *I couldn't walk at all… I was like a drunken toddler skating! You know, I had to get back from that… I am very motivated and I'm fairly bloody-minded so I would get on with it* (CS2, R40, F, 76yrs)

> *As soon as the physio stopped I went to the Gentle Gym… on my own* (CS1, R28, F, 66yrs)

Some respondents compared themselves to others who they regarded as lacking motivation:

> *Even going from the walking frame to the stick, gosh, I was terrified, but you've got to keep going… because if you don't … there are so many people with sticks… I do wonder, if they'd continued, and made an effort, because it's only by making an effort you can progress really* (CS3, R44, F, 79yrs)

Respondents concentrated on developing a daily routine and gradually increasing their activity levels. There was no obvious age differential but this group had been active pre-stroke and were determined to further what they had learnt in therapy. All were extremely motivated, continually challenged themselves and were not prepared to accept the status quo when discharged from therapy. For example, respondent 10 (CS2, M, 55yrs) achieved his goal of getting back to cycling many months after services had ceased.

These respondents had established positive relationships with therapists, clinicians and reviewers. Even when they expressed concerns about specific aspects of their care they framed them within the wider context of stretched resources and service constraints. They appeared to trust staff and followed their advice, although not without seeking further information and clarification, which reflected their proactive approach. For example, one respondent questioned conflicting advice on monitoring his blood pressure:

> *We had all those workshops ['life after stroke']… and she [community SNS] had mentioned how important it was to monitor your blood pressure… and she [acute SNS] said, "Yeah, that's normal. Forget about it. Don't bother doing your monitoring, just forget about it." So her attitude is that thinking about it and monitoring, looking at the figures gets you more worried about it* (CS2, R10, M, 55yrs)

Respondents demonstrated the same enthusiasm for secondary prevention as they did for rehabilitation. They were focused on self-managing all aspects including medication and lifestyle factors. They were well-informed on general health promotion messages such as government guidelines on alcohol consumption and exercise. Most did not have severe residual impairment so were able to exercise, were not housebound and were in a better position to adhere to secondary prevention advice than those in the next two groups.

4.5.2: Respondent type 2: proactive and self-managing on their own terms

This group appeared to be regarded by therapists, clinicians and reviewers as lacking in varying degrees motivation, compliance (a term that was used, rather than adherence) and insight. However, some appeared motivated and were continuing rehabilitation independently, albeit in a way that was at odds with their therapist's approach. For example, respondent 41 (CS1, F, 63yrs) had purchased several arm slings but was wearing them incorrectly despite repeated attempts by the physiotherapist to teach correct use, which she did not follow. Respondents appeared to distrust therapists or clinicians and there appeared to be a mismatch in expectations and outlook:

> *I've done most of it myself…I'm just going to give up with them [physiotherapists], I want someone to tell me what to do and how to get this [arm] moving* (CS1, R32, M, 68yrs)

These respondents were often not sure what their therapy goals were and complained about aspects of their inpatient treatment. However, they were still motivated to improve although they wanted more input than available:

> *She [R41] seems to continue to need somebody to actually walk her through it [her home-based exercise programme] and… is not able to practice the exercises… without anyone there and obviously the level of intervention we're giving isn't enough for her* (CS1, PT1)

Respondent 31 was particularly angry because he felt community therapy had withdrawn too early and had been too infrequent. He complained (during the interview and formally to the service manager) that he only had physiotherapy once a week when he had been promised it would be twice weekly. He had not found goal setting helpful and had not achieved the goals when therapy was withdrawn:

> *I don't think I need to have specific goals but when they give you one they can't make it anyway* (CS2, R31, M, 63yrs)

He thought, as did others, that health and safety took precedence over rehabilitation, that therapists were risk averse and that this impeded progress:

> *The hospital's like it's all safety first and shove you in hoists and everything else… they always have to assess you all the time* (CS2, R31, M, 63yrs)

Respondent 9 also complained that therapists were risk averse and compared the rehabilitation unit to a prison. Staff thought he lacked insight ('he was a faller and his insight wasn't that good' CS1, SNS1) and he had little faith in his physiotherapist. Once home, he started doing activities that he said staff would not allow him to do; both he and his wife stated that he then improved rapidly:

> *The way he came home, not being able to do things, within a few days you were doing different things, weren't you? You were doing more walking* (CS1, C9)

He knew he was at risk of falls but perceived this as necessary to achieve his goal of looking after his wife which reflected a different outlook and priorities to that of his therapists. When re-interviewed, he maintained the view that therapists were too theoretically orientated rather than focusing on practical activities.

Respondents commented that therapy appeared to dwindle prior to discharge, presumably because therapists were focusing on new patients, but this added to their sense of being left to their own devices. Respondent 33 had a semi-formal carer who helped structure her day, carry out exercises, prepare meals and keep her company. She used what she had learnt in therapy alongside her knowledge as an ex-dancer to tailor her exercise routine. She had an exercise booklet from the physiotherapist but needed further assistance to select and grade exercises:

> *Your physio had given you some exercises… we based our work together around that… we sort of tailored it down… when you're tired and fatigued lots of paper is hard to cope with… so we did some exercises… we just kept a record of how you were doing each day* (CS1, C33)

Respondents expressed conflicting feelings about accepting constraints on their daily life versus fighting to improve further and this related to how they had re-framed the stroke:

> *Well, your cards are dealt as it were… I think I no longer think of normal as what I was… I'm hoping it will be an improvement as what I am now but I certainly don't have any expectations to get back to where I was... The difficult thing really is getting your mind round the degree to which you should accept where you are but on the other hand you don't want to just accept it and not feel that there is any forward* (CS2, P31, M, 63yrs)

Secondary prevention was acknowledged as important and respondents wanted to self-manage their condition but found it difficult due to pre-existing long-term conditions, residual impairment and other issues such as finances:

> *I would like to be able to go to a group for exercise… but… there's nothing in this immediate area… the big problem I've got with my condition is lack of exercise and keeping my weight under control is a struggle. I would prefer to be losing weight and to take the load off my legs… but all I'm doing at the moment is maintaining the status quo* (CS2, R3, M, 76yrs)

Many wanted to increase their exercise levels as they knew this was important but could not access or identify suitable facilities. At the 6MR, some were advised to contact the Stroke Association for signposting but the issue often remained unresolved.

4.5.3: Respondent type 3: passive orientation

Only four patients made clear that they did not want to change their behaviour despite the encouragement of clinicians and carers. Three of them had significant co-morbidities that already limited their daily life. All four tended to stay home with limited interests pre-stroke. Respondent 42's (CS3, M, 73yrs) mobility had regressed since discharge and therapists asked the SA co-ordinator to encourage him to join an exercise class. His wife was keen for him to attend but he was not interested because he had resumed the activities he valued pre-stroke (watching sport on television and betting).

Respondents felt that therapists did not understand their situation while therapists were frustrated by their passive approach to rehabilitation and expectation 'to be done to' (CS2, OT2). They tried to engage patients but their outlook was medically orientated and discharge driven, at odds with respondents' priorities who appeared to have genuinely disengaged from rehabilitation. For example, respondent 2 was focused on her weight due to a long-standing eating disorder and respondent 16 hated his newly acquired warden-controlled flat. When respondents did not 'comply' it was regarded as an indication that they had not adjusted to the stroke:

> *We do… set out, right from the word go… discussing expectations, sometimes it is just overall difficulties with acceptance… sometimes… the patient has accepted it but the family hasn't* (CS2, OT2)

Respondent 26 (CS1, M, 72yrs) had not been active pre-stroke. He stated this was due to back pain and a respiratory disease but his carer commented that he had always avoided exercise. He presented as cheerful but his memory was impaired; he could not recall details of the 6MR and was later diagnosed with dementia. However, therapists were frustrated by his perceived resistance to engage and his carer also felt he was not trying:

> *He'll sit in that chair from 12 o'clock to 2am he doesn't do anything, he's completely unmotivated… sometimes I think he's using it as an excuse to be lazy… it's better when I go out because he has to get up* (CS1, C26)

This group had mixed relationships with staff but mostly negative ones. They did not follow advice instead ignoring, forgetting or actively rejecting it. For example, respondent 16 (CS1, M, 64yrs) made clear during his 6MR that he had no intention of reducing his alcohol intake. For the SNS, this was a source of frustration because she could identify secondary prevention strategies but he was unwilling to even consider them.

These respondents were perceived as rejecting self-management and secondary prevention strategies. However, they were struggling to cope with complex social circumstances and ongoing low mood so they regarded the 6MR as somewhat irrelevant to their daily life.

4.6: Chapter summary

This chapter started by describing the case study sites. Stroke prevalence was similar to the England average in sites 1 and 2 but higher in site 3. Reviews were carried out by SNSs in sites 1 and 2 but the latter had instigated a 'life after stroke' group to supplement the 6MR. In site 3, reviews were carried out by a SA co-ordinator.

The chapter then explored the impact of stroke and the ramifications for patient and carer, set against a background of co-morbidities and complex social circumstances. Younger respondents were focused on return to work and where they achieved this, it was through their own endeavours. For those unable to drive, this curtailed many valued activities and left them feeling trapped at home. Respondents had different approaches to managing their experiences: many took an active approach to rehabilitation and sought opportunities to enhance their recovery alongside whatever therapy they were receiving; a second group were also proactive in their approach to rehabilitation but were inclined to disagree with professional opinion and were often labelled by staff as 'difficult' or 'non-compliant'; and lastly were those who took a passive approach to rehabilitation and resisted attempts to encourage them to self-manage.

Important ‘hotspots’ in the care pathway where respondents felt particularly vulnerable and/or unsupported were during the transition between units, discharge home, waiting for community services to commence and when they had withdrawn. Respondents expressed mixed opinions about the information provided to support them through this process which appeared to relate to timing, format and approach. How all these experiences influenced perceptions of the 6MR is explored in the next chapter.

Chapter 5: Findings - the review process

The previous chapter explored the organisation of stroke services and the personal impact of stroke. The inpatient experience resonated through all narratives, as did attitudes to rehabilitation and the need to re-establish a routine and participate in valued activities. Concerns about the timing, format, content and delivery of information were common and linked to anxiety about having another stroke.

This chapter considers patient and carer experiences of reviews, focusing mainly on the 6MR and its perceived usefulness. This is compared with the views of commissioners, managers and reviewers. The findings are drawn together with a conceptual map that demonstrates how experiences of the care pathway influenced attitudes towards the 6MR.

5.1: Views on the 6MR’s purpose

This section considers why commissioners chose to fund the 6MR and how different parties perceived its purpose. Commissioners and managers tended to refer to policy whereas reviewers based their comments on experience. The SNSs had a broad job specification that allowed them to develop their niche and they stressed flexibility and individuality, albeit within the constraints of time. However, patients and carers were unsure about the 6MR’s purpose.

5.1.1: Commissioners and managers

Commissioners referred to policies including the NHS Outcomes Framework (Department of Health 2014b) and National Stroke Strategy (Department of Health 2007) to guide service priorities. Commissioning reviews appeared to depend on whether or not there was a pre-existing service, in which case it would be renewed annually unless there was a reason not to:

> *We tended to commission services that were already in place. So some things you don't make a concrete decision. You simply continue with services that you previously commissioned and then at certain times you might re-commission them* (CS1, CCG2)

Site 1 was the most forthcoming on decision-making. The commissioner considered the overall care pathway to ensure any change in one area did not have a detrimental effect on care at another stage and referred to the evidence base:

> *I just look at everything that's available around what is best practice… everything we do would be linked to best practice and NICE guidance. We would also then be talking to experts in the field. We would normally bring a clinical reference group together, which would include GPs, consultants, any other*

> *specialists that are local, whether they're nurses, therapists, and then decide and scope what perhaps a good model would look like* (CS1, CCG3)

Another commissioner in site 1, also a GP, referred to a committee making the decision:

> *You take your business case and you have to present it to the committee and then it is voted on, so there's some clinical representation, there's patient representation, there's management representation on those committees* (CS1, GP1)

Site 2 had areas where the review was unavailable. The reason was unclear but appeared to be that CCGs did not regard it as a priority. One SA manager thought that it depended not just on the financial position of the CCG and local authority but also on commissioners' understanding of stroke and the emphasis they placed on it, hence the variation in services.

In site 3, stroke rehabilitation services had not been asked to provide the service because they were deemed to lack capacity. The local authority had a long-standing relationship with the Stroke Association and so the 6MR had been a 'legacy arrangement' (CCG1) whereby it was built into an existing contract, thereby saving additional costs:

> *It [Stroke Association] was much more sustainable. And it also means that cutting it becomes a non-issue, why would you cut something where the savings can be minimal… that's my take on why we've still got it and other places are struggling* (CS3, CCG1)

Only a few respondents questioned whether the review was worthwhile, perhaps demonstrating how entrenched it has become. However, they raised concerns about equity of service provision across all long-term conditions, whether resources could be better spent elsewhere and cost-effectiveness:

> *Do I honestly believe that as a nation we should be spending however many millions of pounds implementing this service and is that the most important thing to stroke patients? My honest answer would be, "No." My honest answer would be, "Give them equitable service in their GPs and get the GPs to call them back in at six months to see how things are"… And that should be more than enough… … Are we really providing secondary prevention, which would be the most cost effective thing for health? Probably not* (CS2, M4)

Views were mixed as to whether clinicians or SA co-ordinators were best placed to provide the review and these reflected commissioning decisions across the sites. One manager (and ex-therapist) had changed her opinion (CS2, M4). She initially thought that reviews should only be carried out by clinicians but now, with hindsight, was ambivalent about this.

Purpose and outcome somewhat overlapped and ranged from global aspirations such as improved quality of life and independence to more tangible goals such as provision of information, signposting, a ‘health and social care review at set points in time’ (CS1, M5) and, most importantly, identifying unmet needs:

> *In a nutshell to make sure that there isn’t any unmet need and if there is to seek to address that and obviously to provide secondary prevention* (CS2, SNS5, clinical and managerial role)

Managers and commissioners regarded identifying unmet need as the key role of the review and pointed out that unmet need reflected gaps in service provision. While some had a broader view of the process, others regarded it as a safety net:

> *The pressure on the health system is continuous episodic care where you just treat and discharge… the whole point of the 6MR is to catch things before, you know, it’s almost like a safety netting* (CS3, CCG1)

The review was deemed to circumvent people ‘disappearing into the ether’ post-discharge (SA4), either for those not referred to community rehabilitation or as a link back to such services when the team had withdrawn but patients were struggling. However, it was only in site 3 that the SA co-ordinator timed visits so that they coincided with the withdrawal of therapy. There were no instances of respondents being referred for further therapy but there were occasions where they had not been referred for a 6MR. Managers acknowledged that recovery occurred at different rates but still advocated a rigid timeframe for reviews.

5.1.2: Reviewers

Views were mixed as to whether the review was assessment, intervention, process or therapeutic interaction. Reviewers were realistic about their time constraints but wanted to provide more than assessment:

> *When I was actually doing it, it was more than a review it was a therapeutic process in itself… it rather depends on the practitioner themselves how much you make it more than a question and answer session* (CS2, M4)

The SNSs acknowledged that they were medically orientated but this stemmed from having reviewed patients with urgent medical needs:

> *I have become more medical model orientated these day which I assume is because of the limited other resources we can offer these days to make the patient’s life easier…..cut, cut, cut in everything* (CS1, SNS4)

The SA’s view was broader and more socially orientated:

> *I think very much it is a holistic review and I think it is vital that it is not just a medical review, it needs to be all encompassing* (SA4)

> *I do see it as an opportunity to… talk about post-stroke adjustment, their recovery, give them reassurance about how well they're doing… it's an ongoing process* (SA5)

SNSs sent patients a letter inviting them to review which stated that the purpose was to review their health and medication, explain investigations, and discuss risk factors and health promotion (appendix 19). One SNS regarded the review as 'a full MOT' and took a wider view, for example, asking about breast and prostate screening (CS2, SNS2). She wanted regular contact with patients beyond what her job allowed. The review was also regarded as an opportunity to discuss adjustment issues and provide reassurance as well as answering questions, chasing investigations, providing support and troubleshooting.

The SA invitation letter (appendix 20) summarised the review as 'an opportunity to identify any unmet needs'. The SA co-ordinator explained her purpose was to signpost and provide information because a more comprehensive intervention was not possible within the allocated time. She highlighted a clash in purpose between the medically orientated standardised tool (the GM-SAT) which she had to use and her preference for a wider interpretation:

> *I'm very much looking at the whole person and how to support them after a stroke with social stuff and all sorts of things and that [6MR] is very medically based isn't it? So that is an NHS agenda* (CS1, SA3)

All SNSs acknowledged that a key purpose of the 6MR was to promote self-management. However, the extent to which it was addressed varied. The SNS in site 2 had initiated the 'life after stroke' group to supplement the 6MR and teach people to 'be their own little doctor' (CS2, SNS2):

> *That's a hugely important role… looking at weight, diet, blood pressure, medication, all of that… but also motivation to achieve any kind of secondary prevention goals to me is part of an integral part of the review* (CS2, M4)

The SA co-ordinator was less definite about the role of self-management, stating that the review was really focused on unmet need even though she did address lifestyle issues in the review:

> INT: *Is that [self-management] part of the remit of the six-month review or not really?*
> RESP: *Not really heard it talked about, not put in those terms no, not really*
> INT: *So it's more looking for unmet needs?*
> RESP: *That's the key words we was having even on our letter we sent out… to people*

Discussing the purpose of review led to debate around who was best placed to provide it. SNSs acknowledged the attributes of SA workers, for example their knowledge of community services, but perceived this as complementary, not an alternative for clinical expertise:

> *I think they are only able to deliver a very tick box superficial review… rather than being able to give further advice… or create a care plan… they're much more likely to just automatically refer back to a service such as the community stroke team* (CS2, SNS5)

> *She does not read blood test reports or… look into like other related investigations, such as cardiac or Doppler… she can't integrate those things to the patient, and also can't make a management decision[s]… we… go through each risk factor that can be modified and then we explain to the patient* (CS1, SNS4)

Equally, SA staff championed the wider remit of their reviews and emphasised the importance of looking beyond medical parameters:

> *One of our key aims is about integrating people back into community and things to do after their stroke* (SA5)

In Site 3, the SNS and SA worker appeared to have close links and had negotiated their boundaries such that they had a mutual understanding of each other's purpose:

> *My understanding that I do the education and your [SA1] role outside is in the community, like helping them with the blue badge* (CS2, SNS2)

These comments reflected different opinions about the 6MR's purpose and was reflected in the format and content of review, explored in section 5.3. The next sub-section explores patient and carers' thoughts about the review's purpose.

5.1.3: Patients and carers

Patients and carers did not have a clear idea about the purpose of the 6MR but regarded it as some sort of check on their progress, possibly prior to discharge from stroke services. As already mentioned, each site sent an appointment letter (appendix 19-20) but this did not translate into respondents comprehending the rationale. Ward staff were meant to inform patients about the review prior to discharge but this did not appear routine even though reviewers stated that they often reminded their colleagues to do so:

> *It was out of the blue… I assumed it was to assess my condition now… you don't know that these things are going to happen. I just had a letter to say she would be coming to do a review, but at that point I really didn't know why* (CS1, R1, F, 77yrs)

Respondents raised no objections to attending the appointment but some wondered if it was an audit or tick box exercise prior to sanctioning discharge, while others were unsure who the reviewer was:

> *Is she there to tick boxes or is she in place of the consultant?* (CS1, R28, F, 66yrs)

> *Is this my signing off?* (CS1, R14, M, 85yrs)

The review could be seen as an important marker of progress but only two respondents commented on this explicitly while another had her own approach to monitoring progress:

> *I thought it was very useful to be able to review my situation at a rather longer interval* (CS2, R7, F, 85yrs)

> *I actually kept an extremely detailed stroke diary from the day it happened… it's been quite helpful to look back and see how I've made progress* (CS2, R40, F, 76yrs)

Although respondents were unclear about the review's purpose it prompted them to ask questions. Nearly all wanted more information about their condition, prognosis and unresolved symptoms to supplement what they had already gleaned from their inpatient experiences and their own research. A few respondents, all older people, said they did not know what to ask and trusted the reviewer to tell them:

> *We're not in the position to ask the right questions, are we, I don't think, we're not knowledgeable about, we accept what we are told and we try to follow the, what they've told us* (CS2, C29)

In summary, commissioners tended to continue funding existing review services unless they had a reason not to. Some questioned the 6MR's efficacy while others thought its monitoring element could circumvent problems that might otherwise escalate. SNSs wanted to provide more than assessment and an important aspect was secondary prevention, whereas the SA co-ordinator was more focused on community activities. Many respondents were unclear about the 6MR's purpose but saw it as a forum to seek further information about their stroke. Whether the timing of this was opportune is considered in the next section.

5.2: Timing of reviews and subsequent follow-up

This section considers opinions around the review's timing. While the focus is on 6MRs, respondents often alluded to six-week and yearly reviews because of the policy context. The format of all reviews were similar and are addressed in section 5.3. This section is divided into three sub-sections addressing the perspective of managers/commissioners, reviewers and patients/carers.

5.2.1: Managers and commissioners

Overall, respondents largely accepted the 6MR as a common sense mechanism to identify unmet need so most of their comments related to the one-year review and annual thereafter. None of the commissioners acknowledged the gap between therapy withdrawing and the 6MR as a period when patients felt particularly unsupported. One manager (CS3, M2) thought the 6MR did not ‘work as a stand-alone’ intervention, although her locality only commissioned the 6MR. Commissioners and managers expressed mixed views about the benefits of a one-year review and nearly all had concerns about the feasibility and value of providing ongoing yearly reviews.

The rationale for the 6MR was pragmatic, given that ‘there is no evidence’ (M6, a member of the Royal College of Physician’s Intercollegiate Stroke Working Party). Many studies followed participants for only six months which meant there was a paucity of data on longer term outcomes. However, the Stroke Working Party were aware that patients ‘were just falling off the edge of a cliff’ and as progress tends to plateau around six months post-stroke, it appeared an opportune point at which to review their progress:

> *Traditionally six months was the point that we really didn’t know very much about people after that point. A year was thought to be too late so we thought, and again it’s a guestimate* (M6)

As there was no systematic data collection post-discharge, the 6MR also served as an opportunity to benchmark services across the country and compare outcomes (M6).

Comments about the need for a review at one year were ambivalent and led to reflections around the benefits and feasibility of providing ongoing annual reviews:

> *There should be… a yearly review… if the patient requests it, not all patients need a yearly review and don’t want it… … it’s really down to the patient if they request a yearly review* (M1)

One local authority manager thought it would be feasible to provide yearly reviews but it would impact elsewhere on the service. She thought patients would benefit from consistent input but differentiated the Stroke Association’s open door policy from structured yearly reviews:

> *That door's never closed so they're [SA] able to do that, but I think that's very different to something that's proactively funded to engage with people on a more regular basis* (CS3, M2)

Another manager suggested an open door policy might actually encourage dependency:

> *You could argue that it's building dependence… that it's not necessarily healthy to give that open door approach* (CS2, M4)

Site 2’s therapy manager commented that reviews could not continue indefinitely and that highly trained clinicians should not be used to fill gaps in social care. Instead, for certain issues it was preferable to signpost onto other agencies:

> *We have to be consistent with how that works, otherwise we're not going to be able to deal with a greater group if we've-- dealing with everybody we've got we keep them on ad infinitum. So we've got to be much tighter in terms of how that works, and much more linked to goals and objectives* (CS2, M3)

Equally, another manager thought it unrealistic to carry out ongoing annual reviews because reviewers would not have capacity to manage an ‘ever-growing caseload’. He thought annual reviews were probably within the GP’s remit but acknowledged that they have limited time and would want a financial incentive. Others commented on aspirations versus reality and balancing priorities:

> *All the time I'm talking I am so aware having run lots and lots of stroke reviews and seen patients being rewarded by them, but I'm also very aware that it's such an unrealistic goal to expect this to be commissioned… when there are so many other healthcare needs that are so much more pressing… it's the cherry on the cake…when the reality… is that most patients if they've got a proper issue they'll make an appointment and go and see their GP* (CS2, M4)

While this manager (and therapist) appreciated that historically patients felt abandoned by services, she did not feel that six-month or yearly reviews were as essential as she had previously believed, rather that GPs were best placed to manage long-term conditions:

> *It's kind of like gold leaf that is very nice and yes, we can get carried away with our importance, if you like, at what we're able to do for people in an hour or so of time and how it's going to prevent longer-term problems etcetera, but… on reflection I don't actually believe that that gold leaf is a huge necessity… as long as the patient knows and has an active relationship with their GP that should be the point of contact* (CS2, M4)

The CCG representatives questioned the feasibility of ongoing yearly reviews and potential duplication between the GP and SNS whilst acknowledging that GPs lack time and possibly expertise:

> *You can’t have a perpetual review but something that says six months after a significant clinical event you should be reviewed so I think it’s a valid thing to do… I think you have to look at the benefits… six months is close enough to the original event that you need to check is everything in place but after that there’s a whole load of other things that can affect their health that are not related to the stroke so that’s why… they’ll be reviewed annually by their GP so it’s just about not duplicating* (CS3, CCG1)

SA managers were the only respondents to support ongoing yearly reviews because that is what their service advocates (Wright 2016) and would allow co-ordinators to follow-up issues identified at the 6MR. However, the motivation appeared to be based not on evidence of effectiveness but on ‘mopping-up’ outstanding actions from the 6MR and adhering rigidly to the six-week, six-month and yearly policy imperative incorporated into their recovery model (Stroke Association 2016b).

5.2.2: Reviewers

All reviewers wanted to offer six-month and one-year reviews, but not necessarily annually thereafter. Unlike managers and commissioners they did not advocate a rigid format but wanted to tailor to individual circumstances. The SA co-ordinator deliberately scheduled her 6MRs to coincide with therapy withdrawal which she acknowledged was often a 'hotspot':

> *I see the way the six-month review is timed is they [CST] are either still working with them, just about to finish or they've just finished* (CS3, SNS3)

There were mixed reports on how often patients initiated telephone contact. One SNS stated that she frequently received telephone calls from patients while another stated that she rarely did:

> *As a stroke co-ordinator every single patient that leaves our team gets a leaflet with my name and telephone number on, and I probably get two calls a year* (CS2, M4)

The counter-argument to intervention based on what patients wanted was the view that regular monitoring was important because GPs did not have time and patients could be asymptomatic but have underlying medical needs:

> *A lot of patients when they start to talk and walk they feel fine and blood pressure, secondary prevention… high cholesterol, high sugar, won't make you feel ill. Patient will not have a clue so they'll say, "I'm fine. No thank you."… So sometimes we have to be prescriptive* (CS1, SNS4)

A more pragmatic argument for the one-year review was that it would be useful to check whether action points from the 6MR had been followed through. Although reviewers tried to make sure referrals were initiated, they did not always have the time to do so. However, most needs should have been addressed by one year anyway, although this assumes ongoing contact rather than a one-off review:

> *If you've been in touch with that person for 12 months anyway, you would expect that 12-month review not to unveil too many unexpected needs, because they would have been addressed previously, you would hope* (SA5)

5.2.3: Patients and carers

There were occasions where the gap between services withdrawing and the 6MR was long and patients struggled in the interim. There were instances where patients had not received a review for considerably longer than six months' post-discharge.

Some respondents favoured an early review when they were still adjusting to being home. Although patients were invited to contact the reviewer for an initial visit, only a couple of respondents did so. Others thought the timing was immaterial or that it should coincide with when therapy services were withdrawn. For most, it appeared to be an individualised decision with other contributing factors:

> *That's a ridiculous amount of time, six months. I feel it's just ticking boxes 'oh, six months…tick!'… I do appreciate every stroke is different and everybody's going to have different needs* (CS3, R44, F, 79yrs)

> *It would make no difference, what I've discussed today I would've discussed two months ago and I doubt it will have changed in two months… … it would've been a good follow-on from the physio people when they stopped coming* (CS3, R45, M, 67yrs)

Respondents appreciated that reviewers gave them their contact details although, while some stated it was reassuring to know that they could telephone the SNS, few actually did:

> *The only thing I want and which I've got now is a phone number if anything went wrong* (CS3, C43)

In terms of whether or not people wanted subsequent review, opinions were mixed and some commented on the arbitrary timeframe. Those who had ongoing impairment and/or found the 6MR helpful were more likely to want another review, mainly for reassurance:

> *Reassurance that you are still being monitored when there's a lot of uncertainty in your own mind about what's going on and what the future holds… whether there's a likelihood of another stroke* (CS1, R39, M, 73yrs, after 1yr review)

Those who did not want further review had recovered well and were confident in their understanding and knowledge. They were self-managing and had their own strategies including regular exercise and healthy eating:

> *No, I don't think there's any point, nice as she is, just for a chat! I think it's a waste of her time, I always think they've so much to do and there's people much worse than I am* (CS3, R44, F, 79yrs)

Some respondents declined the offer of a one-year review while others accepted it even when they stated that the 6MR had not been helpful and they saw no reason to have another one. They appeared to feel obliged to attend and had the time to do so:

> *I have a lot of time on my hands because I don't work. If I was really busy I'd think 'not another appointment'* (R10, M, 55yrs)

Overall, there was no sense that the 6MR needed to be at a set point in time. It was often an unexpected intervention and at an arbitrary point in time and this might have contributed to the lack of clarity surrounding its purpose. Having considered the temporal aspect, the next section focuses on the content and delivery of the review.

5.3: Delivery of the review

This section explores the format of the review across sites and issues that facilitated or inhibited its success. It starts by comparing approaches between sites, identifies the key strengths of each model and finishes with a discussion about barriers and enablers.

5.3.1: Process and content

This section discusses and compares approaches to delivering the review (Table 23). All sites used a template: site 1 had devised their own template (appendix 21); site 2 used the GM-SAT (appendix 6) but had slightly altered the format; and site 3 used their own version of the GM-SAT (appendix 22).

Table 23: Different approaches to the 6MR

	Site 1	Site 2	Site 3
Where were reviews located?	Two SNSs did home visits and the third held clinics in community healthcare facilities.	In the clinic at the unit where respondents attended outpatient therapy and the 'life after stroke' group.	Home visits.
How much time was allocated?	45-60 minutes.	45 minutes.	60-90 minutes.
What tool was used to guide the process and record information?	Their own template.	GM-SAT.	GM-SAT.
What was the primary focus?	Medical: explanation and review of medication, investigations and test results. This included psychosocial aspects but the emphasis varied between SNSs.	Medical: explanation and review of medication, investigations and test results. This included psychosocial aspects.	Social aspects. A list of medication was recorded on the form but not discussed.
Were lifestyle factors addressed as a means to	Yes, but sometimes limited by time constraints. There was less	Yes, but sometimes limited by time constraints. Exercise was	Yes, the SA co-co-ordinator had a good knowledge of local

secondary prevention and self-management?	focus on exercise compared to sites 2 and 3.	always asked about but the availability of suitable classes was limited.	exercise facilities. There were no time limits so it was possible to discuss healthy eating and alcohol consumption in detail.
Was therapy or individual goals discussed?	This was not a focus of the review but was occasionally discussed.	This was not a focus of the review but was occasionally discussed, usually in the context of exercise.	This was not a focus of the review but sometimes personal goals were asked about.
Did respondents receive a summary of the review?	All reviewers posted a copy of the report sent to the GP but the majority of respondents did not find it helpful and others did not read it.		

Reviewers had different ways of starting the conversation but the SA co-ordinator was particularly clear in explaining who she was and why she was there:

> *People are confused enough with everyone coming and going and you need to be clear about what you're there for… and what it's all about* (CS3, SA3)

One SNS started by asking patients the date of their stroke even though she had this information on the discharge report:

> *I always start with the event of the stroke to focus the patient on why I am there, to invite the patient to tell me about the experience and to gauge what they feel their problems are. Sometimes not all the information is on the EDN [electronic discharge notification] and it establishes the right information* (CS1, SNS1)

This SNS used a logical form of questioning: what were the main problems post-stroke; what were the main problems now; and what had changed pre- versus post-stroke. This was in order to differentiate stroke-specific problems from pre-existing ones. Similarly, another SNS sometimes started by asking:

> *What are the main things you can't do because of the stroke?* (CS1, SNS4)

This occasionally led to patients focusing on pre-existing issues that the reviewer did not regard as relevant but the respondent did. Consequently, their agendas diverged for the remainder of the appointment and both felt dissatisfied with the outcome.

Reviews at home tended to be more relaxed and patient-led than clinic-based ones. The SA co-ordinator was skilled at making the conversation feel natural but without omitting any areas:

> *I tend to be a bit more informal… because I know what's on there from three years of doing it… on an initial visit you will find out what the key things are, what the concerns are, but then you'll ask other questions to find out if there's other things* (CS3, SA3)

Sometimes reviewers adhered to the question order on the GM-SAT, making the conversation feel stilted and some questions appeared out of context. Respondents commented on a formulaic approach, although accepted this as inevitable bureaucracy:

> *I don't mind answering, but I think they're really for their benefit, not mine, because there wasn't anything really except for explaining about the [exercise class]* (CS3, R44, F, 79yrs)

Respondents also queried repetition, with one person asking why she was asked the same questions at her one-year review as at her six-month, given that attributes like smoking status were unlikely to change:

> *I thought they've got to do these tick box, but I felt that probably quite a lot of the questions were a waste of time. Once you've answered them once, quite a lot of them seemed unnecessary and so you kind of switch off* (CS2, R40, F, 76yrs)

Determination to complete the form sometimes appeared to override a client-centred approach, for example, pressing a respondent on her alcohol consumption and deciding on an arbitrary figure. Instead, the template was meant to act as a prompt:

> *It should be a prompt for discussion, and as long as the major domains of health are covered there, their health and social care… it's perhaps not as important as I once thought it was. I think it's much more the skills of the person using the tool* (CS2, M4)

All reviewers addressed lifestyle factors related to secondary prevention including alcohol and tobacco consumption, diet and exercise. They agreed that it was important to improve patients' knowledge and behaviour and enable them to self-manage their condition but sometimes this was perfunctory because of time constraints. The SNS in site 2 had liaised with the SA worker to find out about local exercise classes and incorporated this into the review. However, this did not circumvent problems for respondents in terms of transport and limited availability. Site 1 was less focused on exercise and one of the SNSs felt this was more within the therapist's remit.

Therapy issues were not reviewed unless the respondent raised a specific question. Reviewers rarely asked about therapy goals, although respondents occasionally mentioned their own goals. Areas that were rarely discussed included seating, wheelchairs, positioning, slings and changes in muscle tone (although Botox injections for upper limb spasticity were discussed on one occasion). Of particular note were the few respondents who had residual vestibular and visuo-perceptual disorders that they raised but the issues were somewhat sidestepped or overshadowed. For example, one respondent had issues with dizziness and vision but the review was rushed at the end. The SNS thought the dizziness might be related to medication and suggested taking his tablets at different time intervals:

> *The [SNS] appeared to have changed her mind because he was dizzy before taking this med[ication] and had been on Ramipril since the start. The review appeared rushed and not all relevant, e.g. talking about wife's [blood] clot. It felt overwhelming and hard to follow* (Fieldnotes)

Finally, all sites wrote a brief summary for the GP (appendix 23), with action points, and respondents were sent a copy. However, they did not find this helpful and sometimes queried if the GP would either:

> *It hasn't got a date on it… she sort of said, "We identified that [R31] has some needs in relation to the following areas: help with bathing." Well what's that got to do with the GP?* (CS2, C31)

Overall, there were similarities in the format and content of review but the key difference between those carried out by SNSs compared to the SA co-ordinator was the focus on medical versus social issues which is discussed in the next section.

5.3.2: Medical versus social model

Key benefits of the reviews are summarised below (Table 24) and reflect the focus of reviewer. The SNSs had a medical orientation and concentrated on explaining and reviewing medication, test results and investigations as well as organising or chasing them up. SNSs could discuss directly with consultants or GPs and arrange urgent follow-up if necessary. This contrasted with the SA co-ordinator who concentrated on social aspects and simply asked for a list of medications to complete the GM-SAT. While this approach felt more relaxed and client-centred, medical queries had to be referred back to the GP even when this had already proved ineffectual. For example, respondent 43 had been back and forth to her GP with various stroke related problems, including dizziness, which remained unresolved.

All patients had their blood pressure checked and other clinical observations taken (Table 25). The SNSs were more thorough with blood pressure checks and able to act immediately when they highlighted concerns, for example, undiagnosed atrial fibrillation. The SA co-ordinator was more limited with observations and could not interpret or act on findings. The GM-SAT has an algorithm for blood pressure readings which she referred to but could only advise the respondent to contact their GP. She was aware of this limitation and questioned the rationale:

> *We're just told to do it! I don't know… I'm assuming it's just a further check because the community stroke rehab team are doing blood pressures… and then obviously if there is a bit of a gap and nobody is taking their blood pressure* (CS3, SA3)

Table 24: Summary of SNS and Stroke Association reviews

	Stroke nurse specialist review	Stroke Association review
Medical issues	In-depth knowledge of stroke, able to review medication and make recommendations; able to liaise with consultants and GPs; access to inpatient and GP databases; understanding of co-morbidities; able to screen for sleep apnoea and refer as appropriate.	Medical management could not be addressed by co-ordinators.
Observations	Able to make meaningful observations including blood pressure, heart rate and blood glucose level; able to interpret observations and act accordingly.	Perfunctory blood pressure monitoring; referred to an algorithm to advice follow-up, as necessary. Unable to diagnose atrial fibrillation.
Education, information and advice	Provided in-depth and tailored explanation around stroke, medication and secondary prevention. Signposting to other services and community facilities was limited but patients were regularly referred to the Stroke Association.	Some patients and carers appreciated generic Stroke Association leaflets but others did not find them helpful, felt overwhelmed by too much information and/or wanted it tailored to their needs. Comprehensive knowledge of local services including exercise classes, aphasia cafés, financial advice and carer support.
Reassurance	Patients and carers trusted SNSs' medical expertise and in-depth explanation that the relatively long appointment allowed (compared to those with GPs or consultants).	Focused on developing rapport and prioritising patient and carers' concerns; not time limited. Adept at filling gaps in statutory services.
Both models lacked focus on:	• Identification of therapy needs and/or goals. • Return to work. • Unresolved vestibular and visuo-perceptual symptoms. • Opportunity to consolidate information discussed during the review, particularly secondary prevention (medical and lifestyle) and much of what had been discussed was rapidly forgotten.	

Table 25: Clinical observations carried out per site

Clinical observations	Site 1: SNS	Site 2: SNS	Site 3: SA co-ordinator
Blood pressure (BP)	Sphygmomanometer. Took BP at least once. When deemed necessary, took BP in sitting, standing and both arms. Able to compare to previous readings on GP/inpatient records. Comprehensive knowledge of anti-hypertensives so able to act on concerns.	Sphygmomanometer. Took BP at least once. When deemed necessary, took BP in sitting, standing and both arms. Able to compare to previous readings on GP/inpatient records. Comprehensive knowledge of anti-hypertensives so able to act on concerns.	Digital monitor malfunctioned due to low battery (but it had recently been recalibrated). Took BP and advised patient to contact GP when readings were high. GM-SAT has an algorithm telling the reviewer what to say.
Heart rate	Pulse taken at wrist. Atrial fibrillation identified and followed up with GP and/or consultant.	Pulse taken at wrist. Atrial fibrillation identified and followed up with GP and/or consultant.	Pulse taken with monitor.
Weight	Often weighed the person. Always asked about weight changes.	Always weighed the person and asked about weight changes.	Asked about weight changes but did not carry weighing scales.
Blood glucose level	One SNS routinely carried out a blood glucose test.	Routinely carried out a blood glucose test.	Did not test.
Sleep apnoea	Asked about sleep pattern. Used Epworth Sleepiness Scale as a screening tool and asked consultant to refer for sleep study when necessary.	Asked about sleep pattern. Used Epworth Sleepiness Scale as a screening tool and asked consultant to refer for sleep study when necessary.	Asked about sleep pattern.
Visual check	Basic screen for homonymous hemianopia and scanning problems.	Basic screen for homonymous hemianopia and scanning problems.	Did not screen.
Mood	Informal questions with occasional use of Hospital Anxiety and Depression Scale.	Screened for depression and anxiety (respectively) with the Patient Health Questionnaire 9 and Generalised Anxiety Disorder Assessment 7.	Meant to use Warwick-Edinburgh Mental Well-being scale but preferred informal approach and used her judgement.

All respondents were asked about their mood and while mood screens were used, nearly all reviewers had reservations about them, preferred to use their clinical skills and only used a mood screen if indicated:

> *My experience is such that I can tell whether a patient is clinically depressed or low in mood and requires a referral to the neuropsychologist. I feel that if I am going to refer to the neuropsych. then it is not necessary to keep doing assessments when she will be doing her own. I like to go with the informal approach so that the patient is comfortable and opens up to me* (CS1, SNS1)

Site 2 always used a mood screen and the SNS thought it was useful to have a score that GPs would understand but this was not necessarily so:

> *There are so many different scores and so many people use different scores actually I'm much more interested in someone telling me that they think someone's low* (CS1, GP1)

Most reviewers agreed that it was more important to develop rapport than complete a standardised tool, especially if it was a one-off visit where there would be no comparator:

> *We're supposed to do all that [mood screen] on our first visit, which I must admit I don't actually do. I like to build-up a little of a relationship with the client first before I start bombarding them with questionnaires* (CS3, SA1)

The SA co-ordinator was aware that the mood screen, alongside other forms, could make the interaction impersonal which was contrary to her approach:

> *I would like to reduce other information we have to collect at the same time because… it makes it impersonal, it makes it not client focused… it needs to be… about meeting the needs of the client not about collecting loads of data… if you were asking me the question I wouldn't be collecting SSNAP data and I wouldn't be filling out 'how you're feeling' forms and I wouldn't be collecting information about their… ethnic group or religion or their sexual orientation, I didn't really think that is really relevant and I'm sure they don't* (CS3, SA3)

Respondents were mixed in their views: some did not mind completing the screen, others stated that they preferred the reviewer to use her skills and a few were outspoken in their criticism of a mood screen, in this case the Warwick-Edinburgh Mental Well-being Scale (appendix 24):

> *That's a silly question… I don't understand that question, that's ridiculous… what a load of cobblers* (CS3, R46, M, 67yrs)

Thus reviewers had to observe whether patients seemed anxious, depressed, sad or withdrawn. They used their own judgement and probed further if observation, or the assessment, suggested depression.

5.3.3: Enablers and barriers

The main enablers to carrying out timely 6MRs were manageable caseloads, administrative support, integrated databases and good working relationships with other professionals and services (Table 26). Where SNSs carried out reviews they valued good communication with community therapists and SA workers but this was variable. There were instances where reviewers did not liaise, or were slow to do so. For example, respondent 16 had input from several services but the SA worker, neuropsychologist, therapist and SNS took considerable time to co-ordinate their input. Similarly, respondent 2 had several services involved and it was difficult for the reviewer to untangle who was doing what. Communication with therapists was also mixed:

> *Not loads actually, we're trying to involve [SNS] in the stroke MDM [multi-disciplinary meeting] but I think because of the caseload she's got and because we work in the community we don't actually physically see each other very often but I do always catch her or email her if I've got particular problems* (CS1, PT1)

One SNS had a good relationship with the stroke consultant, monthly meetings and informal contact. He respected her opinion and acted on her recommendations but this was not always the case and sometimes both the SNS and consultant reviewed a patient at six weeks which appeared unnecessary duplication:

> *This is the worst feeling because there's no respect of each other's professional position, and it does make you feel really demoralised at times. And also they [doctors] don't have time to listen… I did e-mail [consultant's] secretary and they haven't come back to me, as usual, nothing surprising at all* (CS1, SNS 4)

In addition, some SNSs found specific consultants reluctant to discuss patients and this was potentially detrimental to their care and demeaning for the SNS:

> *With [consultant]… you are there with the patient's notes that you want to discuss, you wait, wait, wait, wait, wait, and at the end they say, "Oh, I'm busy today. I can't give you any time."* (CS1, SNS4).

The other key barrier was identifying needs but not having services to refer onto, or knowing that there were long waiting lists, particularly for exercise classes and neuropsychology. It was also difficult to track if referrals had been followed through and sometimes reviewers had to assume this had happened:

> *Sometimes I do refer them to the healthy weight management… or exercise… but even that one there's a long waiting list… all these services are not highly integrated, so we have got a lot of work to do and…*

> *I'm the [community trust] and then hospital team is different trust, and within our service as well there are so many departments… which we don't integrate as much as we should* (CS1, SNS4)

This barrier highlighted the dissonance between guidelines and reality and the implications for patient-led services:

> *[Stroke consultant] who presumably is absolutely aware of the lack of resources and the fact that no matter how well-meaning we all are… resource led. We're still recruitment led… But we're producing guidelines that are unachievable… I would be utterly amazed if anywhere in the UK it ran that smoothly, you know? That everyone was able to provide everything to all people. It just doesn't happen* (CS2, M4)

Finally, respondents' own outlook and response to the stroke and rehabilitation acted as an enabler for some and a barrier for others which is discussed in section 5.4.

Table 26: Summary of enablers and barriers

	Barriers	Enablers
Referral process	• Missing contact details so unable to telephone to confirm appointments (site 3). • Not all eligible patients referred, especially those in outlying hospitals.	• Formal process of capturing when patients were discharged and checking for miscoded diagnosis. SNS1 had a monthly coding meeting with the stroke consultant.
Communication and integration between NHS Trusts and services	• Lack of integration and communication resulted in extra work for example, chasing referrals. Social services 'completely separate' (SNS1). • SNSs did not have any protocols between their service and the acute Trust so felt they were relying on the 'goodwill' of consultants to instigate their requests (SNS4).	• Efficient inter-professional working, especially between consultants, SNSs, therapists and SA workers, aided referrals and follow-up. • Lack of written protocol allows professional autonomy (SNS4).
Integrated databases	• SA co-ordinator had limited access. • Where databases were incompatible SNSs had to fax or post reports.	• Data sharing agreements whereby SNSs could access GP and inpatient database; able to review patient records prior to appointment.
Onward referrals	• Difficult to track if referrals were actioned and if identified need was met.	• Easier to track for NHS referrals when SNS had database access.
Format	• Time limits on 6MR sometimes made them feel rushed; this was stressful for the reviewer. • Clinics needed suitable space; some respondents had difficulty getting to the clinic. • Home visits time consuming, especially in rural areas.	• SA allocated 60-90 minutes per visit which made them feel relaxed and patient-led. • Similarly, home visits felt more relaxed and patient-led than clinics.

	- 6MR was a 'snapshot' so it was difficult to make decisions based on what a patient said in this single interaction (SA3). - At times it was difficult to elicit what was a stroke related problem or a pre-existing one (SA3).	
Caseload	- Managing caseload especially where reviewer had another role (SNS2) and/or empty posts leading to backlog of reviews (SNS3). - Difficult to find the time to ensure referrals were activated. - Administration was time consuming: arranging appointments, writing report, referrals, telephone calls and entering SSNAP data. Insufficient or no administrative support curtailed time spent with patients (SNS3).	- SA co-ordinator carried out one or two reviews per day and was able to write reports and make referrals straight away.
Follow on services	- Lack of services to refer onto, particularly exercise classes and neuropsychology.	

5.3.3.1: Care homes

Although it was not possible to recruit patients discharged to care homes because they lacked capacity and/or it felt unethical given the enormity of their situation, it was possible to discuss the issues with reviewers. Although the data is limited, it has been included because this client group are so often excluded from research despite their vulnerability and distinctive needs. All reviewers wanted these patients to be represented in the research.

Care homes had their own set of barriers (Table 27) and were regarded by all reviewers as challenging due to staff attitudes and expectations, the nature of the review and the likelihood that patients were unable to communicate their needs. Residential homes' reluctance to pay for specialist equipment, poor handling techniques and keeping residents in bed for long periods meant therapy gains were often lost and patients deteriorated quickly. In addition, rather than focusing on the stroke, SNSs sometimes found themselves addressing basic nursing care issues, particularly pressure care, continence and falls. SNSs also expressed concern that there was little they could do if a resident hinted that they were unhappy in the home but would not explicitly state this:

> *You can suspect when you talk to them that everything's not quite right but when you ask them they wouldn't really say they're unhappy, they'll give you a hint* (SNS4)

Table 27: Summary of barriers for 6MRs in care homes

Barrier
Homes are reluctant to pay for specialised equipment.
Patients often have dementia and/or communication difficulties so reviewers are reliant on staff and/or relatives for information.
It is difficult for patients to express dissatisfaction with the home or for reviewers to address their concerns.
It is difficult to sustain any recommended changes due to the nature of a one-off visit, high staff turnover and their lack of stroke training.
There is a mismatch of expectations between staff, relatives and reviewers.
Mobility tends to deteriorate as staff are untrained and do not have therapy support. This could lead to other problems such as pressure sores or contractures.
Over time changes in need for positioning, seating and splinting are not addressed.

The SA co-ordinator found it distressing for residents, and herself, because those with dementia did not understand the purpose of the review and were unable to answer the questions. She had discussed this with her manager and decided to only review those who could express their needs. She concentrated on finding activities that they would enjoy either within or outside the care home, reflecting her social orientation. This was the only tangible benefit identified.

5.4: Respondents' experience of the 6MR

This section focuses on patient and carer perspectives on the purpose, timing and perceived benefits of the review. Observations about its merits are differentiated into the three categories of response presented in the previous chapter (section 4.5). The six-week and annual review are briefly mentioned where relevant.

5.4.1: Remembering the review

Most respondents remembered their 6MR but a few did not, as it appeared to have been forgotten amongst a multitude of other appointments and concerns. For example, respondent 36's wife was focused on continence issues and could not remember the SNS's visit, while respondent 9 could not remember his 6MR which had coincided with his nephew visiting to do the shopping:

> *I can't remember it's just been the most amazingly busy, busy week* (CS1, C36)
>
> *He [R9] was distracted by doing the shopping list and she [C9] didn't participate in anything* (CS1, SNS1)

Others did remember the visit but had forgotten much of what had been discussed. Two couples were interviewed within two days of their 6MR and although they appreciated the visit they had forgotten the content and recommendations:

> *I can't remember much about her, we've had so many people coming* (CS1, R42, M, 73yrs)

The six-week review, where available, was particularly unmemorable and appeared to merge into a background of appointments whilst settling back home. Only three respondents remembered it and did not find it beneficial because of its truncated nature, advice that was regarded as unhelpful and a perception that it was a tick-box exercise:

> *It wasn't very long, the appointment. It seems to me she [SNS] gave me a review thing to tick all these boxes… I told her about the things that I was concerned about, like the inaccuracy of the thing [discharge form] and also my incapacity-- I couldn't feel heat in my right side… but she didn't seem to be concerned about that and she was more interested in giving me this letter [an evaluation form]* (CS2, R10, M, 55yrs)

Moreover, the inpatient SNS could only allocate twenty minutes per patient and acknowledged that this was often too short and narrowed her remit to deal with medication, blood pressure and test results:

> *She [SNS] literally just went over what the GP has gone over, you know, checking his blood pressure and stuff like that, it was nothing new. We didn't gain anything out of it* (CS2, C23)

So while some respondents struggled to remember the review, most had definite views on its relevance and value, which are discussed next.

5.4.2: Response to the 6MR

Respondents' perception of the review was influenced by factors other than how well their concerns were addressed during it. These included their experiences of the care pathway preceding the 6MR, their attitude towards rehabilitation and their relationship with clinicians, as delineated in the three respondent types (section 4.5). In addition, where respondents were unclear about the 6MR's purpose and/or had different priorities to the reviewer they tended to be less satisfied. Some respondents received a medically orientated review where a more socially orientated one might have been more helpful, and vice versa.

5.4.2.1: Respondent type 1: 6MR as a source of reassurance, information and advice

This group was proactive in their approach to rehabilitation and self-management. They had no major complaints about their inpatient experiences and had a positive view of clinicians which was consistent with their favourable assessment of the 6MR. They valued the expertise of reviewers and were reassured by the process:

> *I feel happy that people are still concerned. It makes you feel that you're not forgotten about* (CS1, R10, M, 55yrs)

Many respondents commented favourably on the comprehensive nature of the 6MR and the extensive knowledge of the reviewer whose advice they trusted. This was often coupled with comments (but not complaints) about inpatient staff and GPs being rushed:

> *I don't think GPs have the time or probably the expertise… The fact that she's [SNS] working with people who've had strokes almost exclusively, and she allows time. I mean 45 minutes is much more valuable than 10 minutes with the GP* (CS2, R19, M, 63yrs)

In addition to concerns about stroke, respondents discussed wider issues such as their social circumstances, co-morbidities and resuming valued roles and activities. They appreciated that the review was long enough to allow detailed discussion and address specific concerns. Most valued was information, advice and explanation tailored to their needs compared to the generic leaflets previously provided:

> *Seeing [SNS2] was wonderful because we learnt so much from her, more than when he was in hospital… we're ever so grateful to have met her, she was wonderful* (CS2, C8, M, 31yrs)

Reassurance was important and related to feeling comfortable with the reviewer, listened to and not rushed:

> *I could express my concerns to her. And she was very good at listening to them and trying… I wouldn't say being totally reassuring, but she was certainly good at listening to them and providing possible solutions* (CS2, R40, F, 76yrs)

There was a personal connection between some respondents and the reviewer which appeared to relate to therapeutic use of self, particularly one of the SNSs who had a very 'warm' personality. It was this rapport that was remembered more strongly than the content of the review. Having someone to talk to who understood their condition was important:

> *I find her easy to talk to, she listens to the answers and she, yeah, kind of works on them, I just find her a nice easy person to talk to* (CS1, R18, F, 87yrs)

For those in site 2 who had already met the SNS in her ESD role, respondents appreciated the consistency, especially those who lived alone:

> *She saw me right at the beginning and I just feel very confident after I've seen her* (CS2, R4, F, 85yrs)

The key difference between SNS reviews and those of the SA co-ordinator was that the former included a medication review and SNSs were able to adjust medications and liaise directly with the GP or consultant. Although many respondents had a basic understanding of what they were taking and why, they still found further explanation helpful even if they did not always heed the advice:

> *The best thing for me was her knowledge on the drugs that I'm taking. She told me more about the drugs than I've been told by the doctor or anybody else… it was reassuring… although I still take the Anadin… and… the brufen… when you get in real pain, as I do, you take anything* (CS1, R37, M, 77yrs)

Sometimes it was around demonstrating that they were being listened to rather than instructed. For example, the SNS wanted one respondent to increase his statins but he was reluctant to do so because of what he had read about side-effects. The SNS addressed his concerns and by the end of the review he agreed with her recommendation.

5.4.2.2: Respondent type 2: 6MR of limited benefit

This group were also proactive but their approach was at odds with that of reviewers and they tended to drive their own rehabilitation. They were more likely to question the reviewer's advice and less likely to concur, instead preferring their own personal knowledge and understanding which superseded professional advice. For example, respondent 25 was diagnosed with epilepsy by the stroke consultant but the neurologist disagreed. There was considerable confusion over his diagnosis and medication, which took the SNS substantial time to disentangle. After the 6MR the couple were angry and dissatisfied because they were still unclear whether or not he had epilepsy. However, following their one-year review they better understood and accepted the SNS's explanations and that the seizures precluded him from driving:

> *She was very good. She explained all his, you know what problems he's having, and all his medications, there was a big mix up about that* (CS1, C25)

The SNS commented that in hospital explanations may be limited or the patient may not be able to absorb the information, whereas she had time to explain:

> *All of a sudden he was being told and started on this medication [Keppra] and they didn't even know if he needed it… I explained to them the risk he is at having seizure activity… I reassured him that since he's been on this combination of anti-epilepsy [meds] he's not been having the symptoms so his seizure activity is well controlled* (CS1, SNS4)

Respondent 43 still wanted medication advice after her review with the SA co-ordinator and a more medically orientated review may have been helpful. She had ongoing balance problems that did not appear to have been properly investigated and she questioned whether it could be a side-effect of medication. The SA co-ordinator was unable to address this and advised the respondent to go back to her GP:

> *No-one's told me and that's the bit that's annoyed me all the way through, nobody's told me a whole thing about the medication I'm taking except for those, I couldn't tell you what I've got* (R43, F, 80yrs)

There were instances where respondents found the review of limited benefit because it duplicated the involvement of consultants or GPs. Respondents had specific queries and questioned the advice they were given. For example, respondent 35 was encouraged by the SNS to write a list of questions for the GP who she was seeing later the same day but they were issues the patient had already identified:

> *There isn't anything on this list which I wouldn't have discussed with the doctor anyway* (CS1, R35, F, 72yrs)

Whereas the SA co-ordinator would carry out two visits per day, the SNSs saw up to seven patients per day which meant that reviews were occasionally rushed. Consequently, respondents felt unable to ask questions at the end or were unclear about follow-up:

> *Because we've had our discussion, she's doing her summing up and the summing up has to be a sort of compressed summing up to get it into the time. I was very aware that the clock had run out* (CS1, R39, M, 73yrs)

Most trusted the SNS which was linked with a sense of reassurance, but in this group respondents were more likely to question the reviewer's expertise, especially if advice was inconsistent with that of their GP. For example, respondent 28 did not find the six-month or annual review helpful and questioned the SNS's role:

> *I don't know is she a nurse? Is she a consultant? Is she-- you know, when she said something about some pills I shouldn't be having, I thought, well that's really… my doctor's responsibility… … I just dismissed that [advice] and thought well maybe I'll see-- when I see the doctor I will ask her about it* (CS1, R28, F, 66yrs)

Others carefully evaluated different professional's advice, selecting what they found helpful or convincing. Respondent 27 noted that no expert was 'infallible' and they often disagreed with each other. He had seen several specialists, including a diabetes nurse whom he trusted and this influenced his view of the SNS:

> *GPs are what they are: general practitioner. And a lot of people think that however obscure the disease they've got they go to the doctor and he should know all about it, but he doesn't. He's the general practitioner. He can give you advice or to some extent, but I considered her [SNS] to be a bit of a specialist in what she was doing* (CS1, R27, M, 88yrs)

5.4.2.3: Respondent type 3: 6MR is considered irrelevant or unhelpful

These respondents perceived their inpatient care as poor and tended to distrust professional advice. They criticised rehabilitation and were regarded as 'difficult' by therapists. Wider concerns about their social circumstances and co-morbidities took priority and respondents did not feel the 6MR adequately addressed these issues. Thus advice that may have been useful tended to be disregarded because it did not fit with their priorities, or the distrust instilled during their inpatient stay carried over into the review. They may have found a Stroke Association review more beneficial given that it is an independent organisation. Two respondents declined review because they distrusted staff and while one only trusted her stroke consultant the other distrusted all professionals:

> *I'd rather go off their books, I haven't been treated very well by them… I finally decided that there's no point in my going to see them anymore, I'm getting on alright on my own, I've been on my own from day one really and I'd rather stay that way* (CS1, R32, M, 68yrs)

The rest of this group attended the review but did not find it helpful. A notable example where reassurance was absent and clinical reasoning went awry was when the reviewer started by asking the respondent to complete a mood screen without fully explaining the purpose of the review or the screen. Despite the respondent's obvious hostility, she persisted in reading out the questionnaire. She later asked him about exercise when she had already seen how difficult it was for him to walk into the room (using a mobility aid) and this further alienated him. He found the 6MR pointless and his wife found it depressing. However, this was in the context of ongoing impairment that he was struggling to accept. He was articulate, motivated and desperate to improve his mobility but had been discharged by therapists because he had evidently plateaued. The 6MR emphasised his ongoing disability without providing any useful outcomes and the couple felt worse afterwards:

> *I thought it was awful… if you weren't depressed when you went in, after all of that lot, my gosh* (CS2, C31)

Part of the problem was time limitation because the SNS did not want to run late for the next review and stated that she found it stressful when reviews overran. She was only allowed to allocate forty-five minutes per review which was insufficient for some patients, especially those with communication impairments.

Two respondents (site 1, respondent 2 and 16) illustrated a particular disparity of agenda with the SNS, similar to differences in priorities that they described with therapists. Neither appeared entirely sure who the SNS was and were unable to differentiate her from other professionals involved in their care. Both had several long-term conditions and while one actively resisted advice the other passively ignored it and neither appeared interested in self-management. Respondent 16 was being helped by a SA support worker who went to great lengths to link him with other services. Both were examples where a social orientation to review appeared better suited to their needs at that time, despite medical concerns.

Some respondents chose to disregard the advice they were given during the 6MR. For example, respondent 42 agreed to join an exercise class during his review but the next day, when I visited, made it clear he had no intention of doing so. He had not been physically active pre-stroke and had no incentive to change. As attending an exercise class had been the main focus of the review, this led to an unsatisfactory outcome for his wife while he appeared unperturbed.

Respondent 9, regarded as lacking insight, complained that therapists were risk averse. He was highly motivated but that related to his role caring for his wife. He did not remember any outcomes from the review because it had coincided with a visit from his nephew who did the weekly shop. He may have benefited from the SNS's advice but he had a different agenda and a distrust of clinicians and this dissonance rendered the review ineffectual.

Respondent 17 had significant long-term disability and her husband was struggling to look after her. She had other long-term conditions and falls subsequent to the stroke. Although they did not complain about the 6MR it clearly did not meet their needs because they approached the SNS soon afterwards asking for further support. Unfortunately, this was not available and the SA worker would not become involved because they were out of area.

Finally, a few respondents who did not find the reviews helpful were articulate, motivated and had recovered well. Respondent 28 suggested that the review might be more helpful for those who had more severe disability:

> *Really and truthfully if you put the whole thing together it was a little bit of a waste of time… I think if I'd suffered a lot more and still suffering quite badly… then it could be very useful… … they're governed by their rules, so you know unfortunately we all have to along with it* (CS1, R28, F, 66yrs)

In summary, the three types of response reflected different outlooks, needs and experiences which influenced respondents' perspective of the review. The next section considers the wider context, or how the review is positioned within the experience of illness and recovery.

5.5: Positioning the 6MR in long-term adaptation to stroke

This section considers the outcomes of the 6MR, intended and otherwise, and what it contributed to long-term recovery. Overall there was little evidence that the 6MR played a key role in recovery, rather that it was one event along the care pathway, often unexpected, that provided reassurance and supplemented information and advice that had already been received. For a few respondents, the 6MR identified significant medical need, was a marker of progress or a prompt to adjust their lifestyle. Site 3 timed the review to coincide with the 'hotspot' of therapy services withdrawing which helped embed the process into the care pathway but elsewhere more arbitrary timing added to the sense that it was a stand-alone event.

5.5.1: Outcomes: what unmet needs were identified and how were they met?

The literature review considered locally defined outcomes for the 6MR (Table 8, section 2.7.2) which reflected national policy but were more specific and arguably more aspirational. Table 28 compares the intended outcomes with what was substantiated from the data. Lack of supportive data may reflect factors other than lack of effect, for example, some outcomes lent themselves to a quantitative approach such as readmission rates. Where there was evidence that the 6MR achieved outcomes it was often only for Type 1 respondents who were more resourceful and proactive. While access to information was valued and could contribute *indirectly* to improvements in daily life, it cannot be assumed that access to information leads to accessing the service or meeting the need.

Table 28: What evidence supported locally defined outcomes for the 6MR?

Patient outcomes (Hargroves, French and Trickey 2014, p21)	**Any evidence from the data?**
Greater involvement in identifying and planning to address their ongoing needs.	Minimal evidence, and only for Type 1s, who were already pro-active in addressing their ongoing needs.
Access to a wide range of information about NHS, voluntary, community and social services that will contribute to achieving stroke related goals.	The SA co-ordinator (site 3) provided comprehensive information about local services; the SNSs provided limited information (particularly in site 1) and/or advised the patient to contact the SA.
Feeling supported and more confident.	Limited evidence, mainly type 1s.
Will be less likely to be readmitted to hospital.	No evidence but SNSs did identify medical concerns requiring follow-up (and urgently, in a few instances).
Will be less likely to have another stroke.	As above.
Improved health and general well-being.	No evidence but indirectly may have contributed to some improvement (Type 1s).
Reduced GP appointments.	No evidence.
Reduced dependency.	No evidence.
Carer outcomes (Hargroves, French and Trickey 2014, p21)	
Support carers improved health and general well-being.	No evidence but indirectly may have contributed to some improvement for carers of Type 1s.
Reduced GP appointments.	No evidence.
Carers have back-up plans in place.	No evidence.
Community outcomes (Hargroves, French and Trickey 2014, p21)	
Reduced readmissions.	As above, no direct evidence but SNSs did identify medical concerns that needed follow-up.
Reduced dependency on social services.	No evidence.
Improved health and well-being.	No direct evidence but signposting to sources of support could have indirectly improved well-being.

What could be substantiated were tangible outcomes such as referrals that were observed during 6MRs and are summarised in Table 29.

Table 29: Outcomes from reviews that were observed

Referrals/follow-up with stroke consultant or GP	**SNS**	**SA**
Ask GP to: • Amend the type and/or dosage of medications including anti-hypertensives, anti-coagulants, statins, analgesia, steroids. • Prescribe alternative medications due to side effects or drug interactions; prescribe folic acid for 3 months • Carry out regular blood tests and/or check for specific indicators e.g. cholesterol, kidney and liver function, vitamin D, vitamin B12, C-Reactive protein, homocysteine, prostate-specific antigen. • Monitor blood pressure • Initiate or chase referrals (see below)	✓	✗
Ask stroke consultant to: • Review patient e.g. complications, medication, Botox for spasticity • Initiate or chase referrals (see below)	✓	✗
Ask GP or stroke consultant to refer patient for: • Sleep study (sleep apnoea) • ECGs (although SNS can arrange for home ECG)	✓	✗
Refer patient to:		
Therapists: physiotherapy, occupational therapy, speech therapy and dietician	✓	✓
Neuropsychology	✓	✗
Continence team	✓	✗
Falls team *(SA provided information on how to self-refer)*	✓	✗
Pain management	✓	✗
Driving assessment	✓	✗
‘Life after stroke’ group (*site 2 only*)	✓	**N/A**

Voluntary organisation to assist with Attendance Allowance application	✗	✓
Mental Health and well-being organisation	✗	✓
Advice, information, signposting:		
How to complete medical details for driving license re-application	✓	✗
Support groups for patient and carer	✓	✓
Exercise classes (*sites 2 and 3 only*)	✓	✓
Information on pendant alarm	✓	✓
Where to purchase kitchen aids and bath equipment	✗	✓
General advice, reassurance and/or leaflets e.g. fatigue	✓	✓
Suggests visiting optician for eye test (*site 2 only*)	✓	✗
Suggests carer gets carer assessment from social services	✗	✓
Suggests carer registers with their service (*site 2 only*)	✓	N/A
Suggests carer does ‘message in a bottle’ (*site 2 only*)	✓	✗
Health promotion and secondary prevention (lifestyle factors):		
General healthy eating e.g. eating fish and nuts (*site 2 only*)	✓	✓
Recommends dietary supplements e.g. coconut oil, omega 3, cod liver oil supplements (*site 2 only*)	✓	✗
Recommends reduces alcohol and tobacco	✓	✓
Managing constipation and increasing fluid intake (*mostly site 2*)	✓	✗
Take carer’s and patient’s blood pressure and advise both to monitor	✓	✓
Increase exercise levels	✓	✓

With SNSs, outcomes focused on follow-up investigations, adjusting medication and liaising with GPs or consultants to action recommendations. These clinician-led actions did not vary between respondent types. SNSs looked for medical issues that might have been overlooked, for example undiagnosed atrial fibrillation, and followed up as necessary:

> *It is fairly typical that when I see [consultant] I have several heart monitors for him to order and I generally would ask the GP to prescribe the right meds, but I back it up with a letter from [consultant] also. The junior doctors complete the EDNs [electronic discharge notifications] and order the investigations and sometimes there are oversights. Not every patient is seen in clinic and this is why I look for these things* (CS1, SNS1)

The SNS was rectifying oversights that should already have been addressed, so whether this equated with unidentified need, as defined by policy (Royal College of Physicians 2016a), is arguable. Similarly, when patients highlighted delays in follow-up appointments SNSs were able to chase directly although most delays were due to administrative errors. Guidelines (Royal College of Physicians 2016a) already stipulate that patients should have a named contact and asking the contact to follow-up would appear more efficient than waiting for review.

SNSs referred primarily to services within the NHS, such as neuropsychology, while the SA co-ordinator referred to other non-statutory organisations. Most respondents (type 1) were grateful but some either initially acquiesced and later refused or dismissed the suggested referral straight away (type 2-3).

The SNS's advice and information was largely related to aetiology, treatment, prognosis and secondary prevention. Many patients (type 1) valued this while others were more questioning, or rejected the advice. However, the SNS was often consolidating information that had already been provided but at a time when respondents found it hard to absorb. This appeared more a reflection on inpatient and community services' approach to the provision of information.

Some patients had recovered and did not identify any needs but reviewers thought it would be too difficult to detect them in advance and risked overlooking those who might benefit from review. One SNS had considered screening but decided against this:

> *We kind of thought that we would do a first telephone contact because our caseload was so big, instead of seeing them… but then what we found out is that even when you do a telephone consultation at the end of-- after talking half an hour, you have to say, "I think I have to see you."* (CS1, SNS4)

The outcome was reassurance (predominantly for type 1 respondents) that investigations had been completed and that all was being done to prevent another stroke. Those seen by the SA co-ordinator also felt reassured but were unaware of the tailored medical advice that they did not have the opportunity to receive.

Reviews in site 3 were not tailored to the individual in terms of medical issues but instead focused on signposting respondents to community facilities and SA groups of which the co-ordinator had excellent knowledge. This signposting, alongside provision of the generic SA information pack (the same one as provided in hospital) and supplementary leaflets, was the cornerstone of reviews.

The SNSs also signposted respondents to other services, often the Stroke Association, but this was less prominent and related more to follow-up appointments:

> *I'm a sign-poster. I make sure patients get the right service through referring them to the right people. Sometimes patients are discharged home without any therapy referral, and then I'll see them and I'll think that they should have had therapy and I'll refer them* (CS1, SNS1)

Although referring or signposting to other services was common, reviewers did not have any mechanism to check the outcome. If time allowed, they would follow-up and the SA co-ordinator had more leeway to do so but this was not always possible.

All reviewers were interested in health promotion as a means to secondary prevention and this was considered both a purpose and outcome. The SNSs focused more on secondary prevention through medication while the SA co-ordinator concentrated on lifestyle factors. Both aimed to encourage self-management. Many respondents were aware of general health promotion messages related to eating, exercise, alcohol and smoking so the outcome was that the review endorsed what they already knew:

> *Neither of us have ever smoked and we drink only very much in moderation and that was just our lifestyle, wasn't it, and we've always… exercised a lot* (CS1, C14)

A few respondents wanted to change their behaviour but lacked motivation and the 6MR prompted them to do so. For example, respondent 37 had been drinking too much alcohol and the SNS advised him to reduce his intake which he did between the six-month and annual review. His wife had dementia:

> *I've known for a long that I was drinking too much and I was using it as a crutch because of the worry about my wife* (CS1, R37, M, 77yrs)

Many respondents (excepting type 3) were already effectively self-managing their condition, for example, monitoring their blood pressure and regulating their diet. In terms of outcomes, the review did not add to this beyond reassurance. One SNS was keen to include tips such as drinking more water and eating nuts and oily fish. She wanted couples to jointly self-manage and occasionally took the carer's blood pressure. SNSs were realistic about how much they could achieve in a session and acknowledged limitations:

> *They all tell me they're on a healthy diet but I don't believe it… they'll be overweight or… they're diabetic and they've got chocolate on the side… I can't force… I can leave them a leaflet… you sort of get to know whether they're interested or they're not* (CS1, SNS1)

The SA co-ordinator had more time to discuss lifestyle factors. For example, she had a glass to demonstrate alcohol units which was an effective visual reinforcement which respondents liked. She took a common sense approach and stayed within her remit:

> *I say everything in moderation…olive oil rather than animal fat…the other key thing is fruit and veg…I don't think they can ever say fruit & veg are bad for you!* (CS3, SA3 to R42, M, 73yrs)

One commissioner questioned what a single review could achieve and suggested that self-management needed to be supplemented, for example with an online intervention, because this aspect was not sufficiently embedded into the review:

> *It kind of is and it isn't… asking people questions about their diet, their exercise habits, their drinking habits, smoking habits… having conversations with people around those things… is supporting someone's self-management, but that… is only a brief intervention. So I think that you would need longer-term support and perhaps quite specific coaching* (CS1, M5)

In terms of needs being identified but not met, exercise was a common problem. Although reviewers provided information on classes (rarely in site 1) there were gaps in services and difficulty with access. For some respondents, particularly with severe impairment, there was nothing suitable:

> *The big problem I've got with my condition is lack of exercise and keeping my weight under control is a struggle. I would prefer to be losing weight and to take the load off my legs and especially my arms and shoulders, but all I'm doing at the moment is maintaining the status quo* (CS2, R3, M, 76yrs)

Many respondents had been discharged from community rehabilitation but wanted further therapy. As previously discussed, therapists could only offer ongoing intervention if there were identifiable goals but this did not coincide with what respondents wanted, so further therapy remained an unmet need from their perspective. Other therapy needs that would have benefited from review included positioning, seating, muscle tone and splinting.

Reviewers did not ask patients about current or previous (therapy) goals and it could have provided some sense of continuity had they done so. None of the reviewers felt this was within their remit and raised concerns about inappropriate referrals even though they could have discussed with therapists before agreeing to re-refer:

> *Sometimes there are those patients who I think 'would you benefit from physio again? … I don't want to overload the already limited service with people I do wonder sometimes am I a little bit over cautious* (CS2, SNS5)

This compared with one manager, previously a therapist, who regarded reviewing goals as an intrinsic part of the process:

> *For me, it would be revisiting all the goals that you originally had and hopes and desires to see if any of those have come to fruition; to see if they haven't why they haven't, and to see if there's any point at which… re-referral back into any of the rehab systems would be of benefit* (CS2, M4)

All respondents were concerned about residual deficits. Of note were those with unresolved vestibular and visuo-perceptual disorders that did not appear to have been adequately addressed prior to review. Despite acknowledging these symptoms, respondents were not routinely referred to appropriate specialists. The one orthoptist interviewed (as a result of this finding) stated that the GM-SAT did not adequately consider visual problems. Older patients were likely to have other orthoptic problems, such as glaucoma or macular degeneration, which needed to be differentiated from stroke-related visual impairment. Although stroke units are meant to have formal links with eye care services not all do and from her experience patients often missed out on referral to orthoptics. Some respondents accepted that there was no treatment and tried to accommodate impairments, while others pursued alternatives such as clinical trials.

Finally, return to work was a key concern for younger respondents and those who did resume employment managed it through their own endeavours. Rehabilitation should have addressed return to work but services had largely withdrawn before respondents were ready to work. Similarly the timing and focus of the 6MR did not suit their needs.

5.5.2: Unintended outcomes

An unintended outcome suggested by one manager (CS2, M4), but difficult to substantiate, was that the review might encourage dependency. There were respondents who took the offer of a yearly review, even though they stated that the 6MR was unhelpful and/or they were managing well. One respondent (CS2, R40) had additional appointments with the SNS that appeared superfluous but she appreciated the ease of access and length of appointment compared to her GP. SNSs had to decide between what they might like to offer and what their remit allowed. They acknowledged that some issues were not stroke-related and they ought to encourage patients to self-manage:

> *I've got a patient that's due a knee operation and he needs to lose weight… I say to him well you need to do this, that, and the other, and I've got a monthly appointment with him. So I can be motivational*

> *for certain patients if they benefit from it. And other patients I might refer to the dietician and leave it with them* (CS1, SNS1)

> *If somebody has wanted to see me again at like a year… and then 'cos very occasionally I've said that I will see patients at like two years… but I'm in my head as well thinking about this patient needs to be self-managing don't they?* (CS2, SNS5)

Some respondents were confused by inconsistent advice between clinicians, including their GP, and whose advice they adhered to appeared to relate to trust which is explored in the discussion.

5.5.3: Outcome measures

Outcome measures required by SSNAP are the proportion of eligible patients who receive their 6MR and their Modified Rankin Scale (Royal College of Physicians 2015a). Beyond that there was no consensus on what could be measured or how. It was difficult to capture onward referrals and their possible outcomes plus the terminology caused confusion:

> *Is it an unmet need at the point at which the review happens and then therefore it's an identified unmet need and then they refer somebody on somewhere or is it an unmet need because there's nowhere to refer them onto? There's quite a question mark around that. I think it's a bit of a mixture of the two but they don't define them differently* (CS3, M2)

> *If it is identified that someone needs neuropsychology…how am I going to know that you have actually achieved that outcome? Or have you just passed it to the GP and you've almost said, well, we've dealt with our bit, it's now over to the GP to manage* (CS1, M5)

The Modified Rankin Scale scores from zero (no symptoms at all) to six (dead) which leaves five categories in-between to differentiate mild to severe disability (Banks and Marotta 2007); the GM-SAT requires reviewers to record the score which is later entered into the SSNAP database. The SA co-ordinator found the categories unclear and pointed out that such categorisation was of no benefit to patients. All therapists and most clinicians agreed that it lacked sensitivity to subtle improvements that might be functionally significant. They also questioned its inter-rater reliability:

> *The criteria for each category of disability is not very specific… you can categorise people into certain things and think, well, they're a bit in that and a bit in that one, so which one do we really put them in? And you probably always go for the worst because, if they improve, it shows it is a better recovery… it is probably not sensitive enough to demonstrate a real improvement* (CS1, M5)

> *It is a crude tool… you can have two people doing the Modified Rankin Scale who might both come out with slightly different scores* (CS2, SNS6)

Site 3 commissioners had selected a patient activation measure (Roberts et al. 2016) as an outcome measure to implement across all Stroke Association services. However, the rationale appeared to lack clarity within the context of interventions often being short-lived and limited to the provision of information and signposting:

> *It’s being pushed really hard by NHS England … it just means that when they are having a six-month review if they knew they are working with someone with really low activation levels it would give them a more informed basis to know that if they gave that person some signposting information they are highly likely not to act on it* (CS3, M2)

Although reviewers disagreed as to whether the review was a complex intervention or simply an assessment, this distinction does impact on the review’s ability to adhere to particular outcomes, for example, self-management strategies are developed over time. When I asked respondents what they had learnt or changed as a result of the review, comments were limited and much had been forgotten. When reviewers were able to consolidate advice in subsequent sessions the outcome was more substantial:

> *I did have a lady that I was visiting… she was asking me about salt and things so we did take it further, we were in her kitchen looking at what she was eating and looking at the quantities of salt in things, for instance I remember her hot chocolate had an incredible amount of salt in that we didn’t, neither of us realised* (CS3, SA3)

Other outcome measures included verbal feedback and patient satisfaction surveys but they lacked rigour and as one manager candidly highlighted:

> *You could say well most people really like sitting down in a room and talking about themselves for an hour… whether that proves anything… we looked at how many onward referrals… but it was very difficult to know* (CS2, M4)

SNSs regarded secondary prevention as essential but also wanted to achieve outcomes outside their medical remit. The SNS in site 2 who also worked within the ESD team regarded the personal interaction as an essential element of the interaction, as did one of the SA workers:

> *They feel they are being listened to and I take their concerns into consideration and I act on it* (CS2, SNS2)

> *Nothing can really capture the personal interactions you have with people and the results of those* (CS1, SA2)

No one was able to evidence cost-effectiveness yet only one manager, previously a therapist with extensive experience of carrying out 6MRs, questioned whether the outcomes were worth the input:

> *It's trying to put gold leaf on a rusty old toilet seat… it's great in theory, but it's hard to achieve in practice, and really are the outcomes worth it? I'm not convinced in any way that they are* (CS2, M4)

One SA manager stated that co-ordinators could detect atrial fibrillation and that this might avoid further strokes but acknowledged this as a 'leap of faith outcome' (SA5). From observation, it was only SNSs who could correctly identify atrial fibrillation but GPs appreciated this:

> *A lot of things like AF [atrial fibrillation] tend to be picked up incidentally… but you're never gonna pick it up unless you feel someone's pulse and they arrhythmia at that point in time or you get a random ECG… so if someone's got more time to do it then it's useful* (CS1, GP2)

As previously discussed (section 5.1.1), the review could be reframed as 'an early detection system' that provided the opportunity to prevent problems escalating, although considering the six-month interval this appears debateable. However, there was the potential to be cost-effective:

> *If something is detected, then you've got a chance then to intervene…you only have to do that for ten twelve people before you can justify the costs of it but you can't pin it down* (CS3, CCG1)

The respondent on the Inter-Collegiate Stroke Working Party argued that guidelines represented the gold standard and should not be influenced by workforce constraints. Whilst acknowledging that outcomes were difficult to prove, this still did not address the issue of cost-effectiveness or lack of evidence:

> *Good practice recommendations do not have to be based on current service or workforce issues. It is reasonable that if other problems were picked up at these reviews and escalation of these problems could be avoided, we would 'save' further down the line… lack of benefit may not be shown because research hasn't been done… So no evidence doesn't mean not working. And cost-effectiveness is very difficult to show given the different budgets involved* (M6)

Although there was an aspiration that reviews contributed to improved quality of life, nobody volunteered continuity of care or community integration as a direct outcome. This was related to the nature of the review as a 'check-up… but it's not a continuation of anything' (M4). Only one respondent alluded to community integration but this was based on the assumption that clinicians had time to build a relationship and monitor progress over time:

> *Through their review and understanding of their family dynamic, where they live, how accessible support is for them… for me they're all the critical things that would contribute to people keeping well and independent… making sure they're well socialised* (CS1, CCG3)

In summary, this section has considered the outcomes of the 6MR, intended and otherwise. The provision of information and signposting to other community services were the main outcomes of

Stroke Association reviews while SNSs were able to refer to and/or liaise directly with consultants, GPs and other statutory services. All reviewers addressed secondary prevention in some form, whether medical and/or lifestyle factors but the outcomes were intangible given that provision of information and advice does not necessarily translate into behavioural change and the causal mechanisms are complex.

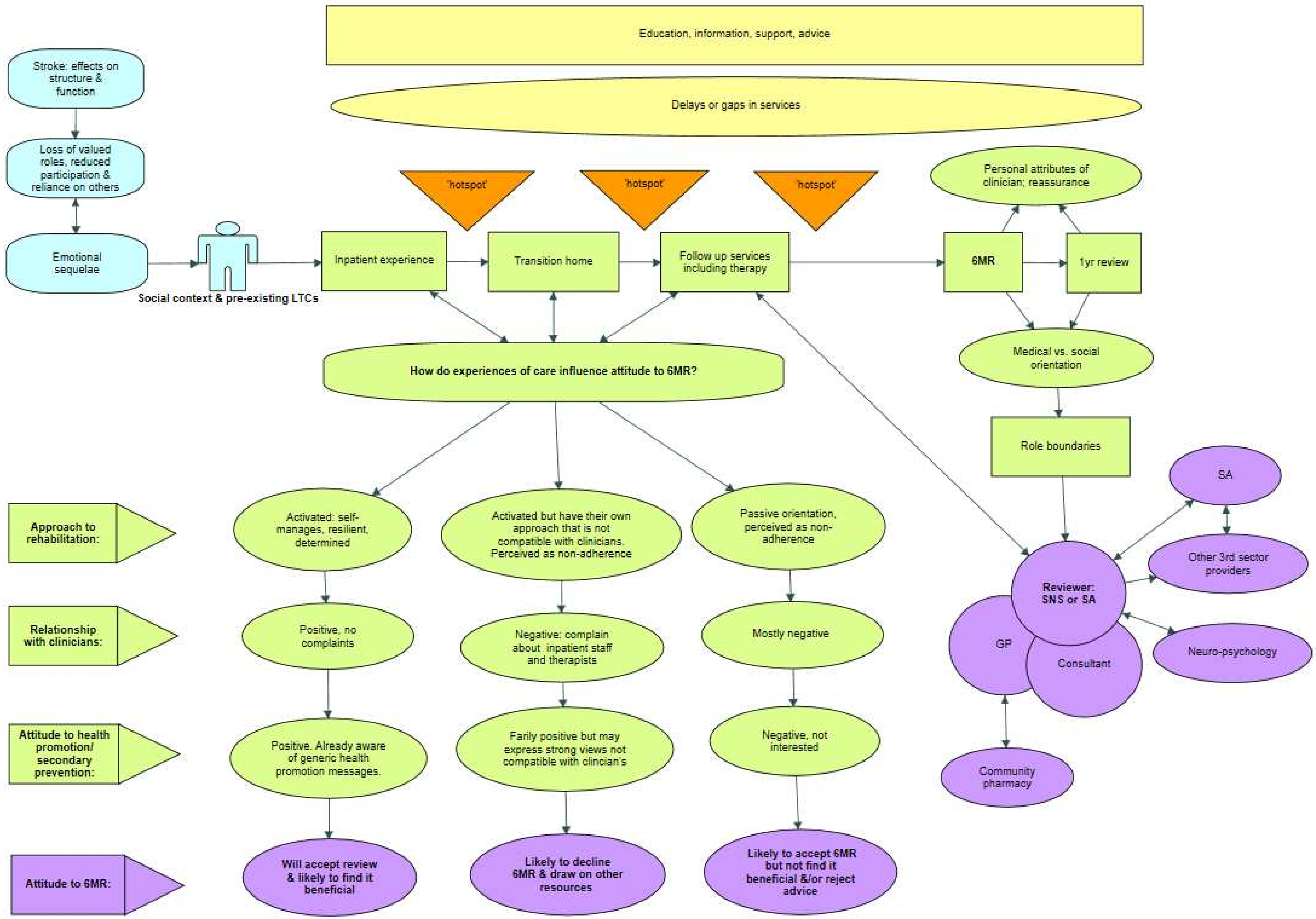
The next section considers the above outcomes alongside respondents' perspective of the review, their experiences along the care pathway and contextual factors that influenced their response.

5.6: The 6MR: stand-alone event or integral to the care pathway?

This section draws together the findings of this and the preceding chapter by presenting a logic model and applying it to three case studies that exemplify how respondents experienced the 6MR as part of the stroke care pathway.

The Stroke Association's social model focused on information, support, social participation and generic lifestyle advice. However, the SA co-ordinator could not match the SNSs' in-depth knowledge or tailor advice in the way that patients and carers found so helpful. However, medically orientated reviews did not suit some respondents who may have preferred a Stroke Association review. Respondents had a different perspective and Figure 17 presents a model demonstrating how their response was influenced by experiences from the stroke up to the 6MR. The exemplars which follow are used to illuminate Figure 17.

Figure 17: The journey from stroke to 6MR



5.6.1: Exemplar: Respondent type 1, pro-active and self-managing, 'Ivy' (CS2, R4)

Ivy, a pseudonym, (Figure 18) was a widow in her mid-80s who lived with her dog in a maisonette. She had lived in the area most of her life. Her son visited fortnightly and took her shopping but she had limited contact with her two daughters (one had mental health problems and the other lived overseas). The maisonette was clean and tidy although she complained that it was difficult to vacuum. She was eager to talk and humorous but this was mixed with great sadness related to various life events culminating in the stroke. She spoke of Dignitas but was very clear that she had no intention of ending her life because she had experienced suicide within her family. Ivy was very stoical but felt isolated because she could not drive or manage the bus and therefore could not visit friends who were also housebound.

Ivy was in hospital for nearly two weeks. She praised the staff and enjoyed the company. After discharge she had a visit from the SNS (in her ESD role) but there were long delays in follow-up therapy for the stroke and bilateral carpel tunnel syndrome. She had several wasted trips to outpatient appointments to find that they had been cancelled or that necessary reports were unavailable. Ivy was proactive and devised an exercise programme. She set and achieved her own goals which were using the bath, accessing the garden and walking the dog.

Ivy attended the 'life after stroke' group and remembered some of the dietary advice, illustrating her positive approach to secondary prevention and self-management:

> *I like them [Benecol], so I'll take them while I'm liking them, I try to be good but I'm 86 soon, so…I'm trying to get my weight down because I've never been as heavy as I am now, I don't know if it's because I have ready meals*.

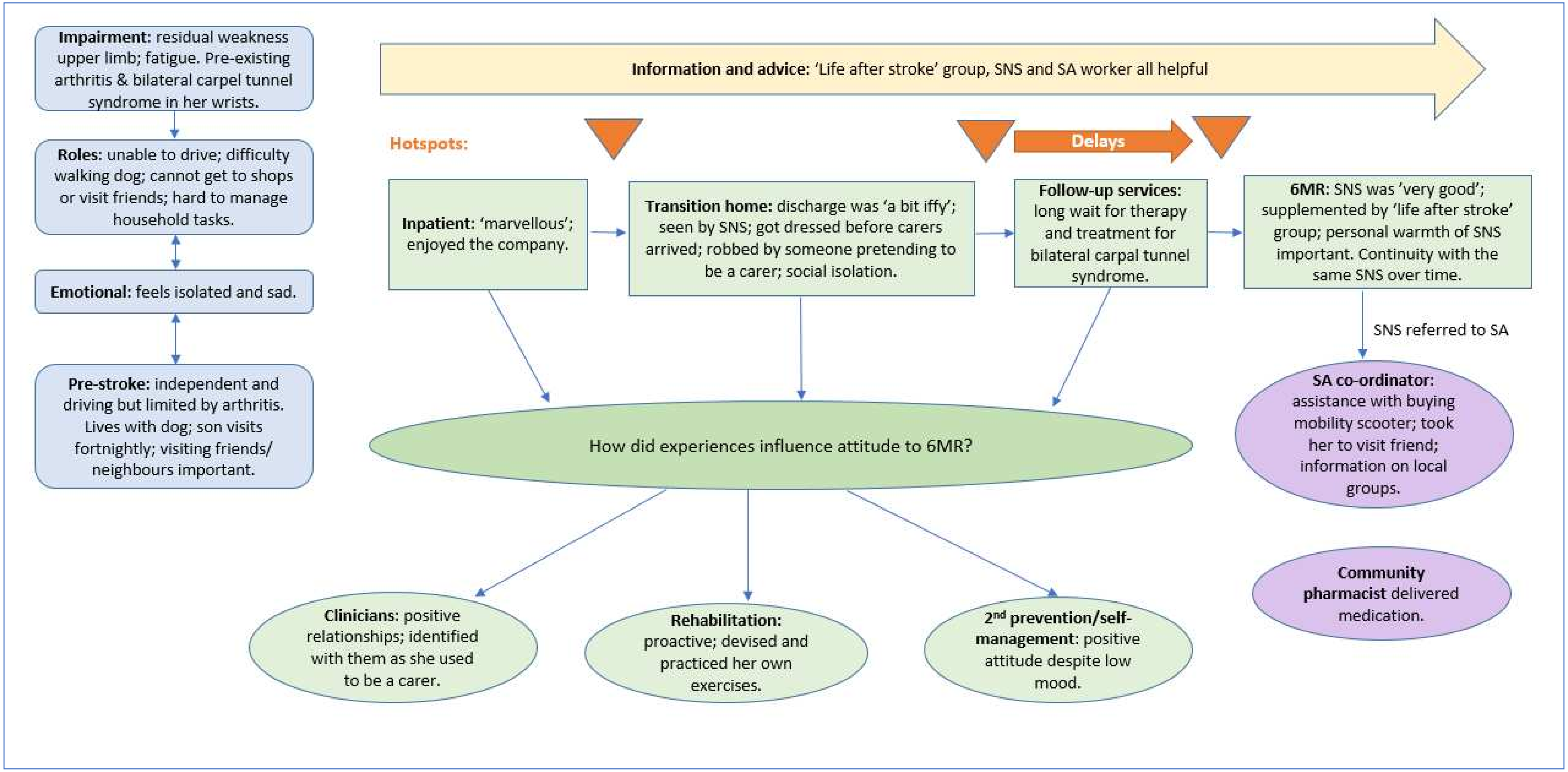
She enjoyed the social aspect of the group and valued seeing the same SNS who was particularly warm and empathetic:

> *You sort of cling onto somebody because you feel good with them, she made me feel good when she came here when I came home from hospital*.

Ivy really appreciated the opportunity to see the same SNS at her 6MR and the reassurance she gained from it. There were some practical outcomes such as checking a cut on her leg:

> *She gives me confidence…she was good about my legs…they're both healed up and I bought a big tub of E45 like she said and I've been rubbing it in*.

Figure 18: Exemplar - respondent type 1, pro-active and self-managing, Ivy (CS2, R4)



Impairment: residual weakness upper limb; fatigue. Pre-existing arthritis & bilateral carpel tunnel syndrome in her wrists.

Roles: unable to drive; difficulty walking dog; cannot get to shops or visit friends; hard to manage household tasks.

Emotional: feels isolated and sad.

Pre-stroke: independent and driving but limited by arthritis. Lives with dog; son visits fortnightly; visiting friends/ neighbours important.

Information and advice: 'Life after stroke' group, SNS and SA worker all helpful

Hotspots:

Delays

Inpatient: 'marvellous'; enjoyed the company.

Transition home: discharge was 'a bit iffy'; seen by SNS; got dressed before carers arrived; robbed by someone pretending to be a carer; social isolation.

Follow-up services: long wait for therapy and treatment for bilateral carpal tunnel syndrome.

6MR: SNS was 'very good'; supplemented by 'life after stroke' group; personal warmth of SNS important. Continuity with the same SNS over time.

SNS referred to SA

SA co-ordinator: assistance with buying mobility scooter; took her to visit friend; information on local groups.

How did experiences influence attitude to 6MR?

Clinicians: positive relationships; identified with them as she used to be a carer.

Rehabilitation: proactive; devised and practiced her own exercises.

2nd prevention/self-management: positive attitude despite low mood.

Community pharmacist delivered medication.

The SA worker attended one of the sessions and later visited Ivy at home which proved invaluable. She helped Ivy purchase a mobility scooter, took her to visit a friend and provided information about support groups, Dial-a-ride and a Blue Badge application.

5.6.2: Exemplar: Respondent type 2, pro-active and self-managing on their own terms, 'Darcy' (CS1, R33)

Darcy (Figure 19) was in her mid-fifties and lived in a flat on her own. Her career as a dancer had ended early due to diabetes and renal impairment but she had retrained and was self-employed prior to the stroke. She experienced a series of strokes and several inpatient admissions, one lasting several months. She found her inpatient experiences profoundly depressing and perceived the care as inadequate citing medication errors, rude staff, insufficient therapy, excess noise and lack of consultation:

> *Having had such good care ten years ago… I've watched the lack of resources, the meals, the broken equipment, the changes of staff, the agency staff, the poor nursing staff in night time… Skeleton staff at weekends, feeling unsafe at weekends because there's no doctors on duty… I'm not out to bash the NHS, not at all, they saved my life umpteen times*.

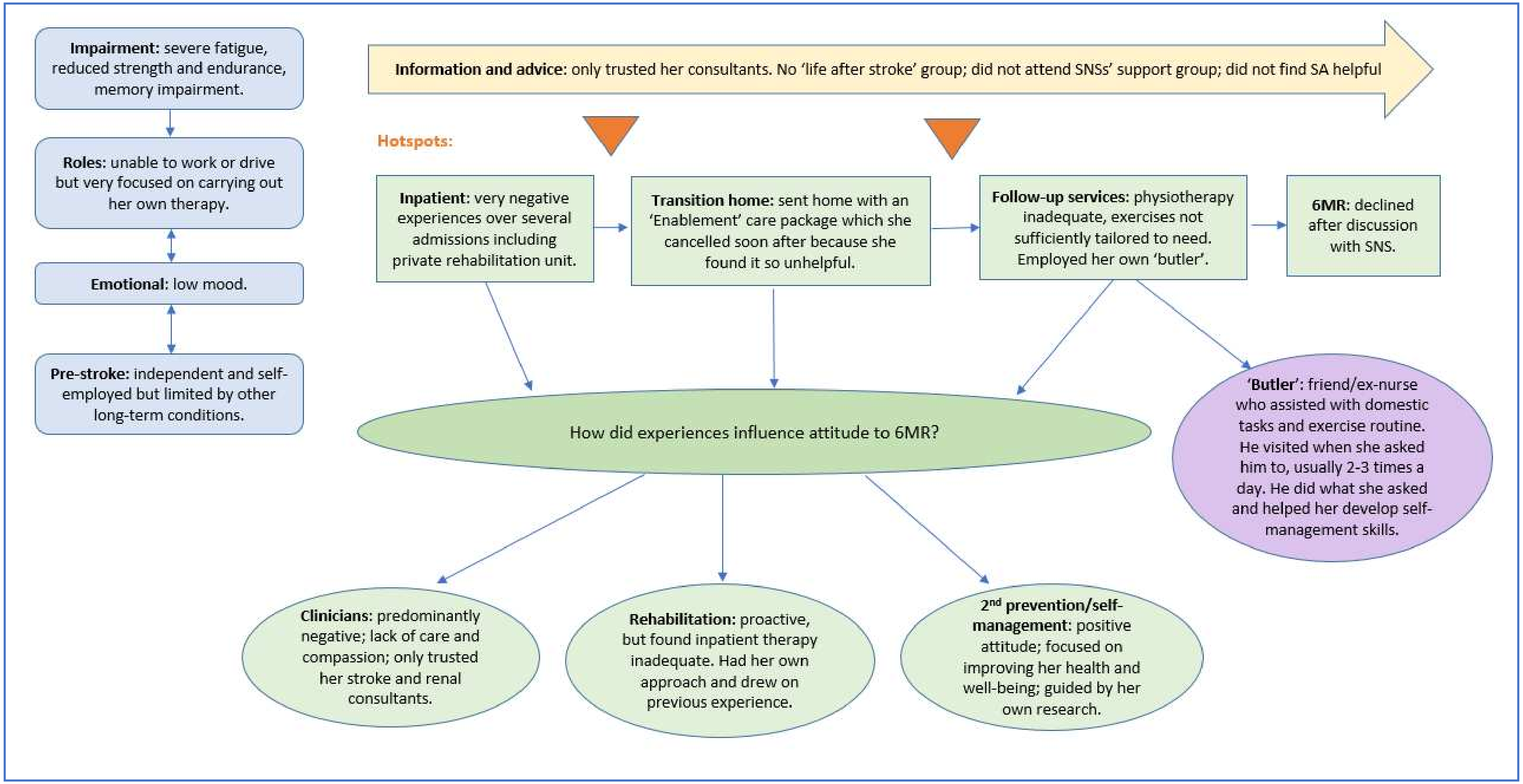
Darcy went home after the latest admission with an 'Enablement' care package but the short visits and limited remit of carers was unhelpful:

> *They're so restricted, "Could you do this?" "I'm not allowed to." "Could you open this cream for me?" "I can't if it hasn't got a prescription label…" "Can you open the window?" "It might hurt my back." They couldn't do anything… they had a 15-minute slot; they spent 10 minutes doing paperwork… I stopped it because I was getting so depressed*.

She appeared to be regarded as a 'difficult' patient. Instead of relying on statutory services she took charge of her own recovery and employed a friend who was an ex-nurse to assist her plan a daily routine that incorporated exercise, domestic tasks, social activities and rest. He helped her manage fatigue and gradually increase her activity levels in a way that was far more flexible than social services could provide. She was unclear what occupational therapists were meant to do, even though what she described was entirely within their remit. The relationship with her carer was on equal terms and they regarded it as a joint venture:

> *We approached it in our own kind of way… you once said "Am I your carer?" You said that [could be] very diminishing… the idea came to me one morning, "Maybe I could be your butler?!"* (Carer)

Figure 19: Exemplar – respondent type 2, pro-active on their own terms, Darcy (CS1, R33)



Darcy did not think a 6MR would be helpful and only trusted the advice of her consultants. The SNS stated that they had discussed the merits of her involvement but because she was seeing the stroke consultant regularly and had such complex needs it was unnecessary and preferable to avoid duplication. Darcy did not find the SA information pack useful and had no further contact with them.

5.6.3: Exemplar: Respondent type 3, passive orientation, 'Dave' (CS1, R16)

Dave was in his early 60s, divorced and estranged from his children (Figure 20). He missed his work in the buildings trade but had to retire early due to respiratory (and other) long-term conditions. Prior to the stroke he was living in a shared rental house, had a dog and spent most of his time in the pub. He referred to his drinking acquaintances as friends but his one close friend/carer thought that they only wanted free alcohol. Dave rapidly spent his personal independence payment and then had no money left for the rest of the month. His friend was critical of professionals and the system:

> *He's got no idea. He gets his money on Thursday and spends it. He needs someone going in to do the finances with him, shopping…he's had so many people, they all listen but don't do anything. You can't give him a lump sum…. that's why he's got no telly, broadband, landline and his mobile is pay as you go and when he runs out of money no one can get hold of him*.

Dave had a second stroke in hospital and it was more than three months before he was discharged to a warden-controlled flat that he hated and called a prison. His view of inpatient treatment was mixed, for example, he enjoyed the banter with staff but had nothing in common with his physiotherapist and found the night time noise unbearable. He did not appear to engage in inpatient or community therapy. His sole concern was leaving the warden-controlled flat and drinking with his friends.

Dave's SA worker was heavily involved, drove him to several appointments and introduced him to another voluntary agency to help with housing. She assumed the role of an occupational therapist in that she addressed leisure activities, memory strategies, managing his mail, meal preparation and accessing transport. She had qualified as a speech and language therapist and this professional underpinning came through in her approach. However, his ability to engage was limited by memory impairment, heavy drinking and a volatile mood. The SA worker saw her role as whatever was necessary and unlike the SA co-ordinator in site 3 was not restricted by the 6MR's parameters:

> *There isn't really a normal about it in this job, I don't really feel that I'm a case co-ordinator, no. I suppose to a certain extent maybe, but certainly I don't want what I'm doing to be done in isolation… I need to keep other people informed… But there isn't really anybody else, there's [neuropsychologist], and I've referred him again to her*.

Dave missed several appointments hence the SA worker drove him to his 6MR (the third attempt). He liked the SNS but rejected her advice and was very clear that he had no intention of changing the lifestyle factors that he enjoyed even though he knew the risks:

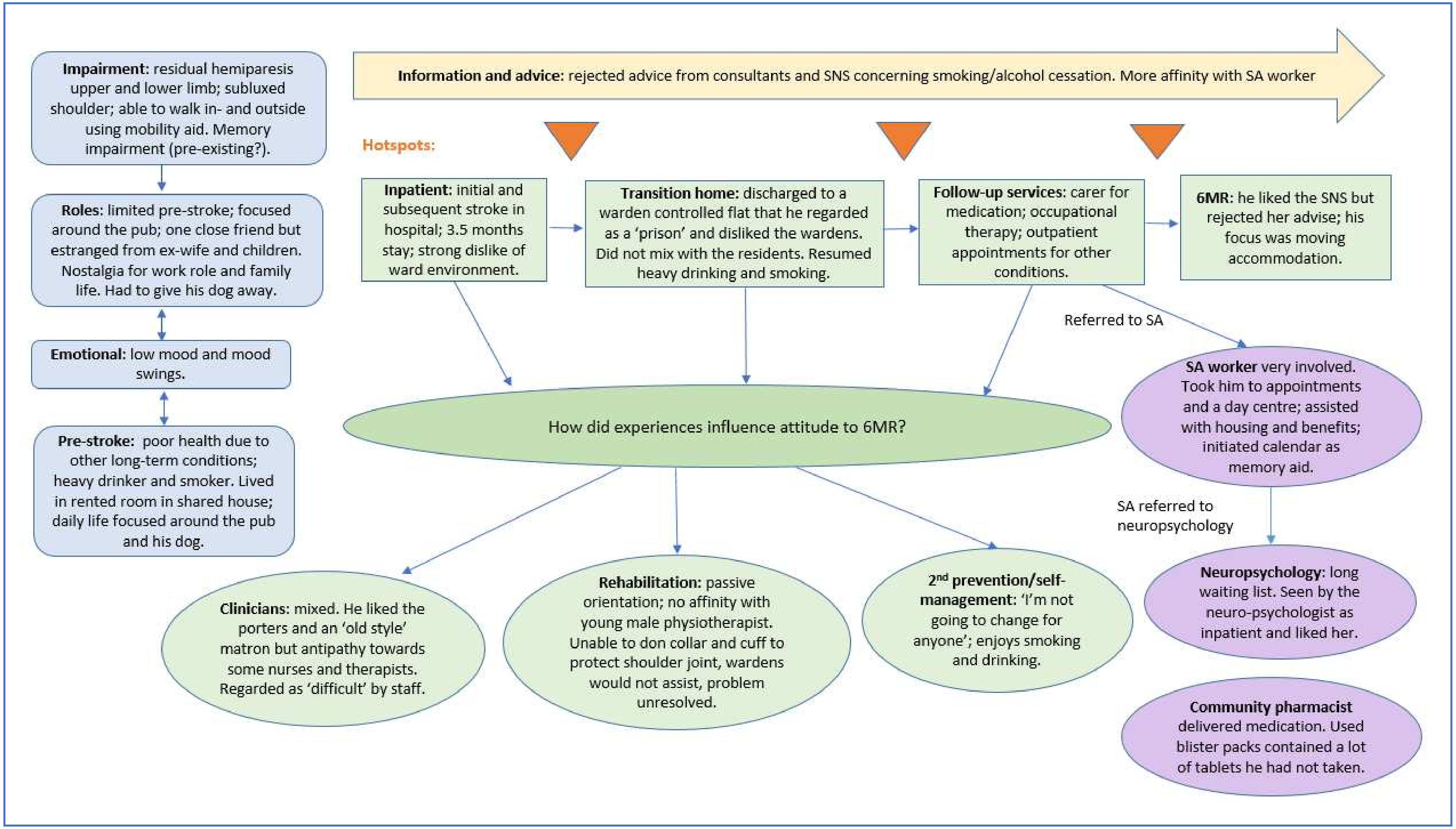
> Dave: *I enjoy smoking*
> SNS4: *Are you fully aware of the health implications?*
> Dave: *To be honest I don't care*

The reasons appeared mixed: he had used alcohol all his adult life as a coping strategy; he enjoyed smoking and drinking; and he would not change his lifestyle to suit professionals. But this could have been bravado overlaying an awareness of how difficult it would be to change his behaviour given his low mood, social isolation, cognitive impairment and lack of incentive. His focus was on moving accommodation which was at odds with the SNS's medical focus and this dissonance dominated the 6MR. She understood his concerns but felt that he should still address his behaviour. Instead, 'non-compliance' was exposing him to a potentially worse situation:

> *If he was sensible it's not the end of the world for him, he's doing well, he could still have a good quality of life… … he's at risk of much more devastating outcomes so he could be worse off than what he is now… … It is very sad but I feel frustrated but on the other side when I see other worse affected people than him I cannot control myself… the vascular surgeon has clearly written he's strongly advised him to stop smoking… but he's not following that at all. And we talked about alcohol and he clearly said he's not interested in that [stopping]… he's not taking on board anything so what you can do? I suppose as health professionals sometimes we have to draw the line what we can do. I will see him again, but whether he's going to turn up! … He did agree to have the sleep study but I don't know whether he'd accept the appointment and even if he goes and has the apnoea I doubt he'd ever become compliant with the treatment* (SNS4)

Thus he was regarded as difficult by therapists and ignored the advice of consultants and the SNS. His care post-discharge did not appear to meet his needs and he struggled to follow the SA worker's suggestions because of his cognitive impairment. Co-ordination between professionals appeared limited and reactive. Although Dave was focused on moving accommodation, his carer thought this would be counter-productive given the incentive was to be near his favourite pubs.

Figure 20: Exemplar - respondent type 3, passive orientation, Dave (CS1, R16)



Impairment: residual hemiparesis upper and lower limb; subluxed shoulder; able to walk in- and outside using mobility aid. Memory impairment (pre-existing?).

Roles: limited pre-stroke; focused around the pub; one close friend but estranged from ex-wife and children. Nostalgia for work role and family life. Had to give his dog away.

Emotional: low mood and mood swings.

Pre-stroke: poor health due to other long-term conditions; heavy drinker and smoker. Lived in rented room in shared house; daily life focused around the pub and his dog.

Information and advice: rejected advice from consultants and SNS concerning smoking/alcohol cessation. More affinity with SA worker

Hotspots:

Inpatient: initial and subsequent stroke in hospital; 3.5 months stay; strong dislike of ward environment.

Transition home: discharged to a warden controlled flat that he regarded as a 'prison' and disliked the wardens. Did not mix with the residents. Resumed heavy drinking and smoking.

Follow-up services: carer for medication; occupational therapy; outpatient appointments for other conditions.

6MR: he liked the SNS but rejected her advise; his focus was moving accommodation.

Referred to SA

SA worker very involved. Took him to appointments and a day centre; assisted with housing and benefits; initiated calendar as memory aid.

How did experiences influence attitude to 6MR?

SA referred to neuropsychology

Neuropsychology: long waiting list. Seen by the neuro-psychologist as inpatient and liked her.

Clinicians: mixed. He liked the porters and an 'old style' matron but antipathy towards some nurses and therapists. Regarded as 'difficult' by staff.

Rehabilitation: passive orientation; no affinity with young male physiotherapist. Unable to don collar and cuff to protect shoulder joint, wardens would not assist, problem unresolved.

2nd prevention/self-management: 'I'm not going to change for anyone'; enjoys smoking and drinking.

Community pharmacist delivered medication. Used blister packs contained a lot of tablets he had not taken.

5.7: Chapter summary

This chapter started by exploring the purpose of the review process. Opinions on this ranged from tangible goals, commonly the identification of unmet needs and signposting to other services, to nebulous aspirations, such as improved quality of life. Purpose and outcomes overlapped but few commissioners questioned the 6MR's overall value. The SNSs regarded it as an opportunity to review medical needs, encourage self-management and promote secondary prevention while the SA co-ordinator was more focused on social aspects. Many patients were unsure of the purpose. There was no definitive view on the chronological timing of 6MRs but patients and the SA co-ordinator thought it should coincide with when rehabilitation services withdrew. This helped embed the review into the care pathway rather than it feeling like a stand-alone event. Commissioners and reviewers queried the feasibility of ongoing yearly reviews.

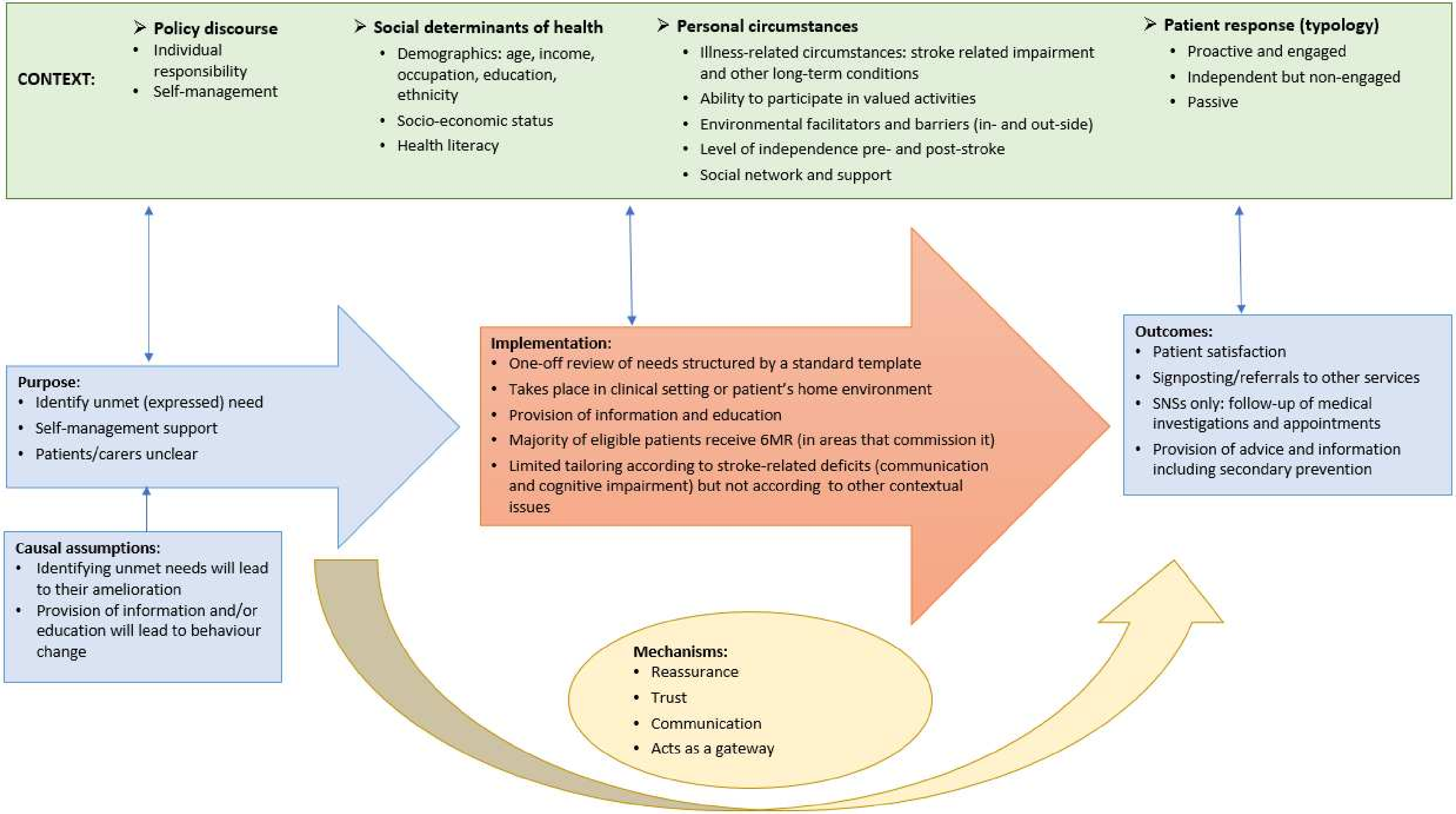
There were many similarities in the format of 6MRs. Reassurance was a key component for patients and carers: they had time to ask questions and received detailed explanations at a stage in their recovery when they were able to absorb and process the information. The SNSs were able to tailor advice and information concerning medical issues while the SA co-ordinator's guidance was more generic, reflecting their different roles. Barriers to carrying out timely reviews included problems ensuring all eligible patients were referred, large caseloads, communication with other clinicians and availability of services to refer onto.

Patients' perceptions of the review were influenced by their experiences of the care pathway and their attitude to rehabilitation. The largest group, who had a positive outlook and were highly motivated, found the 6MR helpful and appreciated suggestions to better manage their condition. A second group were also motivated but their approach to rehabilitation was often at odds with that of therapists. They questioned the advice they were given, reflecting variable levels of trust, and found the review of limited benefit. The third and smallest group took a passive approach to recovery, did not engage with the review process and did not consider it helpful. They all had pre-existing long-term conditions and complex social circumstances.

Outcomes were varied but commonly involved provision of information and signposting to other services. SNSs focused on medical issues and were able to refer for tests, liaise with consultants and follow-up any outstanding investigations. They took a more medical approach to secondary prevention while the SA co-ordinator focused on lifestyle factors that related to her focus on participating in valued activities. While all reviewers had to complete the Modified Rankin Scale, none thought this was a reliable, sensitive or useful outcome measure.

Figure 21 presents a model of the review's components, underlying mechanisms and contextual factors that were drawn from the findings and inform the discussion. The Medical Research Council's guidance on process evaluation of complex interventions (Moore et al. 2015) was used to develop the model. The level of complexity of an intervention can be judged by the number of interacting components, the difficulty of behaviours expected of patient and clinicians, the number and type of outcomes and the degree of tailoring permitted (Craig et al. 2008). An intervention may be considered simple if there is a linear pathway from intervention to outcome but this is rarely the case. In fact, no intervention is inherently 'simple' or 'complex', rather the degree of complexity reflects the researcher's perspective and the questions that need answering (Petticrew 2011). Thus the 6MR, while in some respects is 'simply' an assessment of unmet need, actually fulfils the criteria of a complex intervention and does not constitute a linear pathway as guidance (Hargroves, French and Trickey 2014; Royal College of Physicians 2016a) appears to imply. The next chapter elaborates on these issues, in particular what underlying mechanisms might explain why the review appeared to have limited impact and how this might be addressed.

Figure 21: Context, mechanisms, purpose and outcomes of the 6MR



Chapter 6: Discussion

6.1: Introduction

The aim of the research questions was to clarify the purpose of the 6MR, intended (and unintended) outcomes, and the mechanisms involved. The main findings were that patients and carers were unclear about the purpose of the review but found it a useful space to ask questions and discuss their concerns; the two sets of reviewers had somewhat different purposes, with SNSs maintaining a medical focus and SA co-ordinators focused on signposting to community services (section 5.1). Both sets of reviewers regarded self-management as relevant and were prompted to ask about lifestyle factors by the template they used. The SNSs again tended to focus on medical management and the SA co-ordinator on lifestyle factors. Outcomes could be divided into tangible actions such as referrals and specific requests for GPs/Consultants; advice, information and signposting; and secondary prevention.

Reviewers and managers found it difficult to differentiate purposes from outcomes and could not pinpoint how they might be achieved, perhaps unsurprising given the review's lack of evidence base or theoretical underpinning. Commissioners held wider ranging views from global aspirations of improved quality of life to concrete goals including a check-up and provision of information.

Figure 21 (section 5.7) presented a model of the review's components, underlying mechanisms and contextual factors that were drawn from the findings and inform the discussion. The chapter is divided into three main sections. The first section discusses the policy rhetoric surrounding the 6MR; the second addresses why the 6MR appeared to have so little impact and situates this within the recovery process, or 'illness trajectory' (Corbin and Strauss 1985, p225); and the third considers wider issues that influenced the 6MR. The chapter finishes with a conceptual framework of the 6MR informed by minimally disruptive medicine and burden of treatment theory (May, Montori and Mair 2009).

The chapter also explores tensions between realism, with special reference to critical realism, and postmodern constructivist ideas of which Foucault (Foucault and Faubion 1994) can be regarded as the pioneer. Foucault's ideas about discourse and power resonated with the findings of this study, particularly the context of the review process that is embedded in current political discourse around individual responsibility and self-management.

6.2: Paradigmatic tensions informing the discussion

Postmodernism is at times conflated with constructivism, but while the connection is valid there are different versions of social constructivism which are quite separate. Postmodernism emphasises a version of radical constructivism which problematises any idea of an objective reality, or any approach to describe it. Moreover, throughout much of its development, sociology has marginalised the body which has been an 'absent presence' in ongoing debates (Shilling 2012, p22). Foucault's notion of biopower for managing populations acknowledges the biological, albeit at the population level of managing illness (McHoul 1995). Conversely, radical postmodernism and disability theorists' attempts to deny the reality of impairment stems from conflating ontology with epistemology. This reduces the biological body to what is *known* about it and divests it of its 'ontological depth', or generative structures and causal mechanisms (Williams 1999, p806-7). By denying the physical reality of pain and suffering extreme constructivism does a disservice to those with chronic illness. For those who have had a stroke, embodiment is a key concern and needs to be considered alongside the subjective experience of illness.

So while all postmodernists are constructivists, not all constructivists are postmodernists (Pilgrim 2000). Constructivism, particularly extreme social constructivism, has traditionally been regarded as incompatible with realism, because of its ontological stance but more recent literature draws parallels between the two approaches (Pilgrim 2000; Elder-Vass 2012; Al-Amoudi 2007). Al-Amoudi suggests that a critical realist reading of Foucault would avoid some of the 'pitfalls' attributed to his work such as 'constructivism, determinism, localism, and reductionism' (Al-Amoudi 2007, p543). Crucially, a critical realist approach acknowledges the interaction between body, self and society allowing us to (Williams 1999, p812):

> *i) bring the biological body, impaired or otherwise, 'back-in'; ii) relate the individual to society in a challenging, non-conflationary or 'uni-directional' way, and iii) rethink questions of identity, difference and the ethics of care through a commitment to real bodies and real selves, real lives and real worlds.*

Relating this to the ICF (World Health Organization 2002) it is apparent that disability is neither the sole product of social oppression nor personal tragedy and both models are overstated. Rather disability is an emergent property of the interaction between 'body and society', a dynamic process that unfolds over time, both historical and biographical (Williams 1999, p813).

Al-Amoudi (2007) suggests that in fact Foucault worked with an (implicit) ontology that shared key characteristics with critical realism because it assumed a relational notion of society and viewed structures as able to both enable and constrain agency. Foucault's ontology appears to be stratified because it differentiated between biological, individual and social dimensions albeit using different terminology. Rather than referring to structure and agency he referred to *the political* or *strategies* (processes located at the level of social relations not necessarily attributed to specific people) and *tactics* (processes initiated by people). This distinction implies a stratified and differentiated social reality in which the mechanisms governing strategies (relative to social relations) are not the same as those governing tactics (relative to people). Therefore, any social relation between individuals involves power relations and all power relations suppose a social relation (Al-Amoudi 2007).

Distinguishing between disability and impairment de-medicalises disability but simultaneously leaves the disabled body in the exclusive jurisdiction of medical hermeneutics. However, acknowledging the interactions between individual and social location of disability should move policymakers away from a narrow medicalised viewpoint (Bury 2005).

6.3: Policy rhetoric: an ideology of individual responsibility

A plethora of government policies exhort the concepts of empowerment, self-management and the expert patient who collaborates with health professionals and works towards securing their own 'health and wellbeing' (NHS England 2016, p50). This grew from when New Labour came to power in 1997 and claimed that its policies formed a 'third way' between the paternalistic state of Old Labour and the market forces and privatisation of the Conservatives (Baggott and Jones 2015). At the same time policy sought to shift power from doctors to managers and reduce the former's influence on decision making and funding, thus bypassing resistance from the medical profession (Bury 2008).

It is arguable how different New Labour's policies really were, especially given the refrain of reducing dependence on the welfare state and able-bodied people having an obligation to help themselves in contrast to the 'nanny state' which preceded it (Malin, Wilmot and Manthorpe 2002). This emphasis on personal responsibility pre-dated Labour but was exemplified by the concept of the 'expert patient' who was required to attend an expert patient programme (Department of Health 1999b) to learn to manage their long-term condition. However, this was without an appreciation of structural constraints or that patients are relatively powerless in comparison to healthcare providers who possess biomedical expertise (Tang and Anderson 1999). Thus policies tended to side-step the complexity of living with chronic illness (Porter et al. 2015), the difficulty of self-managing (Parke et al. 2015) (assuming that everyone wants to) and the wider social determinants of health (Banks et al. 2006).

Even more idealistic was the concept of personalisation which envisaged radical service design, 'putting users at the heart of services, enabling them to become participants in the design and delivery' of services not just as consumers, but also co-producers and co-designers (Leadbeater 2004, p19). It argued that top down and bottom up service delivery could be compatible even though the two approaches entail different roles for individuals, professionals and providers. The top down element involved the state's capacity to deliver better services, with limited resources, to provide a platform for patients to become 'more adept at self-assessing and self-managing their health, education, welfare, safety and taxes' (Leadbeater 2004, p17). Interestingly, this new 'script', or approach, acknowledged that choices are made in a social context and the capacity to make them is greater for those who are well educated and informed. The most vulnerable would need additional help to find solutions and draw on available public services (Leadbeater 2004) although this was soon to change.

Following New Labour, the Conservative and Liberal Democrat Coalition government (2010-15) embarked on widespread reorganisation of the health service. The NHS Outcomes Framework (Department of Health 2010) was introduced as a mechanism to improve accountability and measure performance in the health and care system at a national-level across five domains intended to capture key priorities, including reducing cardiovascular mortality in the under-75s. The second domain, enhancing quality of life for people with long-term conditions, included supporting people to self-manage their condition and was measured as a proportion of all patients achieving this target.

Major restructuring was presented in the Health and Social Care Act 2012 (Department of Health 2012). CCGs were introduced to replace Primary Care Trusts under the mantra that this would increase patient choice by giving GPs control of primary care services. However, critics regarded financial issues as the key driver alongside establishing the legal framework for fragmenting and privatising the NHS, which could be regarded as an extension of Labour's neo-liberal public sector reforms (Speed and Gabe 2013). The shift away from public sector dominance towards 'buyer-dominance' was justified because the NHS supposedly had poorer outcomes compared to other international healthcare systems. Although the evidence suggested otherwise, the Act and associated outcome measures were framed to appear evidence based rather than based on ideology or economics (Speed and Gabe 2013). By deregulating provision to the level of CCGs the Act appeared to maintain public provision and improve quality while undermining trust in professionals and simultaneously making public services compete with other providers (Speed and Gabe 2013).

The NHS Five Year Forward View (NHS England 2014) marked another restructuring of services and emphasised collaboration rather than competition. Amongst other concerns was the cost of managing long-term conditions which were estimated to consume 70% of health service resources. The document referred to empowering patients with long-term conditions through increased access to information using digital strategies, increased control of where and how they received care, and supporting patients to manage their own health in tandem with the voluntary sector through education and self-management programmes, although there was little detail.

Current Sustainability and Transformation Plans for health and social care services set out how the NHS Five Year Forward View will be delivered locally (NHS England et al. 2015). The NHS and local councils are required to form partnerships across forty-four geographical areas of England to develop proposals which have continued with the current Conservative government (2015-present). The guidance requires specific deliverables for 2016/17 and overall goals for 2020 set out under seven areas of which some are condition specific but do not mention stroke or cardiovascular disease. Under section 2.2, the patient experience, the goals include 'significantly improved patient choice' for maternity, end of life care and long-term conditions alongside increasing the number of people with personal health budgets (NHS England et al. 2015, p24), although otherwise there is no reference to the earlier rhetoric around empowerment and self-management. However, more recent commissioning guidance for rehabilitation (NHS England 2016) continues the mantra of individual responsibility for self-management (section 6.3.1).

The next section considers the interplay between policy and practice in relation to the 6MR and draws on discourse around knowledge and power.

6.3.1: National policy: a biomedical or social paradigm?

Foucault used the term 'discourse' to describe bodies of knowledge. He moved the term away from the concept of linguistics and closer to that of discipline, used in both its senses: as referring to *scholarly disciplines* such as sociology, and *disciplinary practices*, or institutions of social control, such as prisons (McHoul 1995). He was interested in how some discourses and their associated rhetoric reinforced the oppression of the powerless by the powerful by making this seem the natural state of affairs (Mills 2003). Although Foucault overstated his case, the medical model and its rhetoric was considered to be an example of this, motivated by professional and political interests rather than being based on disinterested scientific truth (which he did not believe existed) (Smart 2002).

The literature review outlined stroke policy recommendations including those specific to the 6MR, which all recommended that the health *and* social care needs of patients should be considered but with different emphases on biomedical versus social indicators. For example, the 6MR should refer for further specialist assessment where appropriate and offer self-management support (Royal College of Physicians 2016a) while NICE recommended that 'participation and community roles' should be addressed (NICE 2013). Visualising policy aspirations for the review (Figure 22) is of little help in elucidating purpose from outcome or underlying mechanism.

Figure 22: Policy aspirations for the 6MR

(NICE 2013; Royal College of Physicians 2016a; Department of Health 2007)

However, if the areas are mapped onto the ICF (World Health Organization 2002) the 6MR appears to incorporate biomedical (the condition) and social (activity/participation) aspects. This brings us back to the differences between SNS reviews and SA reviews and two causal assumptions that policy appears to have made: that identifying unmet need will lead to its amelioration; and that provision of information will lead to behaviour change, self-management and secondary prevention.

Recent generic commissioning guidance for rehabilitation asserts that rehabilitation involves a ‘complex interaction between their [patients’] health conditions, the environments they live in, their values and beliefs, and their aspirations and motivations’ (NHS England 2016, p12). Yet the commissioning guidance makes little reference to environmental or personal factors, demonstrates almost no appreciation of how rehabilitation can be affected by socio-economic and cultural issues, does not address managing multiple co-morbidities and assumes that patients are able and willing to self-manage in a one-size fits all approach. While the guidance endorses regular reviews there are no specific aims or outcomes. Rehabilitation is encapsulated into ten principles that include achieving optimal ‘physical, mental and social wellbeing’ for patients and carers (NHS England 2016, p33) with self-management the means of enabling patients to take control of secondary prevention.

The emphasis on self-management and individual responsibility is consistent with stroke-specific guidelines for the 6MR (NICE 2013; Royal College of Physicians 2016a). Clinicians are charged with empowering patients but policy does not acknowledge systematic constraints, or the power of structure over agency. Further interventions can only be offered ‘if goals for specific functions and activities can be identified and agreed and the potential for change is likely’ (Royal College of Physicians 2016a, p113). These two qualifiers reflect a biomedical orientation and were often at odds with what respondents wanted. Goals were rarely discussed during the 6MRs that I observed and none led to therapy referrals. Many respondents wanted further intervention, often physiotherapy, but there was a tension between their expressed needs and what reviewers considered appropriate. Thus system constraints and professional expertise overruled the concept of the autonomous self-managing expert patient (Department of Health 1999b). Of course, if patients did not have capacity to benefit then it would be an inappropriate use of resources but this discussion did not take place.

Differences between the discourses of stakeholders was a central finding as different professional groups drew on their own profession specific discourse. Thus the rhetoric of frontline professionals differed to that of managers, commissioners and the Stroke Association. Similarly, the discourses of all professional groups did not necessarily match that of individual patients. Within each case study, the discourses reflected power differentials between patients/carers, reviewers and consultants on an individual level, as well as at an organisational level.

Foucault’s ‘bottom up’ model of power countered traditional Marxist philosophy, most notably in that he did not consider it simply a *property* of the State but a *relation*, *strategy* or *product*, that is exercised at all levels of society, including the micro-level. He focused on how power relations permeated all levels of society and the individual’s agency to counter oppression with resistance, even in the most difficult of circumstances. Institutions are a way of freezing particular relations of power so that a certain number of people are advantaged. He also distinguished between power relationships, relationships of communication which meant how information was transmitted, and the capacity of power to modify, consume or destroy (Foucault and Faubion 1994).

With regards to the 6MR, the reviewer exercised privileged, or expert knowledge, over patients; the mode of transmitting information was both verbal and written and capacity was employed to promote behaviours sanctioned at a higher level, such as medication adherence. Constant surveillance (or prompting) to adopt ‘normal’, or socially sanctioned behaviour, appeared to have already occurred prior to the stroke. Most respondents had internalised common health promotion messages and governed their behaviour in certain ways, a process Foucault called governmentality (Mills 2003). Nonetheless some patients chose to ignore or reject advice, which illustrates that they could make choices and exercise agency. Thus power need not be wholly oppressive and for respondents who did comply with advice, led to new forms of behaviour rather than simply censoring discouraged ones (Foucault and Faubion 1994).

Foucault distinguished between political power, exercised over subjects of the state, and pastoral power, exercised over individuals. Society's control over individuals was accomplished not just through (capitalist) ideology but also 'in the body and with the body… medicine is a biopolitical strategy', one concerned with managing births, deaths, reproduction and illnesses of a population (Foucault and Faubion 1994, p137). Pastoral care used the metaphor of the state as a shepherd caring for his flock from birth to death, the rhetoric of the welfare state, with its objective of sustaining and improving individual lives (Smart 2002).

Within the pastoral care of the 6MR, reviewers sanctioned specific health behaviours as their practice reflected the official discourse, supported by rhetoric that requires patients to be responsible for self-management (NHS England 2016). Although this was in the guise of independence and empowerment it may have disadvantaged those with the most severe impairments, co-morbidities and social deprivation. This was exacerbated by lack of time, and of continuity and consistency, which may have increased non-adherence. Alternatively, resistance to advice may have been a response to reviewers' insufficient acknowledgement of patients' own expertise and agency (Tang and Anderson 1999).

Arguing for a neutral conceptualisation of medicalisation, Rose (2007) highlights the diversity of medicine and points out that clinical medicine is just one of many ways that individual and group life have been problematised from the perspective of health. Thus, 'medicine is inextricably intertwined with the ways in which we experience and give meaning to our world' (Rose 2007, p701). In addition, the doctor's 'clinical gaze', a combination of observation (surveillance) and speech (parole) incorporates not just the body but also the environment, allowing 'ever-widening' surveillance whereby the clinical gaze intrudes into the home (Blaxter 2010, p103) as with the 6MR taking place in the patient's home.

More generally, Busfield (2017, p765) argues that the view of patients as 'docile and powerless' has been over-emphasised and does not take into account present less deferential attitudes to professionals and the more informed and active patient. While some adopt a passive role, many actively challenge medical power, including the process of medicalisation, aided by the growth of user groups, consumerism, and patient and public involvement (Busfield 2017). For example, the Stroke Association's online discussion forum reflects an active community of patients and carers who question professional advice and make their own treatment decisions that may be contrary to generally accepted treatments including statins (Jamison, Sutton and Mant 2017). The importance of belonging to some form of community is discussed in the next section.

6.3.2: Community integration

Alongside self-management, integration (or reintegration) into the community is considered the cornerstone of rehabilitation and policy links it to improved quality of life (Royal College of Physicians 2016a). What 'that over-used word community' means (Acheson 1985, p3) is debateable because much of the early literature related to closing institutions for people with psychiatric or learning disabilities in the 1970s and definitions reflect this background (McColl et al. 1998). Normalisation theory was at its centre and was later renamed social role valorisation, with the key goal of 'the creation, support, and defence of valued social roles' for individuals with disabilities so that they could participate in society in a meaningful way (Wolfensberger 2011, p435).

There is no consensus on what community integration means for stroke patients (Woodman et al. 2014). Respondents did not perceive community integration as a function of the 6MR; given its one-off nature and limited time this is perhaps not surprising. However, the 6MR provided information that signposted patients to community facilities which may have indirectly contributed to community integration.

Community integration in the stroke literature does not have the negative connotations that normalisation acquired in terms of promoting assimilation and conforming to normative expectations (Lemay and Taylor 2006). Most current models incorporate inclusion in family and community life, carrying out normal roles and responsibilities, and being an active member of society (Dijkers 1998).

Integration requires adjusting to changed circumstances and may take much more than six months. It involves learning to balance expectations of what can be achieved against the constraints of ongoing impairment whilst still maintaining hope (Lawton et al. 2016; Soundy et al. 2010; Walsh et al. 2015b). When people are unable to re-establish or develop new roles and relationships it can result in frustration and uncertainty. The challenge of community integration involves creating a balance between capacity, self-identity and expectations (Wood, Connelly and Maly 2010) or in other words, biographical disruption requires work to manage these priorities.

The Stroke Association reviews focused more on community integration than medical adherence, reflecting their philosophy, which is discussed in the next section.

6.3.3: The Stroke Association

The SA originated as an organisation for the prevention of tuberculosis, founded in 1899. This became The Chest and Heart Association and ‘stroke’ was added to the title in 1974. It was renamed The Stroke Association in 1989 but did not officially drop chest and heart research for a further three years when it became the only organisation focused solely on stroke. The association gradually expanded its remit to all of the UK either subsuming, or forming partnerships with, competing organisations (Ritchie 2015a). Only in Scotland did the Chest, Heart and Stroke Association oppose a merger and continue to function independently. The language used by the SA to describe this has negative connotations, for example, approaches to joint working were ‘dashed’ by the pre-existing organisation (Ritchie 2015b, p65).

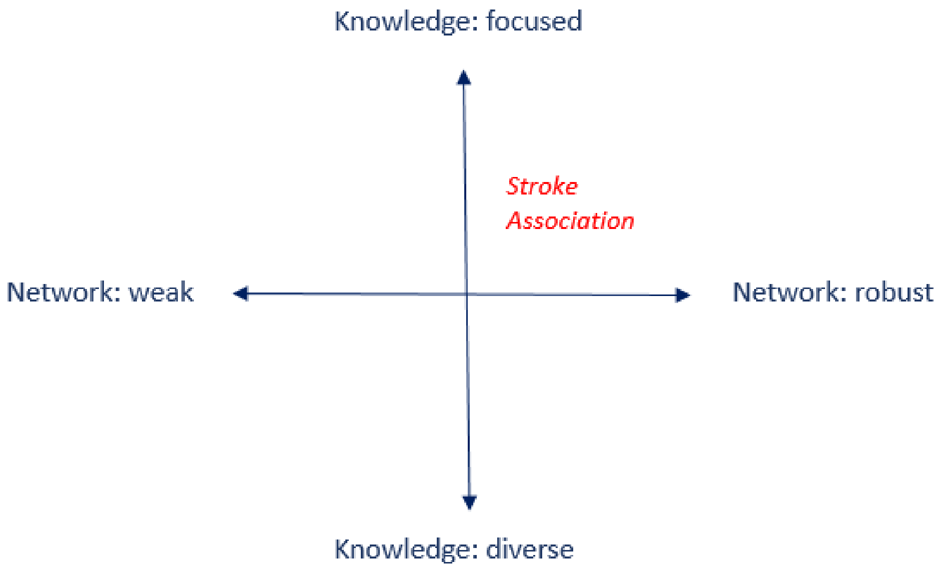
The SA increased its prominence by forming the UK Stroke Forum in 2005 with the support of the British Association of Physicians and various other organisations. This alliance organises a yearly multidisciplinary conference ‘to enable science and good practice activity to come together’ (Ritchie 2015b, p58). It rebranded itself in 2012 (dropping ‘The’) with a new logo that appeared to increase public awareness and its turnover. It had a net income of £36.5 million in 2015/16 and aspires to be ‘recognised as a world-class organisation’ that intends to continue expanding (Stroke Association 2016a, p10).

Although the SA has a strong voice, it cannot set the policy agenda and has to contend with the political climate. For example, New Labour presented opportunities in terms of initiatives to extend patient choice and encouraged voluntary organisations to become more involved in service provision. While this lends status, it is set against the risk of undermining the organisation’s independence when financially dependent on public authorities (Baggott and Jones 2015).

While it regards itself as working for the rights of stroke survivors lacking agency, the SA is a powerful lobby group with its own agenda and it campaigns independently from the Neurological Alliance, despite their common interests. It has a strong focus on community integration and its literature emphasises the importance of social support. However, its approach to national policy is similar to that of statutory services, endorsing self-management, which it purports to deliver as part of its ‘life after stroke’ service that includes 6MRs. Its priorities also reflect medical concerns, for example, campaigning on atrial fibrillation to ensure those who need it receive anti-coagulation treatment (Stroke Association 2016b).

A typology, albeit based only on one case study, suggested that patient organisations’ epistemic identity are a function of the relationship between knowledge activities and network integration (Moreira 2015). Knowledge activities can be ranked according to diversity and network integration relates to the 'strength and heterogeneity' of links with other actors which can be operationalised as robustness (Moreira 2015, p3355). The Stroke Association certainly has a robust network and only funds stroke specific research, a narrower remit than in its early years, so can be considered 'robust focused' (Figure 23):

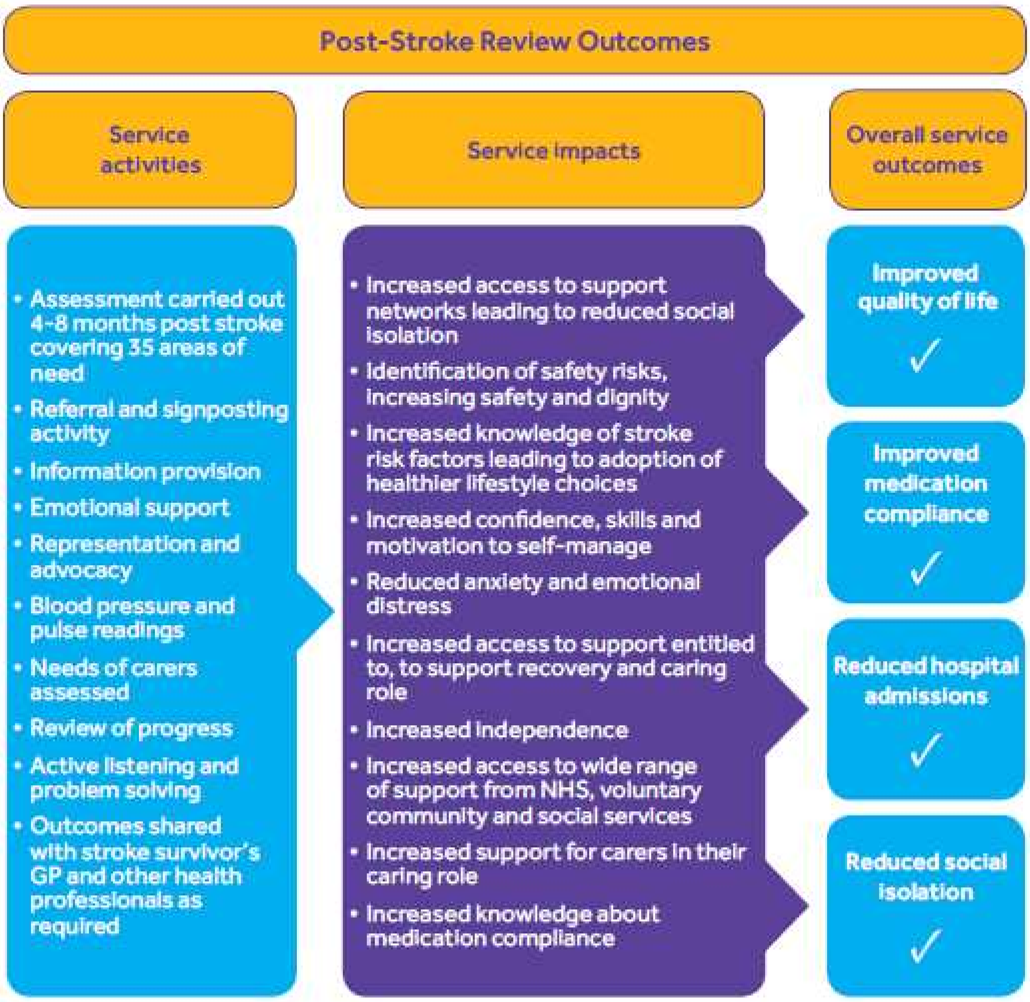
Figure 23: Epistemic identity as a function of the relationship between knowledge activities and network integration



(Moreira 2015, p3356)

With regards 6MRs, the SA literature presents an array of service activities, impacts and outcomes (Figure 24). While the activities could be considered fairly representative of the 6MR, the service impacts and outcomes are unsubstantiated. The claims suggest a simplistic view of cause and effect and do not consider the complexity of human behaviour, underlying mechanisms, the patient's socio-economic context or the interactions that might affect outcomes.

Figure 24: Excerpt from Stroke Association leaflet



Post-Stroke Review Outcomes

Service activities

Service impacts

Overall service outcomes

- Assessment carried out 4-8 months post stroke covering 35 areas of need
- Referral and signposting activity
- Information provision
- Emotional support
- Representation and advocacy
- Blood pressure and pulse readings
- Needs of carers assessed
- Review of progress
- Active listening and problem solving
- Outcomes shared with stroke survivor's GP and other health professionals as required

- Increased access to support networks leading to reduced social isolation
- Identification of safety risks, increasing safety and dignity
- Increased knowledge of stroke risk factors leading to adoption of healthier lifestyle choices
- Increased confidence, skills and motivation to self-manage
- Reduced anxiety and emotional distress
- Increased access to support entitled to, to support recovery and caring role
- Increased independence
- Increased access to wide range of support from NHS, voluntary community and social services
- Increased support for carers in their caring role
- Increased knowledge about medication compliance

Improved quality of life ✓

Improved medication compliance ✓

Reduced hospital admissions ✓

Reduced social isolation ✓

(Stroke Association 2016b)

The service outcomes make leaps of logic that lack theoretical, or evidenced based, underpinning. To suggest that information provision could lead to, for example, increased medication compliance makes many assumptions. For example, it ignores the SA co-ordinators lack of medical expertise and assumes that information leads to behaviour change. Similarly, it suggests that increased knowledge of risk factors will result in healthier lifestyle choices (Stroke Association 2016b). However, one-off provision of information, even with discussion, is highly unlikely to result in behaviour change (Forster et al. 2012).

The rhetoric of co-ordinators having extensive knowledge of stroke, being able to take blood pressure, identify atrial fibrillation, liaise with GPs, improve medication adherence, target lifestyle choices and promote self-management (Stroke Association 2016b) suggests professional training. This may be intended to appeal to commissioners, many of whom are GPs, but is at odds with the social orientation of the staff interviewed, which was their key asset.

Morris (2016) explored SA workers' views about their role, understanding of and ability to respond to patients' psychological needs. Many wanted further training in categories that reflected basic skills such as active listening but other areas might be considered an encroachment into professional territory. For example, 'training in psychological assessment' and 'listening and counselling' is ambiguous but in whatever guise would require careful supervision. While current psychological provision for stroke is limited (Kneebone 2016), the rhetoric of training non-specialist staff is appealing and a niche that the SA appear eager to market.

Perhaps the Stroke Association has blurred the boundaries between its 'life after stroke' service and 6MRs. Two service evaluations highlighted that patients and carers valued personal contact with the same support worker over time and their focus on social and emotional needs (Wright 2016; Jenkins, King and Brigden 2012). But this appears inconsistent with the literature (Stroke Association 2016b) which portrays a one-off pseudo-medical intervention. This lack of clarity was reflected in both reports which commented that patients and carers 'were unsure of the boundaries of what it [SA] did and did not offer' (Jenkins, King and Brigden 2012, piv) and were unclear which support needs could be raised with their co-ordinator (Wright 2016, p4).

It was not possible to access any documentation regarding the SA's corporate strategy but the focus on presenting the 6MR as a pseudo-medical intervention might be a marketing decision given that it is mostly commissioned by CCGs, representing GPs, (Walker, Fisher and Fletcher-Smith 2014) who are under obligation to fund it. However, short-term contracts leave the organisation vulnerable and in some areas the 6MR was bolted on to pre-existing services with no additional funding. Thus, the SA is caught in the 'pinch area' of aspirations versus reality for third sector providers with insecure funding despite recognition of the value of the service (Jenkins, Brigden and King 2013, p260). This might explain the inconsistency between its pseudo-medical orientation to the 6MR set against the largely socially orientated 'life after stroke' model. However, whatever the paradigmatic framing of the review, there was little evidence of its intended impact. The reasons for this are discussed in the next section.

6.4: Why did the 6MR have limited impact on patients?

Despite reviewers' patient-centred approach, there were areas that the 6MR did not adequately address that appeared to impact on patients' experience. These mainly related to the overall impact of having had a stroke, the trauma of the inpatient phase and transition home, and insufficient attention to self-management and community integration. In terms of the review's performance, these omissions reflected the barriers imposed by insufficient time and a rigid format not tailored to individual needs. However, this was countered by the reviewer's personal attributes and professional expertise, both of which engendered trust and reassurance, which appeared to be the mechanism by which outcomes were achieved. Although none of the reviewers in this study were therapists, this section draws on literature appertaining to clinicians which includes occupational therapists and physiotherapists.

The section starts by exploring the work involved in living with a chronic condition (Corbin and Strauss 1985); the recovery process, or illness trajectory, within the context of biographical disruption (Bury 1982); and notions of reconstructing the body and self (Charmaz 1995). Although these authors take an interpretivist stance this can be tempered by a realist perspective that acknowledges the biological body 'without stripping agency of agency or structure of structure' (Williams 1999, p798).

6.4.1: The impacts of stroke

The literature review discussed the impairments that can result from stroke and the impact on daily life. This study's findings were consistent in terms of the physical, cognitive and psychological sequelae and the disruption of daily routines, social networks and the ability to participate in valued activities once home. Patients had to contend with varying degrees of dependency and a limited ability to reciprocate with carers which had the potential to undermine self-confidence (Horne et al. 2014), sense of identity and/or self-esteem (Walsh et al. 2015b; Salter et al. 2008) and was often compounded by loss of roles and social standing (Sarre et al. 2014).

Corbin and Strauss (1985, p224) proposed the idea of 'three lines of work' needed to manage the burden of chronic illness which they conceptualised as illness work, everyday life work, and biographical work. They focused on the social context and social relationships of the illness trajectory, or journey, rather than physical impairment. Illness work relates to all the everyday tasks involved with managing a condition, for example, medication regimes. Everyday work refers to the normal tasks of running a household, such as cooking and cleaning. Each type of work requires varied amounts of effort and takes place in fluctuating circumstances as the demands of the household and the illness change over time. The third type of work, biographical, is that required to reconstruct daily life and interacts with the other two types of work. It has to be balanced against the demands of illness and everyday work, the respective demands on patient and carer, and competition for resources (Corbin and Strauss 1985). For example, during a period of acute illness, medical management takes priority but a family crisis might push the illness into the background. This 'management in process' reflects the interplay between the three lines of work. The 6MR could be a means of redress when demands outweigh capacity, were it to occur when needed.

Biographical work can be regarded as a response to biographical disruption which encompasses the many ways that chronic illness interrupts 'the structures of everyday life' (Bury 1982, p169-70), or the pre-existing habits and routines. Bury referred to the 'insidious onset' of chronic illness (1982, p171) and the gradual shift from relatively predictable life course to one marked by uncertainty. Although this differs from the sudden onset of stroke, many of my study's respondents were already struggling with pre-existing co-morbidities that added to a pervading sense of uncertainty including the fear of another stroke. Physical changes and fluctuating symptoms can magnify feelings of loss of control and, specific to stroke, early progress can be interrupted by periods of limited progress, or plateaus, resulting in a perception of the body as unreliable and unpredictable (Salter et al. 2008) although plateaus can also be seen as platforms for further progress.

Chronic illness impacts not only on the body but also undermines self-identity and to 'reunify body and self' requires adaptation to accommodate physical losses (Charmaz 1995, p657). Self-body unity is a subjective experience and individuals may not have considered this aspect as a defining feature of their identity pre-stroke (Charmaz 1995). People adjust in different ways and at different stages and while some may reconcile themselves with illness, others may deny, minimise or fight against it (Charmaz 1995). Bury (1991, p460) referred to psychological 'bracketing off' as a coping strategy to normalise the situation, either through minimising the impact on identity or incorporating it into self-identity; either way, these strategies allow patients to maintain a sense of purpose in life, or agency, within their social environment. The 6MR incorporated an element of both but the emphasis of the SNS was clearly the body, concomitant with a biomedical approach, while the SA co-ordinator had more time to address the effects on self.

The disruption of chronic illness also affects carers and they had to adjust, although caring had positive aspects (Mackenzie and Greenwood 2012). However, changes in the normal rules of reciprocity, the uneven distribution of tasks and lack of opportunity to have time to themselves can lead to resentment (Corbin and Strauss 1985). In addition, couples may choose to restrict activities outside the home to avoid the embarrassment, or stigma, of disability (Charmaz 1995). However, policy is very much directed at the individual, as either patient *or* carer, for example The Care Act 2014 (Department of Health 2016) entitles carers to a separate needs assessment. This sharp distinction and the nomenclature of carer rather than, for example, husband, wife or daughter seems to push relatives into a semi-professional caring role with concomitant responsibilities. This overlooks an often inter-dependent relationship where both ‘patient’ and ‘carer’ may be managing multi-morbidities (Abrahamson et al. 2016) and be supported by a wider social network. In considering the impact of illness, this wider network, including family and other informal support needs to be considered (May et al. 2014).

Many people draw on their own knowledge and experience in an attempt to normalise their situation whilst recognising that medical knowledge has limitations. Bury (2001) later differentiates two broad views of illness: the *categorical view* separated ‘the normal and the pathological’ in a typically bio-medical approach while the *spectral view* saw illness as ‘matter of degree’ and regarded it as a social process dependent on circumstances and societal reaction. This dichotomy reflects the two models of 6MR, medical versus social, and the positivist versus interpretivist view of illness. However, biographical disruption depends both on the type of illness, its symptoms, trajectory and the stage of life as well as the social context, the response of others, and the individual’s perceptions of both the internal experience of illness and the external response of others (Bury 1991).

Although stroke is not a progressive condition, accumulative losses may prompt patients to reassess their identity (Charmaz 1995) and develop goals in an attempt to reconstruct, or resume, their life as it was prior to the stroke, or as near as possible. Such goals help adapt to loss and change but are very different to the functionally orientated goals of rehabilitation. Charmaz (1995) noted that individuals will avoid lowering their goals if they think others, usually a spouse, need them to function as before. Of course, money and social support allow more choices about which ‘identity trade-offs’ to make and when (Charmaz 1995, p670) but policy focused on individual responsibility (Department of Health 2001a; Royal College of Physicians 2016a) does not sufficiently take into account personal and socio-economic variance.

The notion of biographical disruption has dominated the stroke literature (Faircloth et al. 2004). Yet stroke, with its sudden onset, does not always result in biographical disruption; age and severity appear to be key factors mediating between experience and response (Williams 2000). The biographical components of the trajectory emphasise helping individuals to participate in valued activities and continue to adapt to their disability but this downplays the social and environmental causes of disability (Burton 2000). An early and much cited study suggested that socio-economic hardship *reduced* the perceived impact of stroke. In the context of poverty, ageing and/or co-morbidities individual responses were characterised by attitudes of ‘resignation and pragmatism’ (Pound, Gompertz and Ebrahim 1998, p498). Faircloth et al. (2004, p245) also found that older people normalised their experience of stroke within the context of ageing and the ‘ongoing flow of events, actions, reactions and self-preservation of identity'. They perceived the stroke as part of the normal life course or 'biographical flow' rather than a disruption (Faircloth et al. 2004, p245). However, stroke treatment and attitudes to old age have since changed and it is likely that co-morbidities are compounded by poverty; either way, biographical disruption appears to carry class- and age-related connotations, as well as gender and ethnic variations that have been under-played (Williams 2000). Research also rarely addresses the need to place clinician-patient interactions within the wider socio-economic determinants of health (Street et al. 2009)**.** The claim that there is a clear split between self and body resulting in biographical disruption overstates the case while the argument for biographical flow is likely to have limited application.

In contrast to the above findings, my respondents were largely elderly but did not regard stroke as an expected consequence of ageing. It was not age but attitude and pre-existing levels of independence that defined their response. Those who were independent pre-stroke were most affected by the disruption to their normal life style, while those who were already managing multiple morbidities that significantly restricted their choices were more sanguine. Younger people were most affected in terms of the impact on identity and biographical disruption and had different priorities, particularly return to work, which reflects their stage of life.

The 6MR took place against a background of disruption, uncertainty and variable continuity of care. The shock of having had a stroke, the severity of impairment and the quality of care dominated patient and carers interviews. Even at six months, the trauma of the initial stroke, hospital admission and inpatient phase, especially negative experiences, resonated strongly through all the interviews. From a critical realist perspective, the domination of inpatient care could be seen as a mechanism triggered by perceptions of care (positive or negative) with the outcome that this was the key area of concern and distracted from the 6MR. The next section situates this within the recovery process.

6.4.2: The illness trajectory: an accurate reflection of the stroke pathway?

Corbin and Strauss (1992) proposed a generic model to illustrate how the work of chronic illness changes over time (Table 2). Each phase has its own tasks and there can be movement in either direction. The model aimed to assist clinicians' understanding so that they could help patients develop their own understanding of the illness trajectory and support rehabilitation (Kirkevold 2002). Although the model is somewhat dated, given medical advances since it was developed that reduce the relevance of the last two phases, this seminal work can be a reference point against which to compare the stroke trajectory.

Table 30: Trajectory model of chronic illness

Trajectory phase		Characteristics
1	Pre-trajectory	Before illness begins, no signs or symptoms (preventative stage)
2	Trajectory onset	Signs and symptoms appear leading to diagnosis
3	Crisis	Life threatening event
4	Acute	Active illness or complications that require hospitalisation for management
5	Stable	Illness course/symptoms controlled by treatment and able to return home
6	Unstable	Illness course/symptoms not controlled by treatment but hospitalisation is not required
7	Downward	Progressive deterioration characterised by increasing disability/symptoms
8	Dying	The days or weeks prior to dying

(Corbin and Strauss 1992)

The pattern of stroke differs from the eight phases above given that if death occurs it is more likely to occur at the start, and the downward phase is not generally associated with stroke. Corbin and Strauss (1998) later added a 'comeback' phase to cover the process of rehabilitation, readjusting daily life and biographical re-engagement.

There is a considerable literature exploring experiences of inpatient stroke care (Gallacher et al. 2013; Kouwenhoven et al. 2012; Sarre et al. 2014; Harrison et al. 2017; Satink et al. 2013; Salter et al. 2008; Morris et al. 2011) and this study's findings were consistent with it. Gallacher's (2013) systematic review of treatment burden experienced by stroke patients highlighted that patients had to comply with the hospital routine (system led), endure negative environments, long waits for personal care, inadequate support at mealtimes, poor food and lack of stimulating activities. Overall, this lack of agency led to an overriding sense of vulnerability in the context of loss of autonomy, privacy and dignity. Some patients felt that time spent with inpatient and community therapists was too short, as was the time spent imparting information, and they were uncertain who to contact post-discharge (Gallacher et al. 2013).

Taylor et al.'s (2015) narrative synthesis focused on factors affecting the delivery of inpatient therapy. Many of the problems were common to my findings including limited duration and frequency of therapy, lack of opportunities to engage in meaningful activities and the stultifying ward environment. Patients wanted to focus on wider, non-physical needs and measured recovery in terms of fully regaining their former identity, whilst therapists focused on impairments and specific functional abilities. Thus there was a tension was between therapists' orientation to short-term functional outcomes, as dictated by the hospital system, and patient needs. An earlier study, included in Taylor et al.'s (2015) synthesis, found that discharge planning was prioritised at the expense of 'hands-on' therapy with decisions based on competing priorities due to the need to manage limited resources, and moral evaluations of patients in terms of their suitability for rehabilitation (Mold, Wolfe and McKevitt 2006).

More recently, stroke literature has focused on the transition home and the first few weeks' post-discharge, although this is not explicitly addressed by the trajectory model. It is a complex process that marks the transfer of responsibility from clinicians to patient, carer and families (Gallacher et al. 2013) and can be made more difficult by poor discharge, waits for follow-up interventions, fragmented care and the need for emotional adjustment to long-term impairment (Allen et al. 2017). Gaps in care, or 'hotspots', were at the forefront of my respondents' minds and the cause of considerable stress, as other studies have found (Allen et al. 2017; Abrahamson et al. 2016; Pringle, Drummond and McLafferty 2013; Hodson, Aplin and Gustafsson 2016). Patients and carers had to re-establish daily routines whilst either negotiating a busy schedule of poorly co-ordinated appointments or enduring an anxious wait for follow-up (Abrahamson et al. 2016; Gallacher et al. 2013). Feeling frustrated and unsupported appeared to hinder adjustment, especially when patients were awaiting adaptations, unable to resume driving or return to work, and had financial concerns (Gallacher et al. 2013). In terms of the illness trajectory, this equated to an 'unstable phase' marked by uncertainty and challenges (Corbin and Strauss 1991) all of which detracted attention from the 6MR. However, the instability was not due to the condition, as Corbin and Strauss (1992) suggested, but more to do with service provision and the gaps, or hotspots, my respondents identified.

An alternative model proposed four stages (Kirkevold 2002) and although it was based only on nine patients with mild to moderate stroke it does reflect the stroke trajectory more accurately (Table 3).

Table 31: Trajectory model of stroke

Trajectory phase		Timeframe	Environment	Characteristics
1	Trajectory onset	1-7 days	Acute inpatient	Surprise and suspense
2	Initial rehabilitation	1-8 weeks	Rehabilitation unit	Hard physical work
3	Continued rehabilitation	8 weeks - 6 months	Home/out-patient unit	Focus on psychosocial and practical adjustment
4	Semi-stable phase	6 months - 1 year	Home	Going on with life

(Kirkevold 2002, p891)

Continued rehabilitation, once home, involved re-establishing a daily routine in the absence of professional help, and gradually widening the nature and complexity of activities within and beyond the home environment (Kirkevold 2002). The first few weeks at home involved hard work and experimentation; the personality and attitude of the patient, as well as the stroke, influenced the process (Kirkevold 2002). By about six months, progress started to slow and ongoing effort reaped limited rewards. The focus of this semi-stable phase was on engagement in valued activities, whether adapting previous or developing new ones. Improvements were still expected and patients were still looking towards regaining a sense of normality but the effects of the stroke had to be integrated into daily life and minimised as far as possible (Kirkevold 2002). The focus had moved from the body and functional tasks to ‘practical and biographical concerns’ in line with a growing understanding of the stroke trajectory (Kirkevold 2002, p897).

Kirkevold’s (2002) phases resonated with my respondents’ experiences but omitted the ‘hotspots’ related to transfers of care and services withdrawing that caused so much uncertainty. Burton (2000) also compared the stroke trajectory with Corbin and Strauss’ phases and highlighted the importance of the transition home. However, nursing care is often focused on progressing the patient through the care system (structure over agency) rather than on facilitating recovery.

In summary, the 6MR with SNSs addressed illness work but not the work of everyday living or biographical work. Conversely, the Stroke Association review addressed the work of everyday living but not the other two lines of work. Many respondents were struggling with the three lines of work and demonstrated aspects of biographical disruption but those with pre-morbidities, already leading very restricted lives, were closer to Faircloth’s (2004) notion of biographical flow (section 6.4.1). However, many respondents perceived the review as a source of reassurance and trusted the advice of the reviewer, which is discussed in the next section.

6.4.3: The therapeutic alliance

What respondents appeared to value most was the interaction with a reviewer they perceived as an expert and a source of reassurance. Exactly what reassurance means is poorly defined but it has been conceptualised as a combination of affective (emotional) reassurance, which immediately reduces anxiety, and cognitive (informational) reassurance, which develops more slowly and is assumed to contribute to behavioural change (Coia and Morley 1998). Similar to reassurance are notions of trust (Calnan et al. 2006) and therapeutic engagement (Bright et al. 2017) but the literature relates to longer interactions than a one-off review. Trust compares closely to reassurance given that it helps people cope with uncertainty and both involve a cognitive element (rational judgements) and an affective component (generated though interaction and empathy) (Calnan et al. 2006).

Reassurance and trust are both components of the therapeutic, or working, alliance between one person seeking change and the other who offers to be an agent of change. Bordin's (1979, p253) seminal work proposed that the effectiveness of therapy was a function in part, 'if not entirely', of the strength of the working alliance and this held true beyond the confines of psychotherapy. His model had three aspects: congruence in relation to therapy goals; collaboration on specific tasks to meet those goals; and establishing a therapeutic bond. However, within the confines of the 6MR the therapeutic bond was limited to establishing rapport and the other two aspects were absent.

A recent meta-ethnography of the therapeutic alliance in stroke rehabilitation endorsed its importance and found evidence of an association with treatment adherence (Lawton et al. 2016). Rehabilitation generally allows therapists to establish a bond over several weeks but even so, therapists and patients demonstrated diverse approaches to participation that reflected an asymmetry of expectations, much as with the 6MR. Some patients adopted an active role and others wanted therapists to direct rehabilitation (Lawton et al. 2016). Factors that appeared to influence the degree of collaboration related directly to the stroke, such as depression, as well as to other factors including previous illness, age and personal characteristics. More experienced therapists appeared better able to negotiate with patients and promote engagement, or a sense of agency. Where goal setting was directed by hospital policy this often resulted in a dissonance between patient and therapist objectives with concomitant disengagement (Lawton et al. 2016). Thus, organisational drivers had a direct effect on the therapeutic relationship and brought to the foreground inherent power differentials between patient, therapist and the organisation.

Differences in objectives or expectations resonate with the literature on preference-based care, a key aspect of client-centred care, that aims to 'systematically elicit' patients' views about their perceived healthcare needs and preferences for health outcomes (Ruland 1999, p305). In an inpatient setting, when nurses were made aware of patient priorities, there was improved congruence between the two parties' priorities and higher achievement of patient preferences prior to discharge (Ruland 1999). Many of my respondents expressed different priorities to those of reviewers, therapists and other clinicians especially in hospital, which may have contributed to 'hotspots'. Respondents were mostly unsure what to expect from the 6MR and despite establishing a therapeutic relationship reviewers did not explicitly discuss what respondents wanted to achieve from the review, which may have contributed to the dissatisfaction that some expressed. However, there was an expectation from the 6MR provider that the review would be a vehicle to enable self-management.

6.4.4: Self-management

Self-management is a form of behaviour change based on social cognitive theory and is underpinned by self-efficacy. The key determinants are knowledge about health risks and benefits for particular behaviours, goals that individuals set themselves and outcome expectations. Beliefs in personal efficacy are believed to regulate behaviour, mediated by perceived facilitators and social barriers (Bandura 2004). A currently popular approach to behaviour change presents a taxonomy of techniques such as goal setting and problem solving (Michie et al. 2011) and although the techniques are useful, the approach still focuses on individual behaviour rather than systemic, structural or cultural factors (Kennedy, Rogers and Bower 2007).

There are many definitions and interpretations of self-management (Sadler et al. 2017) but an early conceptualisation delineated three types: medical, role and emotional management. Medical management addresses medication and adherence to specific regimes; role management relates to biographical work and involves developing and maintaining meaningful behaviours or life roles; and emotional management refers to learning to cope with emotional issues, commonly anxiety and depression (Lorig and Holman 2003). Self-management is seen as requiring six core skills, all relying on individual agency: problem solving; decision making; resource utilisation; forming a patient/clinician partnership (or therapeutic alliance); action planning; and self-tailoring, or applying skills and knowledge to one’s own situation (Lorig and Holman 2003).

Organisation drivers affect the current discourse around self-management and its integration into the stroke care pathway. It is intended that patients will learn self-management skills and the 6MR is meant to incorporate them (Royal College of Physicians 2016a). While the reviewers in my study considered self-management an integral component of the 6MR, it was not integrated into the care pathway or part of a wider approach and the one-off nature of the review provided little, if any, capacity to help respondents develop the required skills. Furthermore, respondents were expected to continue to self-manage without an ongoing supportive therapeutic alliance able to address problems as they arose and over time. In practice, SNSs focused on medical management but lacked time to address role and emotional management while the SA co-ordinator was unable to address medical management.

Similarly, the 6MR is intended to address behaviours such as smoking, exercise, diet and alcohol consumption. The guidelines emphasise individual responsibility supported by clinicians (Royal College of Physicians 2016a) but a one-off review is unlikely to lead to behaviour change. In addition, information, advice and support provided by the 6MR cannot be equated with self-management (Forster et al. 2012).

A whole systems approach to self-management goes beyond individual responsibility and places self-care within a wider context of professional behaviour change and community engagement (Kennedy, Rogers and Bower 2007). The approach aims to improve patient information and access to services. It challenges professionals to respond flexibly to individual need and engage with aspects of self-management outside their professional remit. However, clinicians may be reluctant to handover control to patients, not all patients want an active role in self-management and clinicians may themselves be constrained by institutional demands (Norris and Kilbride 2013).

A stronger criticism suggests that the discourse around self-management has been dominated by policymakers who regard it as a means to reduce the financial impact of chronic illness on health and social care (Kendall et al. 2011). The notion of individual responsibility, for the greater good of society, implies that those who do not comply with professional interpretations of self-management are likely to be deemed as problematic or non-compliant, as was the case with some 6MRs. The ideology of ‘choice’ is actually a paradox given that health professionals often maintain an expert role rather than transferring responsibility to patients (Norris and Kilbride 2013). However, patients do express agency in their response to advice which may include cynicism, non-adherence, drawing on information from other sources and personal experience (Kendall et al. 2011). This relates to biographical work but appears to be given insufficient attention by professionals. Finally, the discourse of individual responsibility may actually accentuate existing health inequities because only those who comply will benefit. Patients who are already struggling with structural constraints and have fewer resources are likely to have more complex problems and less resources to address them (Kendall et al. 2011).

Sadler et al.’s (2014) systematic review and narrative synthesis of fifty-five qualitative studies (pre-2014) compared lay and healthcare professional understandings of self-management for a range of long-term conditions, including stroke. It was apparent that the understanding of self-management, by patients and clinicians, appeared to encompass traditional or paternalistic models of the professional-patient relationship based on compliance with professional advice. Professionals assumed that given the right information patients would be motivated to self-manage and when they did not comply, this was attributed to negative characteristics such as lack of engagement.

Understanding self-management also encompassed different expectations of responsibility, expressed in ways that appeared to mirror my typology. Some patients were happy to take control and concurred with professional advice while others chose to combine aspects of professional advice with other sources. However, some rejected self-management and wanted to be told what to do. Many of these patients lacked social support, had a lower educational level, and felt abandoned when services withdrew, akin to the ‘hotspots’ identified in my study. Most striking was the dissonance between the ethos of self-management, which focuses on empowerment, and the model employed, based on compliance (Sadler, Wolfe and McKevitt 2014).

A similar systematic review and qualitative synthesis (2004-2015) of patient and professional understanding of self-management also highlighted the dominance of a traditional model of care and an emphasis on personal responsibility (Franklin et al. 2017). Didactic delivery of information, similar to the 6MR, was intended to increase knowledge and promote behaviour change. While some patients were satisfied, others wanted help to apply the knowledge to their situation and again expressed a preference for tailored advice with specific strategies as a way of making information relevant and practical.

Patients felt that clinicians paid insufficient attention to their social circumstances. Aspects such as embodied knowledge, the lived experience of chronic illness and wider structural influences seemed to be marginalised. This was set against professionals' frustration at not being able to address wider issues and not understanding why patients failed to make 'correct' choices (Franklin et al. 2017). Those from lower socio-economic backgrounds appeared least able to manage the burdens of their condition and were most likely to be blamed for failing to comply (Franklin et al. 2017).

In summary, the effectiveness of the 6MR appeared limited by its narrow remit set against the profound impact of stroke. Respondents and their families who were struggling with the three lines of work (Corbin and Strauss 1985) needed to adjust to changed circumstances, against a background of uncertainty. The 6MR occasionally coincided with a 'hotspot' but the timing was mostly arbitrary and it thus appeared as a separate entity, not an integral part of rehabilitation or the care pathway. Similarly, as self-management was not part of an overall approach what the 6MR could offer was limited.

The next section explores the concept of treatment burden and identifies related concepts that could be used to maximise the impact of the 6MR.

6.5: Improving impact: 6MR within the context of long-term conditions

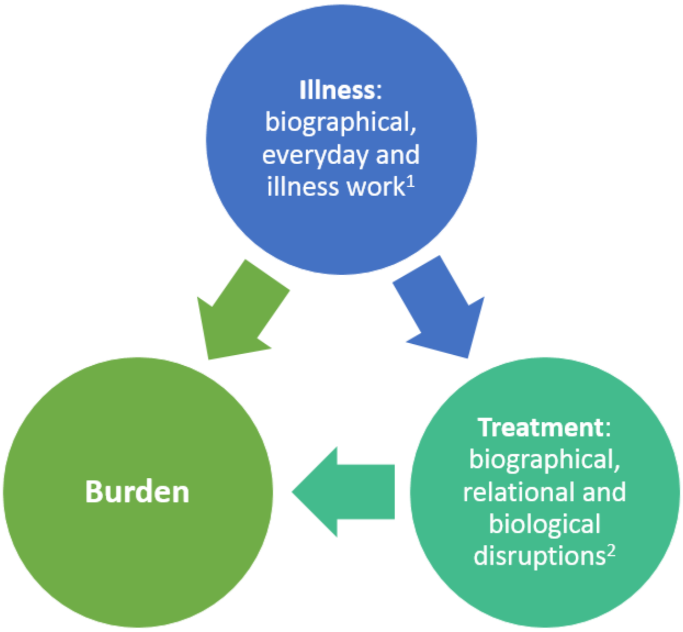
This section positions the 6MR within the context of managing long-term conditions and the concept of treatment burden is used to elucidate wider influences on the review process. Treatment burden is a relatively new term that refers to the workload of healthcare and its impact on patient functioning and well-being. May et al. (2014) points out that whereas previous generations experienced communicable diseases that were often rapidly lethal, today non-communicable diseases predominate with treatment modalities that extend life for many years, thus challenging the solutions currently provided by healthcare systems and policy makers.

Alongside treatment burden, problems with information provision, education and health literacy are discussed because they were prominent areas of concern with my respondents. This leads to the concept of illness understanding because disparate beliefs can undermine the therapeutic process through which treatment burden can be addressed. The chapter finishes with a conceptual model that proposes how to ameliorate these issues and maximise the impact of the 6MR.

6.5.1: Burden of treatment theory

Patients are required to carry out work to manage a long-term condition and must possess the capacity to do so. When demand exceeds capacity, treatment becomes burdensome and is likely to result in reduced adherence, wasted resources and poorer outcomes (May, Montori and Mair 2009). The concept of treatment burden relates to others including minimally disruptive medicine, multi-morbidity, polypharmacy and patient capacity. It is distinct from but related to illness burden (Figure 25). For example, attending outpatient appointments would be categorised as treatment burden but hemiparesis would be classified as illness burden. Polypharmacy (the prescribing of multiple medications) and multi-morbidity are common in stroke (Gallacher 2016) and may contribute to treatment burden.

Figure 25: Relationship between illness and treatment burden

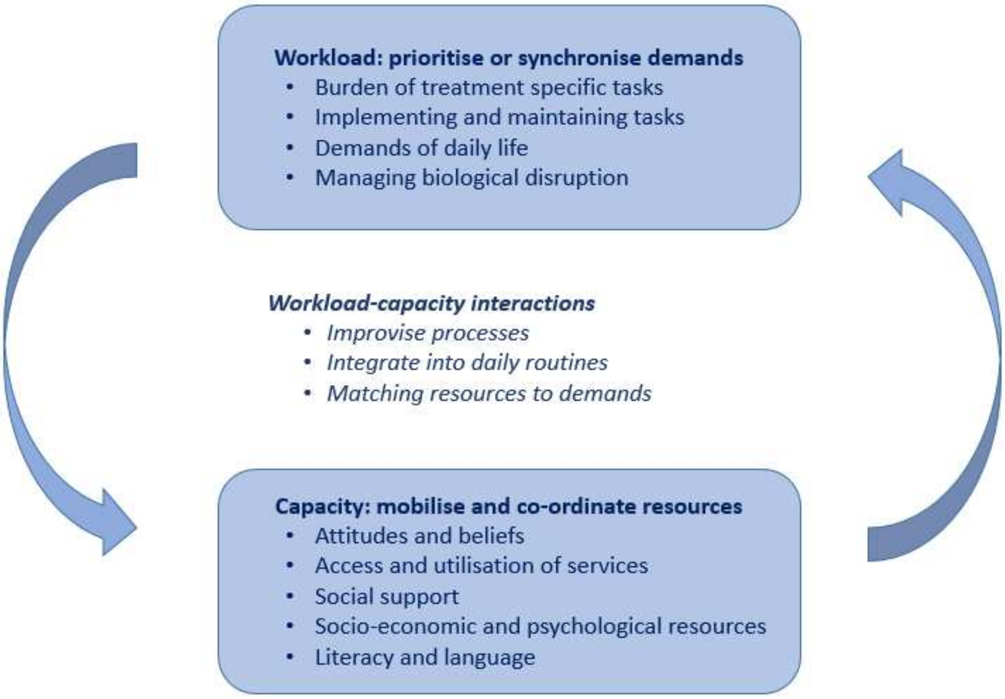


[1] Corbin and Strauss, 1985; [2] Demain et al. 2015

Patient workload encompasses all the demands of daily life including treatment, self-care and life in general. This requires time, energy and a continual process of prioritising or synchronising demands.

Challenges that can exacerbate the felt burden of these demands include health provider constraints and personal factors, such as fatigue (Eton et al. 2015). Capacity denotes the ability to manage this work and includes socio-economic and psychological resources, literacy, language and social support (Shippee et al. 2012) (Figure 26).

Figure 26: The interplay between workload and capacity

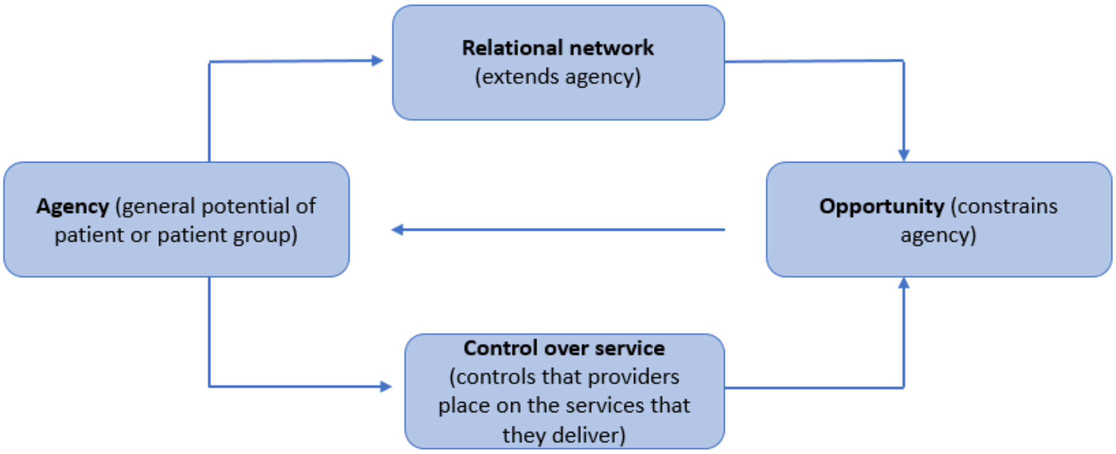


Adapted from Shippee et al. (2012)

Capacity extends beyond personal agency and exercising it may depend on relationality, which refers to social networks including family and other forms of support (Eton et al. 2015). While most people have a relational network, older people are more prone to experience an unstable and diminishing network and may become socially isolated. The strength, size and complexity of networks vary over time, in part due to the demands placed on them. Importantly, these networks include healthcare and other professionals who are often essential contributors (May et al. 2014).

The implications of agency and relationality are firstly that an individual condition may not be the appropriate unit of analysis. Instead, agency is likely to be influenced by the cumulative effects of, for example, co-morbidities and poverty. Secondly, the appropriate unit of analysis is not necessarily an individual patient but might be their immediate family whose collective actions bolster capacity (May et al. 2014). These networks need to be co-ordinated and mobilised in order to absorb and compensate for disruption (Demain et al. 2015), an expression of structural resilience. Conversely, capacity can be diminished by the controls that providers place on the services that they deliver and unequal distribution of opportunities (Eton et al. 2015). In summary, capacity is the interplay between agency, relational networks and the properties of social systems that constrain them (May et al. 2014) (Figure 27).

Figure 27: Mobilising capacity



Adapted from May et al. (2014)

Patients have to co-ordinate and mobilise resources whilst balancing capacity against demands which is a dynamic process that takes considerable effort. With multiple long-term conditions, the burden can accumulate over time while personal and collective resources may diminish, making it harder to manage daily life (Shippee et al. 2012). The concept of minimally disruptive medicine recognises the time and effort required to adhere to treatment regimens and aims to impose the smallest possible burden so allowing patients to focus on achieving their own goals (Leppin, Montori and Gionfriddo 2015). It also challenges individualistic policy by acknowledging *collective* treatment burden as well as recognising that capacity is likely to be highly sensitive to pre-existing health inequalities (May et al. 2014).

Further difficulties reflects lack of co-ordination between services, and the need to prioritise the demands of each condition whilst trying to maintain a 'normal' life. Patients may need to develop multiple techniques to manage symptoms and be able to distinguish between, and respond to, exacerbations of different co-morbidities (Morris et al. 2011). If a treatment appears to work, they may be more easily convinced to continue it but the reverse can also be true, in that it is regarded as no longer necessary. For example, side effects attributed to statins may outweigh perceived benefits once cholesterol levels are within normal limits. When care involves multiple specialities, patients can become overwhelmed by fragmented, demanding care and may resort to making their own treatment decisions without discussion (Shippee et al. 2012), as was the case for some of my respondents.

Gallacher's (2013) systematic review of qualitative research found that many services appeared led by the priorities of healthcare systems rather than patient need. The review took a pragmatic view of treatment burden post-stroke. Burden was characterised by the need to learn about stroke, develop and enact management plans and interact with other people including health professionals. Enacting strategies involved different tasks at different times, such as managing re-admissions to hospital. While the model is limited, of note was the difficulty patients had in differentiating the roles of multiple health and social care professionals, managing poor continuity of care and problems with information provision, including conflicting advice (Gallacher et al. 2013).

6.5.1.1: Provision of information and the relationship with burden

There is considerable evidence that provision of information does not meet the needs of stroke patients or carers and this adds to treatment burden. Key failings centre around access, timing, format, content and method of delivery (Forster et al. 2012; Gallacher 2016; Hafsteinsdóttir et al. 2011), which my respondents also commented on. Much of the literature fails to differentiate between the provision of information and patient education: the former refers to facilitating *communication* about healthcare, for example providing leaflets, while the latter facilitates *learning*, or the interpretation and synthesis of information in a way that leads to changes in behaviour or attitude (Hafsteinsdóttir et al. 2011). The majority of patients and carers want to learn about their condition, so information provision can be used as a tool to develop shared decision-making, as part of establishing a therapeutic relationship (Roy et al. 2015) and to reduce treatment burden.

In terms of how information is delivered, a comprehensive mixed methods study of patient preferences for cardiovascular related health information found that 'an overwhelming number' preferred to receive health information face-to-face from a clinician. They also wanted a summary handout at the end of the consultation to remind them of what was discussed (Gaglio, Glasgow and Bull 2012, p115), as did many of my respondents. In addition, all participants disliked generic information and wanted it 'tailored and made specific to their individual health conditions and situations' (Gaglio, Glasgow and Bull 2012, p116-7). Interestingly, they did not want information from non-medical professionals for fear that it would be incorrect and their questions would not be properly answered. Respondents with moderate to high levels of literacy also sourced material from elsewhere and made judgements about its reliability (Gaglio, Glasgow and Bull 2012), similar to many of my respondents. In contrast, those with low health literacy levels found written information, including on the internet, the least helpful format.

Linked to information is the issue of health literacy, or the ability 'to gain access to, understand, and use information to promote and maintain good health' (Nutbeam 2000, p263). The concept is relevant in that literacy informs health literacy, and knowledge and understanding supports informed decision-making (Tones 2002). Many patients have stroke related impairments, particularly memory and language that make it difficult to comprehend and apply health information to their own circumstances (Forster et al. 2012). Alongside these impairments, it is important to consider other issues including demographic, socio-economic and cultural factors (Sørensen et al. 2012). The 6MR provides written information but those with lower literacy levels (or English as a second language) may not find this helpful (Paasche-Orlow and Wolf 2007). In addition, low levels of health literacy are associated with less effective self-management, less adherence with medication and poorer health outcomes (Brooks et al. 2016).

Cameron et al. (2013) brings these issues together with a 'Timing it Right Framework' to identify what type of support stroke patients and their families need, when and by whom. The stages loosely accord with those of Kirkevold (2002) (Table 31, section 6.4.2) and information is included under the umbrella of support needs, alongside emotional, practical and training needs. This makes explicit the link between providing information, processing and understanding it, and then integrating it into daily life. Table 32 provides an example for long-term needs.

Table 32: Long-term support needs adapted from 'Timing it Right Framework'

Support needed	Source and type of support	Focus and goal of care
Information: communication; life after stroke; community integration; secondary prevention; coping with potential health events; carer respite. **Emotional**: emotional comfort; caring for the carer. **Practical**: continuation of support received in the first months post-discharge; re-assessment for community and rehabilitation services; peer support groups; respite. **Training**: communication skills; secondary prevention; learning to live with a long-term condition.	**Peers**: emotional support **Professionals**: support not evident **Friends and family**: support dwindles over time	The aspiration is that patient and carer continue to be a focus of care in terms of monitoring well-being, service provision and information.

(Cameron et al. 2013, p320)

For education to be effective, it needs to be interactive and repetitive, with time to check that recipients understand and retain information so that they can integrate it into daily life (Cameron et al. 2016). However, the 6MR does not have the capacity to do this because of its limited one-off nature and is therefore incongruent with the 'Timing it Right Framework'.

The next section considers the relevance of illness understanding to treatment burden.

6.5.2: Treatment burden and illness understanding

While May et al. (2014) conceptualised treatment burden in terms of workload versus capacity, an alternative model views it as a series of biological, biographical and relational disruptions (Demain et al. 2015) which echoes Corbin and Strauss' (1985) three lines of work (illness, everyday and biographical work). Biological disruption refers to the physical effects of treatment such as pain and fatigue; relational disruption incorporates the impact of treatment on carers and family and trying to minimise the burden; and biographical disruption encapsulates disruption to the individual's narrative and sense of self (Demain et al. 2015). The model suggests that patients have to carry out 'adaptive treatment work' to psychologically adjust and re-frame their identity but they may also chose 'rationalised non-adherence' to minimise biological, biographical or relational disruption (Demain et al. 2015, p11). So rather than non-adherence indicating that they lack the skills, knowledge or capacity to comply (May, Montori and Mair 2009), patients may choose partial or total non-adherence as a strategy to maintain control and balance competing priorities and this may reflect their illness understanding.

Clinicians and patients are likely to understand illness and rehabilitation from different perspectives with clinicians focusing on biomedical aspects and patients more concerned with the impact on daily life. Patients expect clinicians to listen to their beliefs about the cause their illness and to understand their experiences and circumstances (Holt, Pincus and Vogel 2015). However, this can be difficult to achieve because both parties understand health through a different lens (Street et al. 2009). Patients' understanding are idiosyncratic and based on a combination of experience and information from various sources while clinicians' understanding are a mixture of 'personal experience, unexamined heuristics, and clinical evidence' (Street et al. 2009, p298). Both need to reflect on their own belief systems and appreciate the other's point of view as a foundation for the interaction and to circumvent mismatched expectations that can increase treatment burden.

Rather than a 'traditional' didactic approach to the patient-professional consultation, it should start by ascertaining what the patient does and does not understand about their condition and reflect on their experience of living with long-term illness (Nunstedt et al. 2017). Through understanding the patient's perspective, clinicians (including reviewers) should be better equipped to support illness understanding and suggest management strategies that are coherent with everyday life. This ought to be a continuous process whereby the patient can trial strategies and review them in collaboration with their clinician (Nunstedt et al. 2017).

In all but a few cases, the 6MR was the first encounter between reviewer and patient and did not appear to incorporate any measure of illness understanding. Some reviewers had discussed patients with therapists, prior to the 6MR. This provided useful background information but also conveyed negative perceptions, such as respondents being 'difficult'. Although the reviewer asked respondents about their stroke, this elicited a factual account rather than uncovering their illness understanding.

Disparate understanding can affect lines of responsibility. Becker and Kaufman's (1995) study of patients' and doctors' views of stroke highlighted ambiguous messages that shaped patients' understanding of rehabilitation. Doctors knew that regaining function was a combination of spontaneous neurological recovery and repetitive task training but did not make this distinction clear. Most patients assumed that if they made enough effort they would recover lost functions, transforming rehabilitation from 'a professional to a moral domain' whereby the burden of recovery was regarded as the patient's responsibility (Becker and Kaufman 1995, p176), similar to guidelines emphasising personal responsibility yet also exhorting client-centred care (NHS England 2016).

The next section presents a conceptual model that draws together the findings and discussion and suggests approaches to ameliorating the 6MR's limitations.

6.6: A conceptual framework for the 6MR: increasing capacity and reducing burden

Figure 28 provide a model of the 6MR that is underpinned by the concept of minimally disruptive medicine and burden of treatment. It encapsulates the key contextual issues that influenced the 6MR and approaches that could be employed to improve its impact, reduce the burden of treatment and address the 'hotspots' that respondents identified. The innermost concentric ring represents the immediate world of patient and carer. It incorporates the burden of treatment and illness and the many contextual influences that influenced their response to the 6MR. The next concentric ring reflects their wider relational network of family, friends and other sources of help including healthcare and other professionals (May et al. 2014). The outer rings represent local structural factors such as the availability of services and wider socio-political factors. Both local and national factors are likely to influence professional assessment of need in contrast to patients' expressed needs. For example, guidelines recommend that further therapy should not be offered unless specific goals can be identified (Royal College of Physicians 2016a) whereas patients may want more therapy precisely because their progress has plateaued. Indirect outcomes of the review, in terms of self-management and community integration, may be influenced by different interpretations of need but the findings suggested that contextual issues were more important, hence they are represented on Figure 28 as crossing into the relational network and local structural factors.

Four principles have been suggested to minimise treatment burden (May, Montori and Mair 2009), all relevant to the 6MR. The first is to identify individuals who are over-burdened, establish the nature of the burden and identify capacity problems. Specific to stroke, limits to capacity might include cognitive and communication impairments that would reduce comprehension of written material such as the Stroke Association's information pack. Memory impairment can also limit capacity and some of my respondents could not remember what was discussed during their review so did not follow-up suggestions or were reliant on their carer to do so. Establishing if patients and carers feel overburdened, and the nature of the burden, should include consideration of their preferences and values, the effects of co-morbidities, social circumstances and changes over time (May, Montori and Mair 2009).

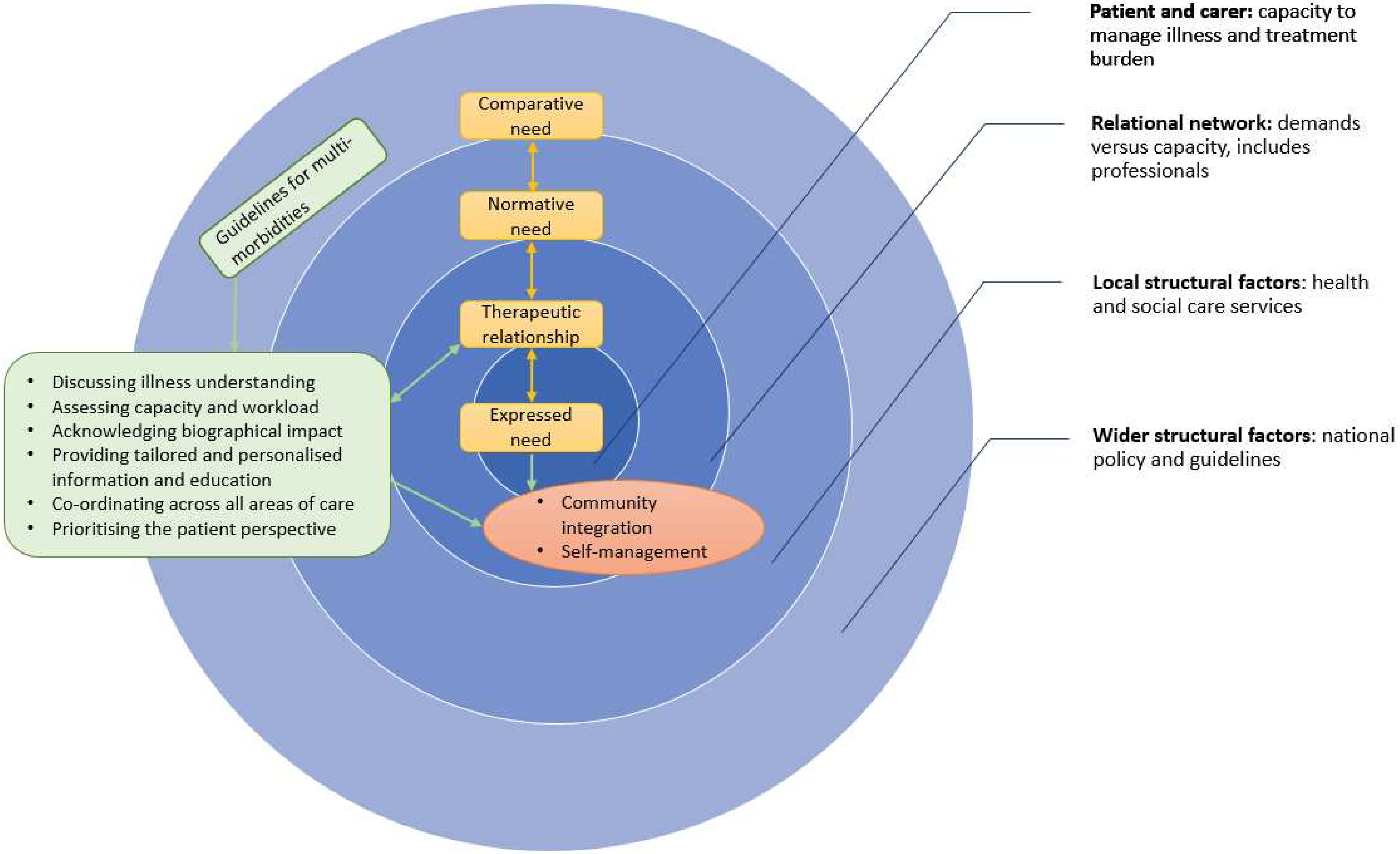
Secondly, clinicians should adopt holistic approaches and co-ordinate across all areas of care rather than remaining condition specific. This was recommended with reference to GPs, who are incentivised by the Quality and Outcomes Framework to meet specific clinical targets for individual chronic diseases to align with policy objectives (Allen, Whittaker and Sutton 2017). Moreover, the SNSs and SA co-ordinators interviewed in this study did not want to become generic workers; they valued their area of expertise and did not stray beyond their remit. Clearly there needs to be a balance between co-ordinating across conditions and services whilst maintaining specific understanding of, and expertise in, stroke.

Further reflecting the tension between condition-specific expertise and a more holistic approach, the third recommendation suggests that clinical evidence should acknowledge and specifically address managing co-morbidities, for example, stroke and diabetes. In fact, improved dissemination of clinical knowledge across conditions might indirectly improve care co-ordination (May, Montori and Mair 2009). While the most recent guidelines acknowledge that 'many of the needs of a person with stroke will relate to other co-morbidities' (Royal College of Physicians 2016a, p119), they stop short of crossing condition specific boundaries. Similarly, integrated working across health, social and voluntary sectors is recommended as part of a whole systems approach to 'alleviate the personal and social impact of dependency' (Royal College of Physicians 2016a, p120) but the implications are not addressed. While this is understandable given the remit of clinical guidelines and their underlying medical discourse, it reinforces a medical/condition specific focus that is at odds with the priorities of many of my respondents and the complexity of their lived experience. It is worth remembering that policy aspirations for the 6MR (Figure 22) included participation and community integration, although this outcome was not substantiated in my findings.

Finally, prioritising the patient perspective is key and starts with an appreciation of illness understanding and forming a therapeutic alliance. As only patients and carers can report on the burden of treatment, they should collaborate in deciding what problems to address, when and to what extent. Enabling patients to take control of their treatment means recognising that they can make meaningful choices about the interactions between illness and treatment, including disentangling individual from collective burdens (May, Montori and Mair 2009). The implications for the 6MR are that patients may identify priorities that are not stroke specific but need addressing. Again, some of my respondents had priorities (and illness understanding) at odds with that of the reviewer, which resulted in an unsatisfactory encounter.

In conclusion, drawing on minimally disruptive medicine and treatment burden has provided a different perspective through which the 6MR can be viewed. It has highlighted potential areas for improvement in the review and also identified aspects that merit further investigation; these will be presented in the conclusion of the thesis.

Figure 28: 6MR: increasing capacity and reducing treatment burden



6.7: Chapter summary

The 6MR is set against a background of policy exhorting individual responsibility and self-management based on a medical discourse that alludes to wider contextual issues but cannot fully address them. As a one-off interaction, the 6MR struggled to address the impact of stroke and the work of managing a long-term condition and this highlighted a dissonance between policy aspirations and actual outcomes. The concept of treatment burden helped conceptualise the workload of managing life after stroke but there appeared to be a tension between providing expert stroke-specific advice, which most respondents valued, and taking a more holistic approach cutting across services and conditions, which took precedence for other respondents.

The next and final chapter provides an overview of the study, reflects on the findings and outlines implications for practice and recommendations for further research.

Chapter 7: Conclusion

7.1: Introduction

This chapter will start by reviewing the study findings in relation to the research questions. This is followed by discussing study limitations, the implications for practice, suggestions for future research and personal reflections.

7.2: Returning to the research questions

The study used a case study approach underpinned by critical realism. It intended to explore the purpose and outcomes of the 6MR and the underlying mechanisms by which these were achieved. The questions it set out to answer were:

1. What is the purpose of the review process from the perspective of patient, carer, provider and commissioner?
2. What are the intended and/or unintended outcomes of the review process from the perspective of patient, carer, provider and commissioner?
3. By what mechanisms does the review process achieve the intended outcomes? What are the enablers and barriers?

The intended purpose of the review varied according to who was asked and the model of review but in essence it was an assessment of need, as policy dictates (Royal College of Physicians 2016a). Commissioners suggested that it could act as a safety net but there was no evidence to substantiate this or other wider aspirations such as cost-effectiveness. Reviewers wanted to address self-management and secondary prevention but did not sufficiently differentiate between provision of information, education and the complex process of behavioural change. While SNSs focused on medical issues, the SA co-ordinator was more concerned with social and emotional adjustment. Patients and carers were mostly unsure of the purpose.

Observation of reviews, coupled with interviews, differentiated the outcomes into tangible actions specific to SNSs such as initiating referrals or investigations; signposting to other agencies; provision of information; and providing advice about lifestyle factors. Reviewers were skilled at forming a rapport with respondents which appeared to be the key mechanism by which they engaged them in the 6MR. However, due to the limited nature of the review this could not be developed into a full therapeutic relationship. Moreover, not all respondents trusted reviewers or followed their advice with some preferring to instigate their own approach to self-management.

The impact of the 6MR appeared to be limited due to its narrow remit set against the profound impact of stroke. Although it occasionally coincided with a 'hotspot', the timing was mostly dictated by systemic procedures and it therefore appeared as a separate entity, not embedded into the care pathway. Similarly, as self-management was not part of an overall approach what the 6MR could offer was limited.

There were no significant unintended outcomes although occasionally patients were confused by inconsistent advice from different clinicians. While it was suggested that the review could increase dependency this did not appear to be the case and there were more instances of patients rejecting the intervention because they wanted to get on with daily life in their own way.

7.3: Study strengths and limitations

While challenges in carrying out the research have been discussed in the method section it is worth recapping the main study limitations. As anticipated, the most difficult issue was accessing case study sites and then recruiting respondents, both staff and patients (Table 18, section 3.4.7). While most problems were resolved the following are of note:

- It was not possible to include a third model of review where a therapist, or therapy assistant, usually attached to a community stroke team carries out the review. It is possible that a therapist would have attempted to bridge the divide between social and medical approaches and incorporated goal setting, or at least reviewed previous goals.
- There were significant delays in gaining approval for site 3 and therefore recruitment commenced a year later than the other sites, only a small number of participants could be recruited and it was only possible to interview patients and carers on one occasion.
- I had particularly wanted to include patients discharged to care homes because they are so often excluded from research, the SNSs wanted to include them and from clinical experience, their needs often go unmet. However, it was not possible to do so because of ethical concerns and capacity to consent.
- Those with aphasia were included but a small number had severe aphasia and were unable to comprehensively express their perspective, instead relying on their carer who may have had different views and priorities. However, this appeared preferable to excluding them.

- It was not possible to ascertain what proportion of patients invited for 6MR declined it, or how many patients invited to take part in the study declined. Those who rejected the 6MR or taking part in the study may have held different views to those who did participate.
- The case study sites had mixed areas of social deprivation but overall were wealthier than the UK average. Similarly, there was an under-representation of people from Black and minority ethnic groups. Although qualitative work does not seek a statistically representative sample, I wanted to have a more diverse sample but the logistics, in terms of time, money and access, precluded this.
- It was hard to identify and engage commissioners specific to stroke so only a small number were interviewed. Similarly, it was hard to engage GPs and only two were interviewed, although they are peripheral to the review process. I considered interviewing stroke consultants but they are all inpatient based, were unlikely to have time and did not have any input into the 6MR. I therefore decided against this.
- Observing respondent's 6MR was somewhat 'hit and miss' which meant that I interviewed considerably more patients than whose review I observed in order to reach theoretical saturation. It was also surprisingly difficult to elicit feedback from reviewers about 6MRs that I had missed, in terms of their reflections, rather than factual accounts.
- I only gained research governance approval to observe meetings in case study 1 and as these were very illuminating it was a loss not to have had this opportunity in the other sites.

Despite these limitations, the study was underpinned by a clear theoretical and methodological base and fills a gap in the stroke literature. It provides a detailed account of the 6MR drawing on the perspective of all stakeholders and interrogating the evidence base. The case study approach allowed the collection of multiple sources of data and comparison within and across sites in a comprehensive and systematic approach that identified feasible recommendations which have potential to improve the patient experience.

7.4: Implications for policy, practice and recommendations for future research

This section considers the implications for policy makers and those who carry out reviews, as well as suggestions for further research.

7.4.1: Recommendations for reviewers

While reviewers had limited agency and had to work within structural constraints, there are small adjustments that could increase the impact of the review without being onerous for already busy reviewers. These are outlined in Table 33. Recommendations that span the remit of reviewer and commissioner are discussed in the following section.

Table 33: Recommendations for reviewers

	Problem	Recommendations
Timing	The 6MR appeared to have an arbitrary timeframe that did not coincide with the 'hotspot' of community services withdrawing.	The 6MR should be timed to coincide with a 'hotspot' when community services are about to, or have just, withdrawn. Similarly, the six-week review could be timed to coincide with the 'hotspot' identified post-discharge.
Illness understanding and the burden of treatment	Reviewers, patients and carers understand health through a different lens (Nunstedt et al. 2017). Reviewers were often medically focused while patients were more concerned with managing daily life and/or other long-term conditions.	At the start of a review, both parties need to reflect on their own belief systems and appreciate the other's point of view as a foundation for the interaction and to circumvent mismatched expectations that can increase treatment burden. The reviewer needs to ascertain the treatment burden and the patient/carer's capacity to manage it.
Provision of information	On occasion, respondents lacked sufficient health literacy to understand the material they had been given. More commonly, respondents did not read SA information packs especially when provided on inpatient wards. In addition, patients and carers did not find generic information helpful and/or felt overwhelmed by it.	All reviewers need to take into consideration patient's health literacy levels alongside stroke-specific impairments that make it difficult to comprehend written information. Carers may have a different level of health literacy. The SA pack provided on inpatient wards could be more selective and therefore more relevant to the stage of recovery. Rather than providing the same pack at the 6MR, it would be preferable to select relevant material in collaboration with patients.
Tailored and patient-led self-management and secondary prevention.	For information or education to have any potential to lead to behavioural change, it needs to be in different formats, repeated, reviewed and consolidated over time (Michie et al. 2011). Goal setting needs to be an integral part of the process, just as it is for other areas of rehabilitation. However, the 6MR is not sufficiently embedded in the care pathway and does not have the capacity to do this in isolation.	There needs to be a consistent approach to self-management from inpatient admission to 6MR and beyond. This should involve a) opportunities to consolidate information and approaches to self-management along the care pathway, such as the 'life after stroke' group in site 2, and b) a tailored and patient-led approach. However, not all patients found standard goal setting helpful and the process needs to be adapted to what works for the individual.

Remembering the content and outcomes	Some respondents could not remember what was discussed during their review, what follow-up would ensue and by whom. They did not find a copy of the report sent to GPs helpful. Some recommendations were forgotten or not followed through.	A brief summary of what was discussed, follow-up actions and by whom, and any goals, should be recorded during the review. The format can be whatever patients find helpful such as pen and paper, email or voice recorder. This does not need to be time consuming and where possible patients/carers can make their own notes. There needs to be a mechanism for ensuring referrals are followed up, which could be actioned by an administrator.
Tailored medical advice	Explaining and reviewing specific aspects of a stroke and reviewing medication was a valuable component of SNS reviews and they were able to liaise directly with consultants. Those who received SA reviews missed out on this aspect.	All patients should have the opportunity of tailored advice and a medication review. Although community pharmacists and GPs may be able to address some aspects, SNSs appeared best placed to do so.
Therapy review and goal setting	Therapy (or patient) goals were not reviewed and this added to the sense that the 6MR was a standalone event. Other aspects of therapy, such as specialised equipment and splinting, were not fully addressed.	Therapy goals should be reviewed and patients encouraged to set their own goals. Younger people may need additional input with return to work (although access to vocational rehabilitation appears limited). As already happens in some areas, a therapy review should be part of the process.
Visual/visuo-perceptual impairments	There were instances where visual/visuo-perceptual disorders appeared to lack adequate investigation prior to or during 6MR. While some impairments may not respond to intervention, they still require specialist assessment.	Reviewers need to check what investigations have been carried out and by whom. Patients with stroke related visual impairment should already have been assessed by an orthoptist (Rowe 2014) but may need (re-) referral.
Vestibular impairment	Similar to above, there were instances where vestibular problems appeared to have been overlooked prior to and during the 6MR.	As above, reviewers should check previous interventions and consider (re-) referral to a neuro-physiotherapist with vestibular experience, audio-vestibular physician or an ear nose and throat specialist (Edmans 2011).

7.4.2: Recommendations for policymakers, commissioners and managers

The findings have demonstrated considerable dissonance between the aspirations of clinical guidelines (Hargroves, French and Trickey 2014) and what the 6MR can realistically achieve. As a one-off intervention, the 6MR cannot deliver comprehensive self-management or provide continuity of care unless it is incorporated into a whole systems approach. In addition, the rigid timeframe is service rather than patient-led. Patients do plateau, and this can be for several months, but there may be fresh opportunities for improvement that should be capitalised on in a timely fashion. Equally, patients may deteriorate and need a burst of therapy to stabilise or regain lost skills. Patients are best placed to identify these opportunities rather than waiting for the next review. GPs are unlikely to identify such needs so a 'point of continuous contact' (Gallacher et al. 2013, p11), whether SNS or another clinician should be available.

Most reviewers lacked administrative support and spent considerable time carrying out tasks that were a poor use of their expertise. Whilst acknowledging NHS resource constraints, it is false economy not to provide administrative support that could free-up clinicians to tackle their waiting lists. As well as organising appointments, administrators could check referrals and investigations had been followed through in a timely manner.

Whilst appreciating the importance of outcome measures, the Modified Rankin Scale used by SSNAP is a crude tool that no respondent (reviewers, clinicians and therapists) found helpful. Given that rehabilitation is such a complex intervention and the 6MR is slotted in at different stages of the process, it is unlikely that any one standardised measure would be suitable or able to differentiate the impact of each element of the intervention. However, consideration should be given to a menu of measures including ones that determine outcomes from a patient perspective.

Reviewers had different approaches and strengths. SNSs were able to deliver tailored advice and medication reviews which the SA co-ordinator could not provide. However, the co-ordinator had excellent communication skills, a comprehensive knowledge of community services and more time to support patients and carers. Therefore consideration should be given to clinicians providing the 6MR while the Stroke Association are commissioned to *complement* statutory services and focus on providing 'support in picking up everyday life' (Jenkins, Brigden and King 2013, p258).

7.4.3: Recommendations for future research

Recommendations for further research stem from the study limitations. I have not included self-management as although this is a pertinent area there is already a great deal of research specific to stroke and self-management (Sadler et al. 2017; Jones et al. 2016). Recommendations are as follows:

1. **Care homes**: Reviewers expressed concerns about the experiences of patients discharged to care homes but the problems they identified were often wider than their remit could address. The needs of younger people discharged to care homes are particularly difficult for care homes to meet (based on what reviewers reported). These patients usually have severe impairments, particularly communication and cognitive difficulties, such that they may not be able to make known their needs and preferences.
2. **Diverse experiences:** the 6MR appeared less helpful for younger people, especially those wanting to resume work; those with significant co-morbidities; and/or severe (haemorrhagic) stroke. It would be worth exploring how their needs vary in more depth than this study allowed. Similarly, demographic factors need further exploration including ethnicity, socio-economic status and urban/rural location.
3. **Integrated care, care co-ordination and the role of the GP**: there appeared to be a gap in care co-ordination and while some GPs took on that role, many did not. Reviewers were not able to subsume the role of care co-ordinator but the evidence for this approach ameliorating fragmented care is limited anyway (Hudson 2015). Future research needs to explore how best to embed the 6MR within the care pathway and marry it with a co-ordinated long-term support system with a 'point of continuous contact' (Gallacher et al. 2013, p11) for those who need it.
4. **Targeted reviews and cost-effectiveness:** while research suggests targeting reviews could be an appropriate use of resources (Forster et al. 2015; McKevitt et al. 2011), policy dictates that all patients should be reviewed yearly (Royal College of Physicians 2016a). SNSs thought it would be difficult to screen referrals and ran the risk of missing vulnerable patients. However, many respondents found the 6MR helpful but did not want an annual review, as service evaluations have found (Curtis and Gallifent 2014; Gedge, France and Jones 2013). Given resource constraints it would be worth researching how to accurately target reviews and how to circumvent the SNSs' concerns.
5. **Assessing treatment burden**: although there are tools to assess treatment burden that claim to suit multiple chronic conditions (Tran et al. 2012; Leppin, Montori and Gionfriddo 2015) this needs to be substantiated in the context of stroke and the review process.

7.5: A personal reflection on the doctoral process

The choice of topic was driven by clinical experience and this personal motivation has the capacity to influence the process (Bazeley 2013). For example, data analysis might have been biased by preconceived notions and I could have concentrated on finding evidence to confirm my views. Interpretivism would regard this as a strong possibility because the researcher's perspective and values 'inevitably' influence the findings while positivism suggests that it is possible to conduct 'value free' inquiry because the world exists independently of the researcher (Ritchie and Lewis 2003, p16). However, the critical realist stance taken here falls in the middle ground and Yin's (2014) case study approach builds in mechanisms to enhance rigour (section 3.4.9). This was supported by taking a reflexive approach and having regular supervision to question my decision making and further interrogate the data.

How, or if, the researcher affects the process also applies to interactions with respondents (Bazeley 2013). As a former occupational therapist it was important to maintain a neutral stance especially when interviewing other therapists. For example, when attending inpatient multi-disciplinary meetings, I wanted to comment on the goals that occupational therapists selected *for* patients. While I understood that therapists had to run with the system, the goals appeared led by an emphasis on rapid discharge and the SSNAP audit and this conflicted with the person-centred philosophy of occupational therapy. I have experienced this dissonance both clinically, and when supervising undergraduate occupational therapy students on placement, and it makes me question therapists' values. Similarly, I was occasionally shocked by the tone and content of multi-disciplinary team discussions and evidence of poor communication between staff, patients and carers. While I understood the reasons for this, such as heavy caseloads, it reminded me of wards I had worked on as a new-graduate and it was an uncomfortable experience.

On the plus side, I learnt a great deal from the reviewers who were all generous with their time and explanations. I also had the privilege of getting to know patients and carers whilst learning about their experiences. I chose to interview people at home, not just to save them time and inconvenience, but because people feel more comfortable in their own environment. It changes the power dynamics - it is their home and I am a guest, so they have control over the situation.

In terms of what I have learnt overall, I have a better understanding of methodology and how to manage a larger project than I have previously undertaken. Analysing so much data and ensuring that my analysis was an accurate reflection of it was particularly difficult. Most striking was the profound impact of stroke, even when respondents had recovered well, and the importance of context to their experience of, and response to, illness. This prompted me to reflect at length on clinical practice, the impact of policy on patient care and the undergraduate occupational therapy curriculum.

7.6: Chapter summary

There are many reasons why the above recommendations may be rejected as ‘unrealistic’ by reviewers, commissioners or policymakers but they are grounded in the data and represent the views of a large number of patients, carers and other stakeholders. The review process was a pragmatic strategy to address the feeling of abandonment that stroke survivors expressed in the context of relatively short-term rehabilitation set against long-term sequelae (Stroke Association 2012). However, it is now entrenched in policy with aspirations that do not take account of contextual issues many of which were illuminated by this research.

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Appendices

Appendix 1: Example search update for 'unmet need' (19th Dec 2016)

Search	Search term	Number of hits
CINAHL		
1	Stroke OR 'cerebrovascular accident' OR CVA OR 'stroke unit' OR 'stroke patient'	30,179
2	Limit: 2007 onwards	18,695
3	'Health services needs and demands' OR 'information needs' OR 'needs assessment'. Limit: 2007 onwards	6074
4	2 + 3 Screened by title and excluded those from countries with non-Western health care systems; inpatient focus; veterans or already accessed. Screened by abstract: excluded by above criteria	90 43 **11**
Psychinfo		
1	Stroke OR 'cerebrovascular accident' OR CVA	27,997
2	'Needs assessment' OR 'unmet need'	7137
3	1 + 2 (no limits)	69
4	Screened by title and/or abstract, same criteria as above	**4**
PubMed (truncated)		
1	Stroke OR 'cerebrovascular accident' OR CVA OR 'brain ischaemia'	266,092
2	'needs analysis' OR 'needs assessment' OR 'unmet AND need*'	40,996
3	1 + 2 (no limits)	579
4	3 with limit: published in the last 10 years	398
5	4 with limit: humans only	329
6	5 with limits of 'NOT epilepsy', 'NOT sickle cell disease' and 'NOT veterans' Screened by title and excluded those I already had (plus 1 article in Dutch)	282 **5**

Appendix 2: Studies looking at unmet need post-stroke

Citation	Aim(s)	Design and country	Recruitment, sample size and response rate (RR)	How was need conceptualised and measured?	Key findings and comments
Section 2.6.2 National evidence of unmet need					
McKevitt, C. et al. (2011) Self-reported long-term needs after stroke. *Stroke*. 42:1398-1403.	To estimate the prevalence of self-reported need in community dwelling adults.	A cross-sectional national survey.	National and population registers (Oxford and South London). Adults over 18yrs, 1-5yrs post-stroke. RR 60% (571 of 958 questionnaires) and 78% (228 of 294). n=799.	Self-reported need. Adapted validated psychometric questionnaire for traumatic brain injury. Stroke is an acquired brain injury and has different presentation and prognosis, although arguably similar in terms of long-term needs and community reintegration.	51% reported no unmet need; amongst the remaining 49% the median number of unmet needs was 3 (range 1-13). 54% reported an unmet need for stroke information, 52% reported reduction/loss of work (more from Black ethnic groups, p=0.006), 18% reported loss of income and 31% an increase in expenses. Ethnicity (p=0.032) and disability (p=0.014) were associated with total number of unmet needs.
Stroke Association (2012) *Struggling to recover.* http://www.stroke.org.uk/involved/struggling-recover	To tell the story of UK stroke survivors and the challenges they experienced.	A daily life national survey (2011) of patients/carers and interview based case studies.	No method section. RR: not stated. N=2050-2200 (unclear) 8 interviews.	Appeared to be self-reported.	Patients and carers reported problems with -and gaps in- service provision at all stages of the care pathway, especially post-discharge. The paper did not distinguish between felt, expressed and normative need. E-mailed several times for supplementary data on the method (as the website advised) but it was not forthcoming.

Care Quality Commission (2011) *A review of services for people who have had a stroke and their carers*. http://www.cqc.org.uk/sites/default/files/documents/supporting_life_after_stroke_national_report.pdf	A review of the care pathway for patients and carers from discharge to long-term care.	Mixed methods across 9 areas in England.	Consultation with patient representatives and individuals including 'hard to reach' groups; site visits; data from health and social services; evaluation of patient information; evaluation of care provided to about 25 people in each area in the 6 weeks post-discharge, using case notes.	Not defined as such, instead developed an assessment framework based on the quality markers of the National Stroke Strategy (2007) and created a set of 15 indicators which were grouped as follows: providing the right care and support; involving and informing patients and carers; working together to deliver effective care.	There was significant variation in service provision across the 9 areas. Patients could not always access the services they needed when necessary, including community stroke-specific therapy; services could be difficult to access; they were not always tailored to need; patients and carers were not always involved in decision-making. This is a comprehensive report with additional evaluations. Although not specifically evaluating unmet need it highlights gaps in service provision consistent with the Stroke Association report.
NIHR CLAHRC Greater Manchester (2010) *Post-stroke review pilot project. Evaluation report*. http://clahrc-gm.nihr.ac.uk/wp-	To evaluate the Greater Manchester Stroke Assessment Tool (GM-SAT).	A pilot study across 10 sites in England. 15 Stroke Association support workers attended a 1-day training course before using the GM-	137 6MRs, Jul-Aug 2010. Recruitment restricted to commissioners from whom approval to participate could be obtained within a short timescale (details unclear). 6MRs carried out in patients' homes.	Unmet need was defined as 'a problem that is not being addressed or one that is being addressed but insufficiently (i.e. undermet need)' (p3).	Unmet needs varied between 0-14 per person and spanned 34 of the 35 areas of the GM-SAT. Main concerns were fatigue (34%), memory/ concentration (26%), secondary prevention (22%) and anxiety and depression (15% and 19% respectively). There was no description of demographics, including pre-existing conditions.

content/uploads/Stroke-review-report-web.pdf		SAT; and patient questionnaires.	Not stated how many people declined review.		There was no information on how many declined or why.
Rowe, F (2013) Care provision and unmet need for post stroke visual impairment. Final report. https://www.stroke.org.uk/sites/default/files/final_report_unmet_need_2013.pdf	To quantify unmet need and variations in care in post-stroke vision services.	Organisation scoping and best practice service interviews; survey of ophthalmic and stroke professionals and patient interviews across England, Wales and Scotland.	548 professionals completed survey (unable to calculate RR); 14 interviews with representatives of NHS Trusts; 5 patient interviews; 6 reports of previous surveys/studies accessed.	Not explicitly stated but appeared to be mixture of felt/expressed need (patient interviews) and normative/ comparative need (professionals).	Screening tools for detecting visual problems were used by 22% of the 548 professionals surveyed. There was a clear pathway for vision care but only 46% of respondents reported using it. There was considerable variation in who screened for visual impairment but orthoptists were the 'gold standard' and were able to train team members. Barriers included lack of access to orthoptists and clinicians' limited knowledge base. The study was unable to ascertain accurate incidence/prevalence rates of visual problems but estimated that 60% have problems at baseline assessment, which drops to 20% at 3 months post-stroke.
2.6.3 Service evaluations in the South East Coast region					
Gedge C, France T & Jones L (2013) *Stroke reviews project*. Medway:	To estimate the prevalence of long term unmet needs post-stroke and support a	Service evaluation of a 2-year pilot providing reviews at 6	Patients discharged Apr 10-Oct 11 offered 6 month and annual reviews, most by telephone (82%). 1hr	Unmet need conceptualised as services that were identified as required but were unavailable. Need therefore based on	This was a service evaluation to secure further funding, although this was not forthcoming until 2016. There were surprisingly low take-up rates, especially for the 1 year review. The study was

Medway Community Healthcare.	business case for commissioning reviews on a permanent basis.	months and 1 year for all adults, including those in care homes, in South East England.	appointments. Band 7 occupational therapist used two non-validated tools to identify need. 283 6MRs were offered and 125 accepted (44%); 162 annual reviews were offered and 32 accepted (20%). n=157.	normative rather than felt need and measured in number of resultant referrals.	unable to ascertain if telephone reviews affected take-up. The main referrals were to Consultant (14), GP (16), SA (11) and gym (10). There was a long waiting time for some services including the GP, intermediate care team, ophthalmology and wheelchair service. Key unmet needs were found to be neuro-physiotherapy, community occupational therapy, neuropsychology and counselling, physiotherapy in care homes, lifestyle advice and continence advice. The audit was comprehensive and factual. All 6MRs were carried out by the same therapist so inter-rater reliability was not an issue. 85 patient surveys given out at the first review, RR 62%. All rated the review as 'very good' or 'good' whilst still identifying service gaps.
Curtis A & Gallifent R (2014) *Long term reviews for stroke patients in SW & NW Surrey. Pilot*	To evaluate a pilot of reviews.	Patient questionnaires in 2 localities in Surrey: South West (SW) and North West	Recruited Nov 12- Nov 13 from stroke register established with acute services. Invitation letter and telephone follow-up.	No definition. Need identified through discussion between patient, carer and clinicians.	It was unclear if all SW Locality reviews were 6MRs. For NW Locality it does not state how many declined 6MR versus 1 year review. This could account for the different acceptance rates (61% in SW compared to 36% in NW). However, 36% is

project report. Surrey: Virgin Healthcare/NHS.		(NW) and reviews by a multi-disciplinary team in a clinic setting.	SW: 215 reviews offered, 61% accepted. NW: 413 reviews offered, 36% accepted (40% were 6MRs, 32% annual). 45-60mins appointments in clinic (67%), patient's home (22%) or by telephone.		similar to Gedge et al.'s (2010) 44% acceptance of 6MR. Reasons for declining were good recovery and did not require review, other services meeting their needs and stroke not the main diagnosis. Review 1 year later: 75% wanted to be contacted again; 25% did not. This lends weight to targeting reviews. Multi-disciplinary model meant patients received a review of therapy needs and goals that may have reduced onwards referrals. About 20% needed referral onto community services, including therapies and falls service.
Jenkins L, King A & Brigden C (2012) *Evaluation of the Stroke Association's Life After Stroke services in Eastern & Coastal Kent*. Centre for Health Services	To evaluate the effectiveness of the SA's Life After Stroke service in supporting patients in the first year post-stroke.	Mixed methods, Kent.	Took place May 2010-April 2012. Postal questionnaire at baseline, 4 months and 12 months (n=125, 170 and 172 with RR of 38%, 27% and 20% respectively).	Felt and expressed need (although not clearly defined).	The service did *not* include the provision of 6MRs but used the same model as that used in areas that did provide 6MRs. Key benefits of personal contact with staff were that patients felt reassured that someone had time to listen; continuity of the same person; building confidence; and emotional support. Information and signposting was valued, as were communication groups. Clinicians saw the service

Studies, University of Kent. Report no. TSA FF 2009/01.			Data from quarterly management reports. Interviews/focus groups with patients, carers, staff and other stakeholders.		as complementing their own service and filling gaps in statutory services. The study was limited by small sample and significant loss to follow-up. Very few of those who replied to the baseline survey also replied to the survey at 4 months. The questionnaire was a pre-existing one devised by the SA and referred to an Impact and Satisfaction Survey.
2.6.4 Patient perspective on unmet need in the UK					
Shannon RL, Forster A & Hawkins RJ (2016) A qualitative exploration of self-reported unmet need 1 year after stroke. *Disability & Rehab*; 38(20):2000-07.	To gain insight into why patients report no/low unmet needs despite experiencing residual impairment.	Semi-structured interviews, England.	Sub-study of an evaluation of their tool, the Longer-term Unmet Needs after Stroke (LUNS) to assess unmet need (LoTS care LUNS study team 2013). Purposively sampled those who reported 1 or zero unmet needs in the LUNS evaluation and lived nearest the study site. 10 interviews, 11	Self-reported using LUNS.	The meaning of a ‘problem’ varied between patients and some rejected the term. Although they did not report unmet needs, all experienced ongoing impairment or limitations. 4 themes were proposed to account for this: acceptance of changed circumstances; making comparisons with others; valuing pride, determination or independence; viewing issues in the context of their expectations and experiences of services. The study appears to assume that ongoing impairment equates with unmet need but also suggests that expectations about service capacity influenced health-seeking behaviour.

			months post-stroke (Dec 10-May 11).		
Sumathipala K et al. (2012) Identifying the long-term needs of stroke survivors using the ICF. *Chronic Illness*; 8(1): 31-44.	To investigate how contextual factors, as described by the ICF, impact on function and how needs are perceived in the long-term.	Qualitative methods, South London.	35 people recruited for interview. Between 1-11yrs post-stroke living in South London and on the South London Stroke Register. RR 32% (111 invited).	Used ICF.	Long-term needs were mediated and shaped by a range of environmental factors. Physical functioning plateaus after 1yr and people remain stable. While this is largely true, it does not equate with patient expectations or consider potential to benefit from further therapy (e.g. maintenance). Mentions annual reviews and that the ICF may be useful to frame them.
2.6.5 International evidence of unmet need *(grouped by country)*					
Andrew NE et al. (2014) Understanding long-term unmet needs in Australian survivors of stroke. *World Stroke Organisation*; 9(10):106-112.	To describe the factors associated with the extent to which needs were met in post-stroke Australians.	Cross-sectional survey, Australia. *See linked paper, Andrew 2015, under 'carers' section.*	Recruited over 1 year (2011-12) in 2 phases from National Stroke Register, support group on-line members (non-statutory) and their website. Questionnaire completed on-line, on paper or by phone.	Self-reported: 'something or help from someone that would help you to overcome some of the effects of your stroke and resulting difficulties' (p108). Same questionnaire as McKevitt (2011), adapted for Australian setting with additional questions relating to unmet needs for health;	54% had at least 1 unmet need. Factors associated with needs not being met were 1) greater disability and fatigue; 2) greater disability and being 1-2yrs post-stroke; and 3) increased disability and memory problems. Extent to which needs were unmet varied according to various factors including age, disability level and residential location. Needs were categorised into domains including: 84% reported health needs not fully met, including cognitive/emotional problems; 64% reported unmet leisure needs; 60% needed more support to

			n=765 with varying RR by approach (12-38%).	everyday living; work; leisure; social support and finances. In final survey 88% of respondents felt the survey adequately covered all needs.	return to work; 52% reported support needs and 38% financial needs.
Andrew NE et al. (2016) Is health-related quality of life (HRQoL) between 90 and 180 days following stroke associated with long-term unmet needs? *Qual Life Res.* 25:2053-62.	To investigate the attributes of HRQoL between 90 and 180 days following stroke and their association with long-term (12+ months) unmet needs.	Multivariable regression analysis, Australia. *Data from Andrew et al. 2014 (above) and a national stroke database*.	National stroke registry routinely follows-up patients between 90-180 days post-stroke and administers the EQ-5D-3L (EuroQol, 5 dimensions). Data combined with the Needs Survey (above study) to determine associations between the EQ-5D and reported unmet needs. n=173. RR 29% (173 of 602 surveys).	As above. EQ-5D-3L, including a visual analogue scale, as a proxy measure of HRQoL. Mapped dimensions of EQ-5D and unmet needs on ICF domains.	A significantly larger proportion of those who reported problems with mobility, self-care and usual activities between 90-180 days post-stroke reported having long-term unmet needs in multiple domains. Those who reported having pain or anxiety/ depression in the first 6 months were *less* likely to report unmet needs at a median of 2 years but this may have been related to differences in health seeking behaviour. Those who report having long-term unmet needs were more likely to have experienced reduced HRQoL. The brevity of the EQ-5D meant that it did not include many relevant concepts. There was a relatively small sample size and large confidence intervals so potential for type 2 errors.

Olaiya T et al. (2017) Long-term unmet needs and associated factors in stroke or TIA survivors. *American Academy of Neurology.* 89(1):68-75.	To investigate long-term unmet needs in survivors of stroke or TIA and to identify factors associated with these needs.	Survey and multivariable regression analysis, Australia.	Exit survey as part of a randomised control trial. Recruited from 4 hospitals in Melbourne, Jan 2010-Nov 2013. Adults (18yr or over) hospitalised for stroke or TIA. All were 2 or more years post-stroke. Self-administered questionnaire, 48-items. n=391. RR 81% (485 invited).	Self-reported. Needs mapped onto domains of ICF. Questionnaire took 20mins or less to complete and was aligned with that devised by Andrew et al. (2014) and therefore indirectly with McKevitt (2011).	Most respondents (87%) reported 1 or more unmet need with a wide range (0-30) but the majority reported 1-5 needs (43%), similar to other studies. It is questionable how reliable figures are for needs reported post-discharge (memory bias). Supplementary tables break categories into *need not met*, *need not fully met* and *need fully met*. The 87% is a combination of *need not met* and *need not fully met* which rather skews the results. Needs not met at all are considerably lower than the combined figure. McKevitt (2011) also combined categories. More useful was the finding that GPs co-ordinating care, and greater functional ability, were associated with fewer unmet needs. Depression was associated with greater need.
Moreland J et al. (2009) Needs assessment of individuals with stroke after discharge from hospital stratified	To determine the needs, barriers and facilitators of function post-discharge, using Functional	Longitudinal cohort, Canada. Patients were followed-up within 1 month, at 6 months and 1-year post-	Patients were recruited consecutively from 4 acute care centres (2002-06). They were stratified into 3 groups according to their FIM	Self-reported or felt need. Separated needs from barriers in a way other papers failed to do, e.g. emotional, environmental and financial barriers.	This was a comprehensive study with thorough description of method (but no theoretical stance). FIM is a good outcome measure; far more comprehensive than those often used such as the Barthel Index or the Modified Rankin Scale. They justified how patients were divided into 3 groups. Results were broken down by FIM category (which

by acute Functional Independence Measure score. *Disability & Rehabilitation*; 31(26):2185-2195.	Independence Measure (FIM).	discharge. This paper presents the findings at discharge.	score within 10 days of admission (n=241). 2 methods of data collection: a) semi-structured interviews (n=209) and b) closed-ended survey (n=90). Survey RR: 45% at discharge, 37% at 6 months, and 32% at 1 year. Interviews: 87% re-interviewed at 6 months and 71% at 12 months post-discharge.	Interview schedule included all domains of ICF, as did survey.	equated with low, moderate and severe impairment) and quantified needs and barriers (though wide confidence intervals). The study was unable to recruit enough people in the FIM group of <41 (severe disability). There were large variations between the 3 groups - as would be expected- especially for mobility and activities of daily living. Combining the interview groups: most needs related to physical impairments (35%), time for recovery (33%), education (28%), medical advice (25%), therapies 21% social needs (19%) and emotional needs (18%). The most common barriers were physical impairments (55%) and emotional concerns (40%). Facilitators were family support (54%), therapies and medical care (40%) and personal attitudes (22%).
Duxbury, S et al. (2012) Individuals with stroke reporting unmet need for occupational therapy following	To identify the characteristics and needs of patients reporting an unmet need for occupational	Sub-group analysis of patient survey and interviews, Canada.	Patients were divided into 3 groups: receiving occupational therapy; needing it; neither receiving or needing it.	Felt need. Eligibility for therapy defined as those with an expressed unmet need for, or already receiving, occupational therapy.	13% (n=28) who were not being seen by occupational therapy reported a need for it; 16% were receiving it; 71% did not need or receive therapy. Patients reported needs that they were unaware were within the remit of occupational therapy. This suggested that the figure of 71% not needing therapy was an under-estimate and that

discharge from hospital. *Occupational therapy in healthcare*; 26(1):16-32.	therapy post-discharge.	*Data from Moreland et al. 2009, as above.*			there were patients who could have benefited but were not receiving it. Those not receiving therapy were more likely to report unmet needs related to arm function, activities of daily living, leisure, assistive devices and social participation.
DePaul V, Moreland J & DeHuek A (2013) Physiotherapy needs assessment of people with stroke following discharge from hospital, stratified by acute Functional Independence Measure score. *Physiotherapy Canada*; 65(3):204-214.	To determine the physiotherapy related needs of people with stroke at discharge, 6 months and 1 year post-discharge from hospital.	Patient survey and interviews, Canada. *Subset of physiotherapy-relevant findings used from Moreland et al. 2009, as above.*	As above. 47 descriptors categorised into 7 areas: motor control, walking ability, stairs, fitness, fatigue, balance, and need for physiotherapy.	Self-reported physiotherapy needs, described as felt need. *Need for improvement* differentiated in a particular function (e.g. use of foot) from a *need for physiotherapy*.	Although recruitment was over 10 years ago and only appertained to physiotherapy, the study identifies important therapy needs in the first year, even for patients with mild impairment. Physiotherapy needs were fairly stable over 1 year and patients reported difficulty accessing therapy. Key barriers and needs varied between groups but included fatigue, motor control, balance, and mobility, as might be expected. Only 4 patients were in the most severely disabled category who were not reported on.

Vincent, C et al. (2007) Rehabilitation needs for older adults with stroke living at home: perceptions of 4 populations. *BMC Geriatrics*; 7:20.	To explore the partially met and unmet rehabilitation needs of community dwelling adults aged 65 and over.	Qualitative methods, Canada. Focus groups carried out in 2005.	Emphasis on needs that acted as obstacles to social participation in terms of personal and environmental factors and habits/daily routines. 3 geographical areas and 4 separate groups: 17 patients, 12 carers, 24 clinicians and 18 healthcare managers. Mainly focus groups.	Expressed (patients), normative (mostly clinicians) and comparative (mostly managers).	This relatively robust study compared the viewpoints of all stakeholders and differentiated types of need. It used a model of function similar to the ICF. Rehabilitation needs -some partially met- persisted after services had withdrawn. Follow-up needed to better address adjustment and activities of daily living to increase social participation. Patients and carers expressed similar needs to those raised by clinicians. Carers and clinicians identified more unmet needs compared to patients and managers who emphasised resource limitations.
Ekstam L et al. (2015) The combined perceptions of people with stroke and their carers regarding rehabilitation needs 1 year after stroke: a	To explore the associations between patient and carers' perception of rehabilitation needs and stroke severity, personal factors, use of services, amount	Mixed methods, Sweden. *Secondary data analysis from a prospective observational study, 'Life after stroke, phase 1' (LAS-1).*	Used established questionnaires including patient/carer satisfaction with services, caregiver burden scale and standardised open-ended questions on changes in daily life collected at 12 months.	Key question pertaining to need 'I have received the rehabilitation that my condition has required'. Choice of 'met' or 'unmet' (no choice of partially met). Patients and carers were asked this question separately.	No definition of rehabilitation was provided: it was whatever it meant to each respondent. The study's strength was the mixed methods approach and comparing patient with carer views. Open-ended questions for patients and carers were analysed separately and compared at a group level. Of the 86 patients, 67% had mild stroke and 33% moderate/severe and 26% had experienced a previous stroke.

mixed methods study. *BMJ Open*; 5(2):e006784.	of care provided and carer burden.	*Recruitment was 2006/7.*	Barthel index used to categorise stroke severity as mild or moderate/severe. Of 349 eligible patients from LAS-1, 86 dyads (patient and carer) were included who had answered the question about rehabilitation needs.		Among the dyads, 52% perceived that rehabilitation needs were met at 12 months, 13% agreed they were unmet, and 35% did not agree (with slightly more carers perceiving unmet needs). Met rehabilitation needs were associated with less severe stroke, more coping strategies for solving everyday problems and less carer burden. The study concluded that patient *and* carer need support with the process of psychological and social adaptation.
Tistad M et al. (2012) Unfulfilled rehabilitation needs and dissatisfaction with care 12 months after a stroke: an explorative observational study. *BMC Neurology*; 12:40.	To generate knowledge about characteristics in patients that at 3 and 12 months post-stroke contributed to unfulfilled needs for rehabilitation or dissatisfaction with health care	Quantitative methods, Sweden. Questionnaires and 4 logistic regression analyses were used. *Recruited from LAS-1.*	175 participants from LAS-1 who met the inclusion criteria. Data collected face to face at baseline (in the stroke unit), 3 and 12 months later by physio- or occupational therapist trained to do so. Used Barthel Index to categorise into mild, moderate or severe	Not defined, but appeared to be self-reported or expressed need for further rehabilitation.	Unfulfilled needs for rehabilitation at 12 months were predicted by strength at 3 months and associated with poor hand function and self-rated recovery at 12 months. 33% reported unmet needs for rehabilitation and 14% were dissatisfied with the care received. Personality as well as the impact of stroke was associated with dissatisfaction with care. Patients may consider that they have the capacity to recover after services have withdrawn (the implicit suggestion being that therapists may not agree). The study recommended more flexible

	services at 12 months.		stroke; stroke impact scale and sense of coherence scale (all established measures).		services targeted at those in need of them (and presumably with capacity to benefit). Services should also cater for individual characteristics, for example, those with poor coping strategies who may need additional support.
Tistad M et al. (2013) What aspects of rehabilitation provision contribute to self-reported met needs for rehabilitation 1 year after stroke - amount, place, operator or timing? *Health Expectations*; 16:e24-e35.	To explore aspects of rehabilitation provision that potentially contribute to self-reported *met* needs for rehabilitation 12 months post-stroke.	Quantitative methods, Sweden. Questionnaire and multivariate logistic regression analyses were used. *Recruited from LAS-1.*	173 participants from LAS-1 who met the inclusion criteria. *Details as above.* Categorised rehabilitation by amount (days/visits), time period (3 monthly intervals), service level (equated with location) and operator (physio, speech or occupational therapy).	Self-reported.	Patients with moderate/severe stroke who had seen a physiotherapist at least once during each quarter of the first year were more likely to report met rehabilitation needs. Service level and amount of rehabilitation were not associated with needs being met. The study concluded that for those with moderate/severe stroke, continuity in rehabilitation during the first year and/or a re-assessment by a multi-disciplinary team during the 3rd or 4th quarter after stroke (equating with 6-12 months) would be beneficial to address needs that had arisen while trying to resume valued activities and adapt to a new situation.
Walsh ME et al. (2014) Community re-	To document self-reported need in relation to stroke	Cross-sectional national survey, Ireland.	Recruited through stroke advocacy organisations (non-statutory) and	Self-reported needs divided into ‘unmet health needs’ and ‘social participation’.	22% reported no unmet health needs. 80% were satisfied with their overall recovery, yet >70% reported ongoing problems for each of the

integration and long-term need in the first 5 years after stroke. *Disability & Rehab;* 37(18):1599-1608.	recovery and community re-integration.		where these were unavailable, health professionals. N=196. RR 65%.	Community integration or related theory (which is similar to social participation but has its own body of research) not discussed. Same questionnaire as McKevitt (2011) adapted for Irish setting but did not describe how.	following: emotions, fatigue, concentration, memory, arm function, falls and mobility. These were then divided into 'needs unmet/needs to some extent met/needs met', presumably taken from the questionnaire. 68% wanted more information about the cause of their stroke, 77% about secondary prevention and 68% about diet. Results lacked differentiation between ongoing problems and unmet need. This study found slightly higher levels of stroke-related problems than other studies and acknowledged potential bias in the sample (those who attended stroke groups could have had a higher level of need than those who did not). Most questions were phrased as 'Since your stroke, have you had enough help with xxx?' which rather warrants a 'no' reply.
2.6.6 Carers' perspective on unmet need *(alphabetical order)*					
Andrew NE et al. (2015) The relationship between caregiver impacts	To describe the relationship between patients' unmet needs 1 year post-stroke	Cross-sectional survey, Australia. *See Andrew 2014 and 2016*	Data from Australian Stroke Survivor and Carer Needs Survey. Adults in the community and carers, 12+ months	Caregiver component of the survey developed specifically for project. Appeared to be mixture of felt and expressed needs	This was a large-scale survey with a clear method. For carers: the domains of work, leisure and friendships were most affected. The likelihood of carers experiencing moderate to severe impacts increased with the number of reported patient

and the unmet needs of survivors of stroke. *Patient preference & adherence*; 9:1065-73.	and the impact on carers.	*above - same data.*	post-stroke. 738 completed patient surveys; 369 with matched carer data. Multivariable logistic regression to explore association between patient needs and carer impact.	across 5 domains: work, leisure, family relationships and friend relationships; using 5-point Likert scale. Included questions about support and care needs, financial impact and experience of services.	unmet needs and was greatest for spouses and friend relationships. The study recommended that effective interventions need to be directed at carer and patient, personalised and responsive to the changing physical, emotional and relationship needs of both partners' over time.
Le Dorze G & Signori FH (2010) Needs, barriers and facilitators experienced by spouses of people with aphasia. *Disability and Rehabilitation*; 32(13):1073-87.	To describe the needs of spouses of patients with aphasia, to determine if their needs were met and to identify facilitators and barriers.	Qualitative methods, Canada.	Convenience sample, n=11 (9 wives, 2 husbands). Group interviews.	Appeared to be mix of felt and expressed need. Categorised barriers and facilitators according to whether they were individual factors (characteristics, beliefs, fears) and/or organisational factors (availability, accessibility and acceptability of services)	This was a small but robust study, demonstrating the wide range of needs and how carers strove to meet them. Key needs, or concerns, were for emotional and practical support; respite; and improved communication and relationships with their spouse, family and friends. The strain of being the sole communicator for the couple and the emotional turmoil meant that time away from their partner was important. Many of the needs reflected the need of the person with aphasia, while other needs related directly to the carer's role, for example the need for information.
MacIssac L et al. (2010)	To assess the evidence on the	Literature review, Canada.	17 studies were included from a literature search	Individual to each study but collectively categorised into	Although the focus of this study was on transition and carers, it was thorough and made some good

Supportive care needs of caregivers of individuals following stroke: a synopsis of research. *Canadian Journal of Neuroscience Nursing*; 32(1):39-46.	spectrum of supportive care needs of carers during the acute phase of stroke, in order to facilitate the transition into the role of carer.	*Part of a Master's thesis.*	of common databases, mostly 1996-2007.	informational, emotional, psychosocial, physical, practical and spiritual.	points: a) psychosocial and emotional issues were frequently cited as an area of need b) studies looked less at physical support but this was clearly a need c) transitioning into a caring role is multi-faceted and needs change over time d) unmet carer needs cause additional anxiety that can affect carers' physical and emotional health.
MacKenzie A et al. (2007) Family carers of stroke survivors: needs, knowledge, satisfaction and competence in caring. *Disability & Rehabilitation*; 29(2):111-121.	To explore what needs carers anticipated prior to discharge and compare to experiences 4-6 weeks post-discharge; their knowledge, satisfaction and burden.	Survey, UK. *Same scales as Perry & Middleton (2011) see below.*	Survey in South London hospital. 42 family carers recruited and surveyed over 16 months; 37 followed-up 4-6 weeks post-discharge.	Expressed needs.	Recruitment for this study was pre-National Stroke Strategy (2007) although it does not state when (2004/5?) There was a short follow-up: at 6 weeks, services should still be involved for most patients. High satisfaction with the acute stroke unit did not transfer into the community where carers reported feeling alone and described uncoordinated services. Younger female carers (<56yrs) and ethnic minority groups experienced particular difficulties. Priorities changed pre- to post-discharge, as would be expected, but carers did not feel clinicians had adequately prepared them for their new role.

Perry L & Middleton S (2011) An investigation of family carers' needs following stroke survivors' discharge from acute hospital care in Australia. *Disability & Rehabilitation*; 33(19-20):1890-1900.	To identify carers' perceived needs, knowledge, satisfaction and burden. To explore associations between carers' demographics and these factors.	Records audit, interviews and scales, Australia. *Same scales as MacKenzie et al. (2007) see above.*	Medical records audit, self-reported scales and telephone interviews within 1-3 months of discharge. Validated scales used to glean needs, knowledge, competence and satisfaction (open questions at the end of each section). Recruited 36 patient-carer dyads from two acute stroke units, with full data for 32.	Self-reported needs that appeared to equate with felt and expressed needs.	Interviews took place in 2006. However, this is a useful paper combining self-reported scales with interview data. Only 1 carer reported no needs. Key concerns were restricted social life, getting information on stroke prevention, distress with the patient's situation and mood fluctuations and their own fatigue. Carers talked about the impact on the whole family and social network. Some struggled with multiple caring roles (spouse and parents) and had conflicting emotions. Anxiety and uncertainty were common. Recommendations included providing a network of services to cut across boundaries between health, social care and the voluntary sector. Also recommended was access to regular review and reassessment. The study suggested that carers had common issues across countries and healthcare systems.
Wallengren C, Segesten K & Friberg F (2010) Relatives' information	To explore relatives' information needs and the characteristics of	Qualitative methods, Sweden. *Part of a larger project.*	Open-ended interviews (2 open questions with corresponding prompts). 16 interviews within a month of their relatives'	Appeared to be mixture of felt and expressed need for information and knowledge.	Data was collected 2003-04 but it was unclear why there was such a long delay in publication. Most participants were wives and daughters. The study describes how needs change over time: initially focused on medical aspects then on

needs and the characteristics of their search for information – in the words of relatives of stroke survivors. *Journal of Clinical Nursing*; 19(19-20):2888-96.	their information-seeking process shortly after the stroke and 6 months later.		stroke and 9 at 6 months (4 patients had died, 2 carers declined, 1 lost on follow-up). Content analysis.		rehabilitation, their relatives' health status and at 6 months their own future (emotional and physical needs). The level of personal involvement acted as a spur to acquiring knowledge but information needed to be directly relevant. Thus, clinicians needed to focus on what relatives wanted instead of providing standard information based on their own expectations. Carers intertwined factual knowledge, understanding and practical skills.
Studies excluded after reading the full paper (studies excluded by title/abstract are not included) ***(alphabetical order)***					
Daniel K et al. (2009) What are the social consequences of stroke for working-aged adults? *Stroke*; 40: e431-e440.	To identify the social consequences of stroke for working-aged adults.	Systematic review, Western countries and Taiwan.	78 studies included, 66 of which were quantitative observational ones, 1962-2008.	ICF definition of social participation.	Authors concluded that methodological variations (in part) accounted for a wide range of rates of return to work (0-100%). Other indicators also had a wide range of rates. Excluded: Same team as McKevitt et al. (2011); focus on return to work; studies from 1962-2008 with only 4 conducted in/after 2007; huge variation in methodology and outcomes; inadequate discussion of need or social participation.

Kersten P (2002) The unmet needs of young people who have had a stroke. *Disability & Rehab*; 24(16): 880-866.	To examine the unmet needs of young people with stroke living in the community.	Cross-sectional postal survey, England and Scotland.	Southampton Needs Assessment Questionnaire. 2 age bands: 18-45yrs and 46-65yrs. People identified by their consultant across 8 stroke centres. 639 sent out and 315 returned. Overall RR 49% (range 35-59%)	Self-reported need (same definition as Andrew et al., 2014).	Median number of unmet needs = 2 (range 0-6). Most frequently reported were provision of information (45%); assistance with finances (24%); non-care activities (19%) and intellectual fulfilments (17%). Interestingly the study did not highlight emotional/ psychological issues, which were reported in most other studies. Excluded: Too long before the introduction of the National Stroke Strategy (2007). Low response rate.
Kristensen et al. (2016) The importance of patient involvement in stroke rehabilitation.	To investigate the perceived needs for health services within the 1st year post-discharge.	Mail survey, Denmark. (Sweden and Denmark collaboration).	Stroke survivor needs questionnaire. Data collected May-Aug 12; survey undertaken 1-12 months after rehabilitation had ended. N=63. RR 40%.	Self-reported.	This was similar to Tistad et al. (2013). Mail survey, 2012, small number of participants and 80% had mild stroke. However, it still reported wide-ranging problems including mobility, falls, continence, fatigue, emotional problems, pain and impaired concentration.
Murray J et al. (2003b) Developing a primary care-based stroke service: a review	To identify the most frequently encountered long-term problems post-stroke.	Qualitative literature review, mostly UK.	Included 17 UK and 6 non-UK studies from an initial 139. Collectively papers represented about 500 patients and 180 carers.	Couched in terms of 'identifying the main problems' rather than unmet need (p137).	Of the UK studies, only 3 related directly to unmet need and were published in 1991, 1995 and 1998 with different parameters. Areas were divided into 5 domains, of which the largest was social and emotional consequences, representing 39% of all problem areas. Included were mood, social

of the qualitative literature. *Brit Jnl General Practice*; 53: 137-142.					changes, attitudes to recovery and changes in self-perception and relationships, consistent with other qualitative studies. Excluded: Pre-National Stroke Strategy (2007); lack of comprehensive conceptualisation of need.
Walker M et al. (2013) Evidence based community stroke rehab. *Stroke*; 44: 293-297.	To identify the key issues when implementing evidence based community services.	Opinion piece, UK.	NA	NA	Excluded: Opinion piece with only brief mention of review process. As for most of the above, a strong 'medical model' orientation. Walker is a well-known researcher in stroke and appeared to be laying the groundwork for future projects.
Wolfe C et al. (2011) Estimates of outcomes up to 10 years after stroke: analysis from the prospective South London Stroke Register. *PLoS Med*.; 8(5):e1001033.	To generate population based estimates of long-term outcomes post-stroke.	Quantitative methods, South London Stroke Register.	Used data collected on the register 1995-2006. Variety of outcome measures including Barthel Index, Mini-mental, SF12 and HADS.	Standardised outcome measures used as proxy estimates of need. Appeared to be conflating impairment with need.	20-30% of people had a poor range of outcomes up to 10yrs post-stroke. A comprehensive analysis of the data was stratified by age, gender and ethnicity and age was adjusted. Some measures such as Barthel and Mini-mental are not stroke specific and lack sensitivity. Excluded: Same team as McKevitt et al. (2011); data is pre-National Stroke Strategy; demographics/ ethnicity specific to S. London.

Appendix 3: Policy drivers for the review process

N.B. Only standards relevant to the review process are included. Standards related to other aspects of the care pathway have been omitted.

Policy	Standard/indicator	Descriptor
National Service Framework for Older People (Department of Health 2001b) *8 standards*	Standard 5: To reduce the incidence of stroke and ensure prompt access to integrated stroke services for those who have had a stroke.	5.27 Patients and carers should 'have access to a stroke care co-ordinator who can provide advice, arrange reassessment when needs or circumstances change, co-ordinate long-term support… any patient reporting a significant disability at six months should be re-assessed and offered further targeted rehabilitation if this can help them to recover further function' (p68).
National Service Framework for Long-term Conditions (Department of Health 2005) *11 quality requirements (QRs)*	QR1: Early recognition, prompt diagnosis and treatment.	Services should be sufficiently flexible to allow for 'planned and unplanned reviews when a person's condition deteriorates or their circumstances change' (p21); regular medication reviews, especially for those taking three or more medications.
	QR5: Community rehabilitation and support.	People with long-term neurological conditions living at home should have access to 'a comprehensive range of rehabilitation, advice and support to meet their continuing and changing needs, increase their independence and autonomy and help them to live as they wish' (p35).
	QR6: Vocational rehabilitation.	'People with long-term neurological conditions are to have access to appropriate vocational assessment, rehabilitation and ongoing support to enable them to find, regain or remain in work and access other occupational and educational opportunities' (p39).
	QR10: Supporting family.	Carers 'have access to appropriate support and services that recognise their needs both in their role as carer and in their own right' (p55).
National Stroke Strategy (Department of Health 2007)	QM3: Information, advice and support.	'People who have had a stroke, and their relatives and carers, have access to practical advice, emotional support, advocacy and information throughout the care pathway and lifelong' (p18).

20 quality markers (QMs) grouped as follows: *QM1-4: Raising awareness, informing and involving.* *QM5-9: Assessment and treatment.* *QM10-16: 'Life after stroke'* *QM17-20: Service and workforce development; audit.*	QM10: High-quality specialist rehabilitation.	'People who have had strokes access high-quality rehabilitation and, with their carer, receive support from stroke-skilled services as soon as possible after they have a stroke, available in hospital, immediately after transfer from hospital and for as long as they need it' (p36).
	QM11: End-of-life care.	'People who are not likely to recover from their stroke receive care at the end of their lives which takes account of their needs and choices and is delivered by a workforce with appropriate skills and experience in all care settings' (p39).
	QM12: Seamless transfer of care.	'A workable, clear discharge plan that has fully involved the individual (and their family where appropriate) and responded to the individual's particular circumstances and aspirations is developed by health and social care services, together with other services such as transport and housing' (p41).
	QM13: Long-term care and support.	'A range of services are in place and easily accessible to support the individual long-term needs of individuals and their carers' (p42).
	QM14: Assessment and review.	'People who have had strokes and their carers, either living at home or in care homes, are offered a review from primary care services of their health and social care status and secondary prevention needs, typically within six weeks of discharge home or to care home and again before six months after leaving hospital. This is followed by an annual health and social care check, which facilitates a clear pathway back to further specialist review, advice, information, support and rehabilitation where required' (p45).
	QM15: Participation in community life.	'People who have had a stroke, and their carers, are enabled to live a full life in the community' (p46).
	QM16: Return to work.	'People who have had a stroke and their carers are enabled to participate in paid, supported and voluntary employment' (p47).
Accelerating Stroke Improvement National	Appendix A: Definition of measures.	Patients should be reviewed six months after leaving hospital, or between five to seven months post-discharge. Reviews should be a 'multifaceted assessment of need' (p20) carried out in a

Programme (NHS Stroke Improvement Programme 2010)		primary care setting but the model could be decided locally. It set a target for April 2011, that 95% of patients leaving hospital would be reviewed. Review should encompass (p20): • Medicines/general health needs. • Ongoing therapy and rehabilitation needs. • Mood, memory, cognitive and psychological status. • Social care needs, carer wellbeing, finances and benefits, driving, travel and transport.
Cardiovascular Disease Outcomes Strategy (Department of Health 2013) *9 actions*	Action 8: Improve care for people living with cardiovascular disease.	*'Patients should have their needs assessed and care plans produced kept under review' (p8). Recommends cardiovascular assessments and 'assessment of needs generally and access to education to support self-management; psychological support and, where appropriate, physical activity, rehabilitation or re-enablement programmes' (p8).*
CCG Outcomes indicator set 2014/15 and 2015/16 (NHS England 2013; NHS England 2015). *5 domains*	Domain 3: Helping people to recover from episodes of ill health or following injury.	Improving recovery from stroke. People should: • Be discharged from hospital with a joint health and social care plan. • Receive a follow-up assessment 4-8 months after initial admission.

Appendix 4: Clinical guidelines relevant to the 6MR

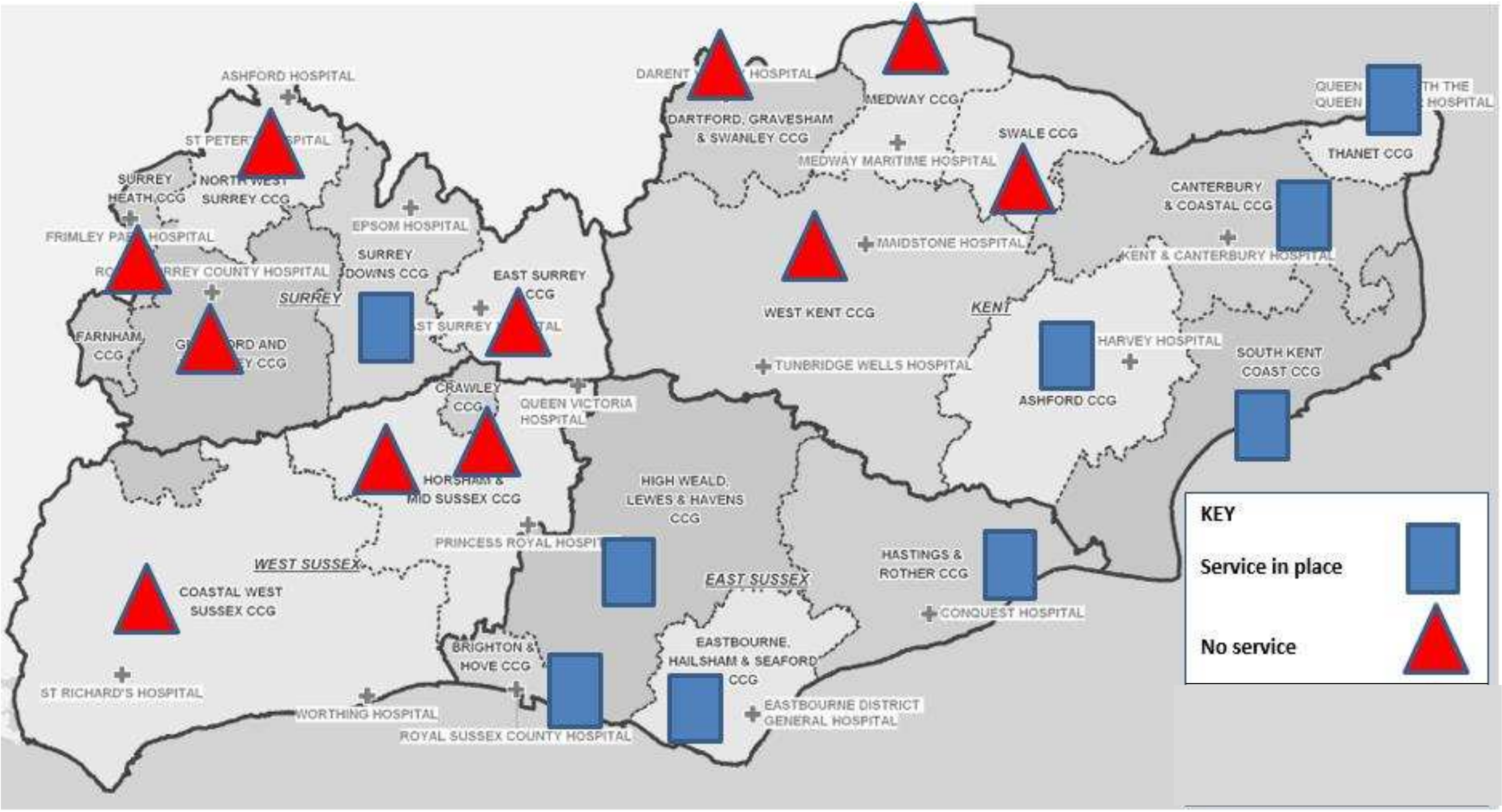
N.B. Only included are aspects of each guideline relevant to the 6MR. Standards related to other aspects of the care pathway have been omitted.

Guideline	Area	Descriptor
SIGN (2010) Management of patients with stroke (118).	5.6: Moving on after a stroke	Scottish guidelines do not have a 6MR but instead state that community rehabilitation teams and care agencies ‘should continue to assess the patient’s progress’ but without reference to a timeframe (p52). Refers to return to work, driving and physical activity. Little mention of self-management.
NICE (2010, updated 2016) Stroke in Adults (QS2) *7 quality statements.*	3: Access to a clinical psychologist	‘Adults who have had a stroke have access to a clinical psychologist with expertise in stroke rehabilitation who is part of the core multidisciplinary stroke rehabilitation team’ [new 2016] (p23). Although this really refers to inpatient care it is relevant in that access is very limited post-discharge.
	5: Return to work	‘Adults who have had a stroke are offered active management to return to work if they wish to do so’ [new 2016] (p29).
	6: Regular review of rehabilitation goals	‘Adults who have had a stroke have their rehabilitation goals reviewed at regular intervals’ [2010, updated 2016] (p32).
	7: Regular review of health and social care needs	‘Adults who have had a stroke have a structured health and social care review at 6 months and 1 year after the stroke and then annually’ [new 2016] (p36).
RCP (2012) National Clinical Guidelines for Stroke *Seven chapters, of relevance are Chapter 5: secondary prevention, Chapter 6: Recovery phase and Chapter 7: Long-term management.*	5.3: Lifestyle measures	Lifestyles measures ‘are as important in secondary preventions as they are in primary prevention’ (p63).
	6.18: Self-efficacy training	6.18.1: ‘All patients should be offered training in self-management skills, to include active problem-solving and individual goal setting’ (p93).
	7.4: Support	7.4.1: Patients and carers ‘should have their individual practical and emotional support needs identified’ before they leave hospital, when rehabilitation ends or at their 6-month review and ‘annually thereafter’ (p127-8).

RCP (2016) National Clinical Guidelines for Stroke *6 chapters, of relevance are:* *Chapter 2: Organisation of stroke services and* *Chapter 5: Long-term management and secondary prevention.*	2.13: Self-management	2.13.1: 'People with stroke should be offered self-management support based on self-efficacy, aimed at the knowledge and skills needed to manage life after stroke, with particular attention given to this at reviews and transfers of care' (p28).
	5.1: A comprehensive and personalised approach	5.1.1: 'People with stroke or TIA should receive a comprehensive and personalised strategy for vascular prevention including medication and lifestyle factors, which should be implemented as soon as possible and should continue long-term' (p90). Those taking medication should: • Receive information about the medication, dosage and side effects • Receive verbal and written information about their medicines • Be offered compliance aids such as large-print labels and dosett boxes • Have their medication regularly reviewed.
	5.8: Lifestyle measures	As in 4th edition: 'Effective lifestyle interventions require changes in behaviour such as smoking, exercise, diet and alcohol consumption. Although it is the responsibility of the individual to change his or her own behaviour, healthcare practitioners have a responsibility to give accurate information, advice and support to help people to make and maintain lifestyle changes' (p108).
	5.9: Life after stroke	5.9.1: 'People with stroke, including those living in a care home, should be offered a structured health and social care review at six months and one year after the stroke, and then annually. The review should consider whether further interventions are needed and the person should be referred for further specialist assessment if new problems are present or the person's physical or psychological condition, or social environment has changes. The review should consider whether further interventions are needed and the person should be referred for further specialist assessment if: • New problems are present • The person's physical or psychological condition, or social environment has changed. Further therapy should be offered 'if goals for specific functions and activities can be identified and agreed and the potential for change is likely' (p113).

		5.9.2: Social integration and participation: ‘Helping people with stroke to integrate back into the community in the way that they want is a key goal of healthcare; engagement in community activity is associated with improved quality of life’ (p113).

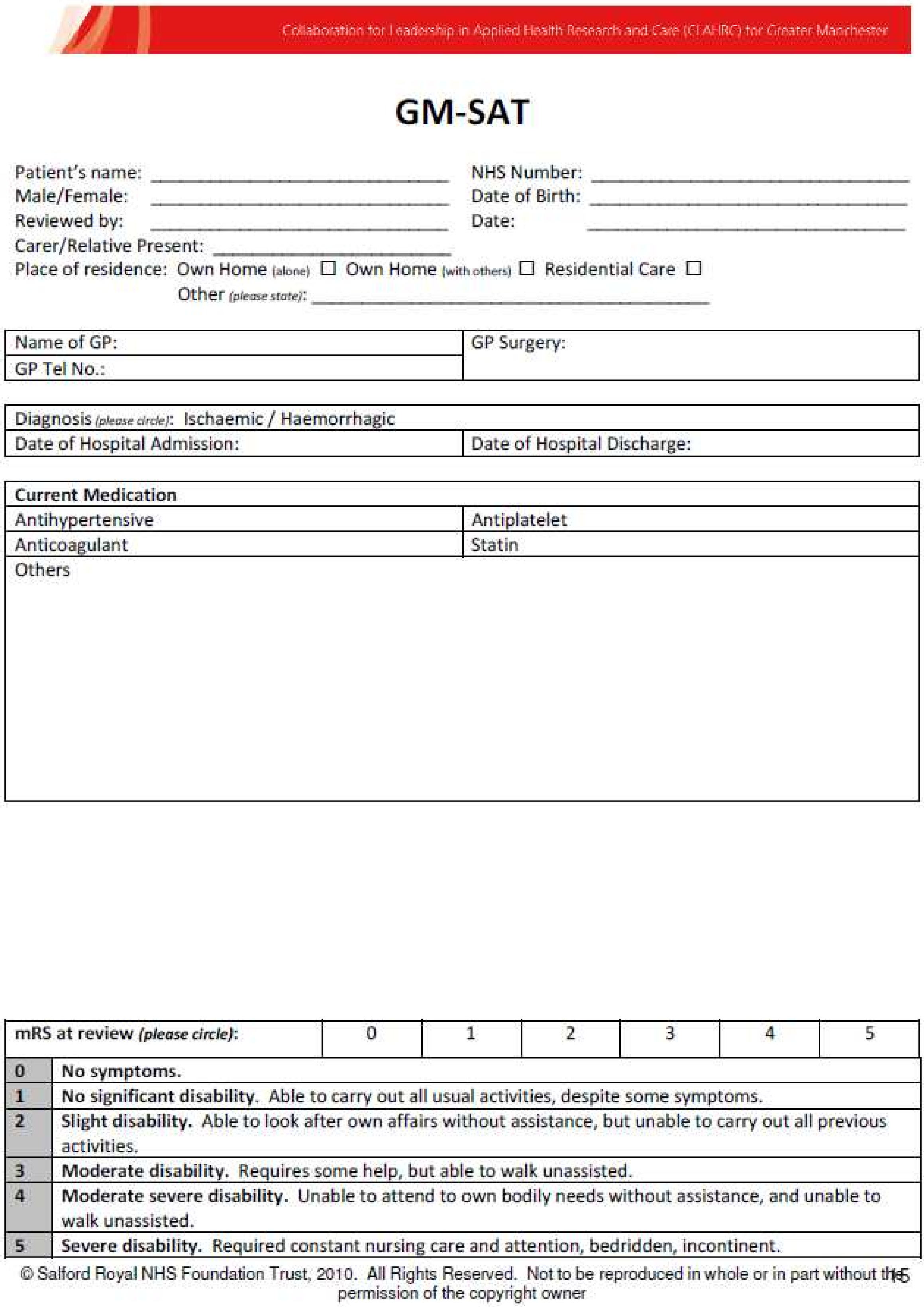
Appendix 5: Availability of 6MR Services by Clinical Commissioning Group (as of October 2014)



(Hargroves, French and Trickey 2014, p34)

Appendix 6: Greater Manchester Stroke Assessment Tool and example algorithm

(The NIHR CLAHRC Greater Manchester 2010)



Collaboration for Leadership in Applied Health Research and Care (CLAHRC) for Greater Manchester

GM-SAT

Patient’s name: ______________ NHS Number: ______________
Male/Female: ______________ Date of Birth: ______________
Reviewed by: ______________ Date: ______________
Carer/Relative Present: ______________
Place of residence: Own Home (alone) ☐ Own Home (with others) ☐ Residential Care ☐
Other (please state): ______________

Name of GP:	GP Surgery:
GP Tel No.:	

Diagnosis (please circle): Ischaemic / Haemorrhagic	
Date of Hospital Admission:	Date of Hospital Discharge:

Current Medication	
Antihypertensive	Antiplatelet
Anticoagulant	Statin
Others	

mRS at review *(please circle)*:	0	1	2	3	4	5

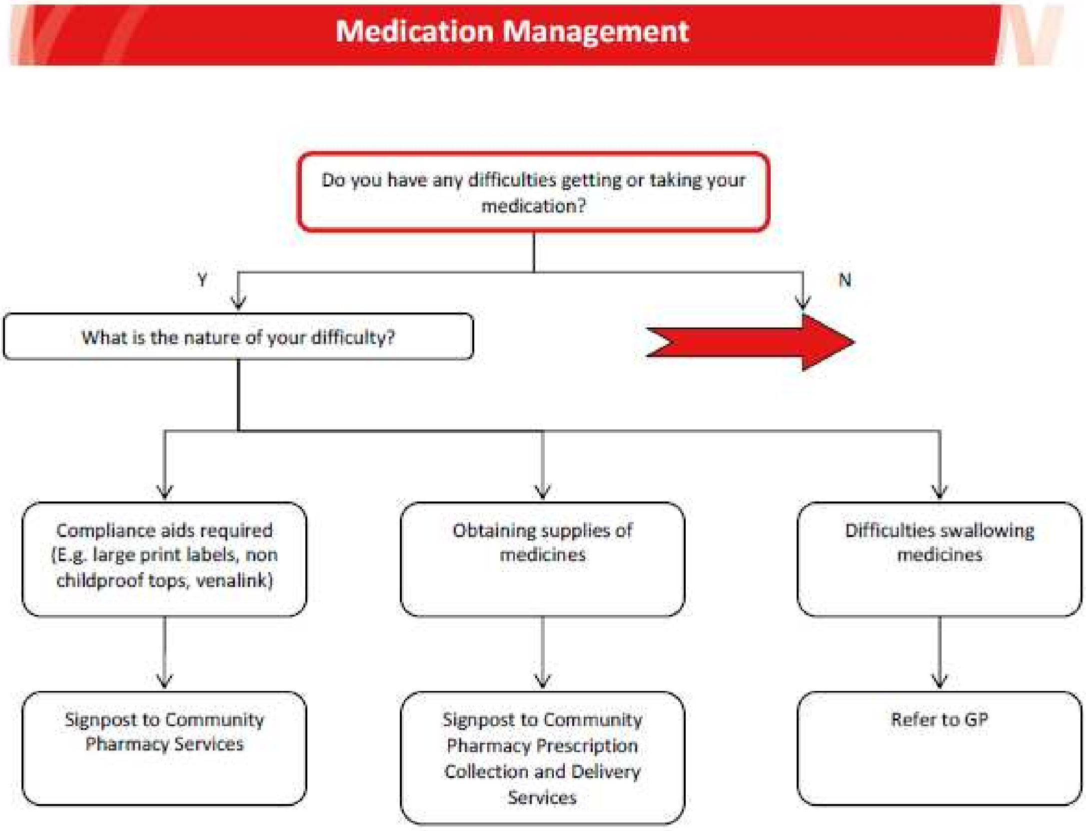
0	**No symptoms.**
1	**No significant disability.** Able to carry out all usual activities, despite some symptoms.
2	**Slight disability.** Able to look after own affairs without assistance, but unable to carry out all previous activities.
3	**Moderate disability.** Requires some help, but able to walk unassisted.
4	**Moderate severe disability.** Unable to attend to own bodily needs without assistance, and unable to walk unassisted.
5	**Severe disability.** Required constant nursing care and attention, bedridden, incontinent.

Question	Notes
Medicine Management Do you have any difficulties getting or taking your medication?	Yes / No
Medication Compliance Are you taking your medication in the way your doctor has advised? Do you feel you get any side effects from your medication?	Yes / No Yes / No
Blood Pressure Is blood pressure below target (140/85; established CVD 130/80)?	**Current blood pressure: /** Yes / No
Anti-Thrombotic Therapy Are you known to suffer from atrial fibrillation (an irregular heart beat)? If unknown, is pulse irregular? *If yes*, is patient anti-coagulated? *If no*, is patient prescribed an antiplatelet?	Yes / No Yes / No Yes / No
Cholesterol Control Are you taking any cholesterol-lowering medication [i.e. statin]? *If no*, has cholesterol been checked since the stroke?	Yes / No Yes / No
Glycaemic Control Are you known to be diabetic? *If yes*, is blood sugar routinely monitored?	Yes / No Yes / No
Alcohol Do you drink alcohol? *If yes*, how much do you tend to drink and how often?	Yes / No
Diet Do you manage to eat a healthy diet?	Yes / No
Smoking Do you smoke? *If yes*, do you wish to stop smoking?	Yes / No Yes / No
Exercise Do you manage to exercise regularly and keep active?	Yes / No
Vision Do you have any problems with your sight (with glasses if worn)?	Yes / No
Hearing Do you have any problems with your hearing (with aid if worn)?	Yes / No
Communication Are you experiencing any new difficulties with your speech, reading or writing?	Yes / No
Dysphagia Are you experiencing any new difficulties swallowing?	Yes / No
Nutrition Since the stroke, have you lost any weight without trying to?	Yes / No MUST Score: _____
Weight Management Have you gained any unintentional weight since the stroke?	Yes/ No
Pain Are you experiencing any bothersome pain?	Yes / No
Headaches and Migraines Have you suffered from troublesome headaches or migraines since the stroke?	Yes / No
Seizures Have you experienced any seizures or loss of consciousness since the stroke?	Yes / No
Continence Are you experiencing any new problems with continence?	Yes / No
Activities of Daily Living Are you experiencing any new problems with daily activities such as washing, dressing, cooking and shopping?	Yes / No

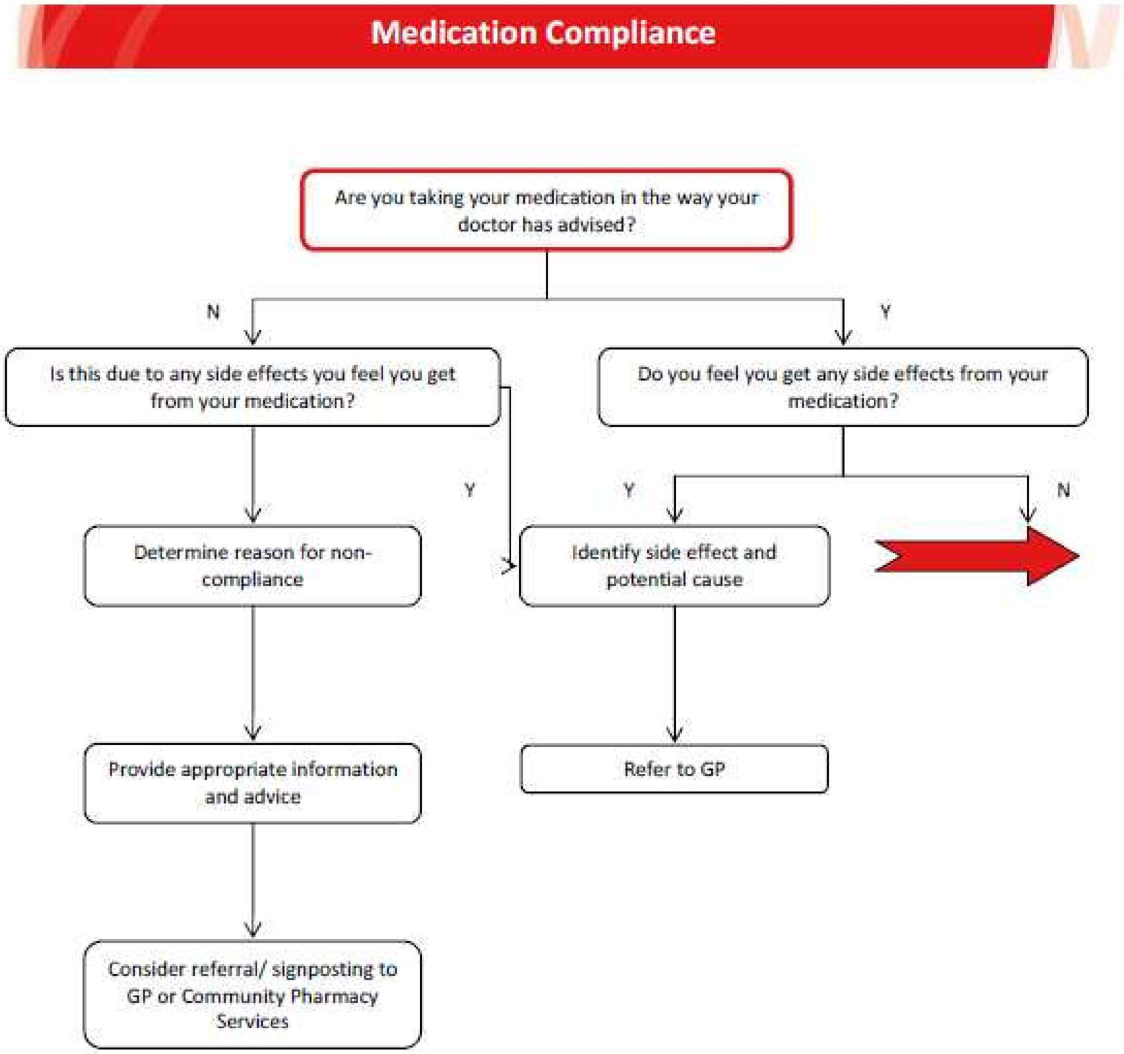
Mobility Do you have any new problems getting around inside the home or outside?	Yes / No
Falls Have you tripped or fallen recently?	Yes / No

Mood Do you often feel sad or depressed?	Yes / No
Anxiety Since the stroke, have you been troubled with anxiety?	Yes / No
Emotionalism Are you troubled, since the stroke, with inappropriate crying or laughing?	Yes / No
Personality Changes Have you or anyone else noticed any changes in your behaviour or personality since the stroke?	Yes / No
Sexual Health Is there any information or advice you would like about sex and relationships after stroke or do you have any concerns relating to this area?	Yes / No
Fatigue Do you feel tired all the time or get tired very quickly since the stroke?	Yes / No
Sleep Pattern Have you had any problems sleeping since the stroke?	Yes / No
Memory, Concentration and Attention Have you had any difficulties remember things or concentrating since the stroke?	Yes / No
Driving Did you drive before the stroke? *If yes*, have you returned to driving <u>OR</u> do you wish to go back to driving?	Yes / No Yes / No
General Transport and Travel Do you have adequate access to a car or public transport?	Yes / No
Activities and Hobbies Do you partake in any leisure activities or hobbies? Are there any (other) activities or hobbies that you would like to be involved in?	Yes / No Yes / No
Employment Are you currently working (paid or voluntary)? *If no*, are you looking to work?	Yes / No Yes / No
Benefits and Finances Would you like any advice or information about benefits and finances?	Yes / No
House and Home Do you have any concerns about or problems with your current accommodation?	Yes / No
Carer/Supporter Needs Do you have a carer? *If yes*, do you think there is anything that he/she needs help or support with?	Yes / No Yes / No

Algorithm for medical management

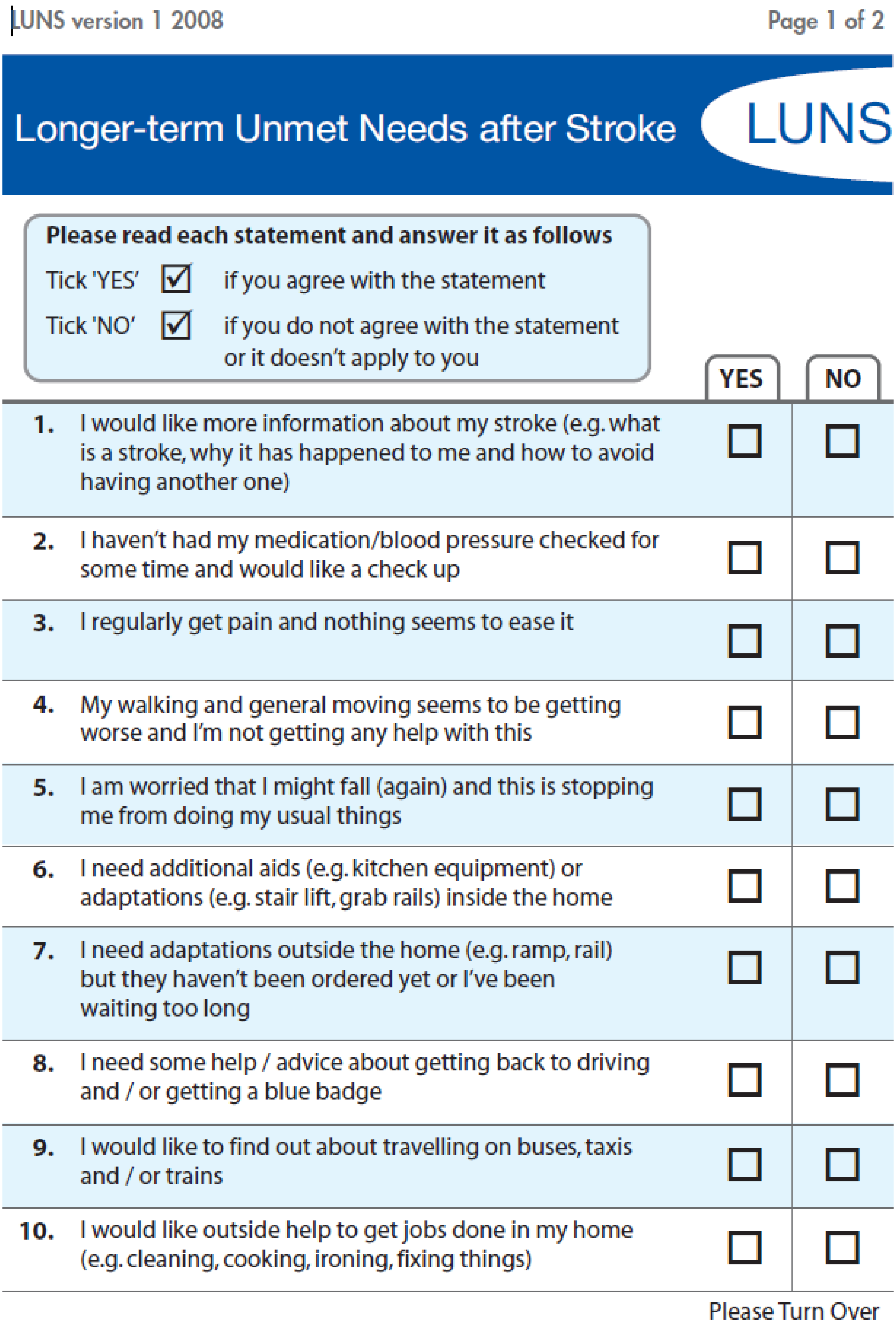


Algorithm for medical compliance



Appendix 7: Longer-term Unmet Needs after Stroke

(LoTS care LUNS study team 2013)



LUNS version 1 2008

Page 1 of 2

Longer-term Unmet Needs after Stroke

LUNS

Please read each statement and answer it as follows

Tick 'YES' ☑ if you agree with the statement

Tick 'NO' ☑ if you do not agree with the statement or it doesn't apply to you

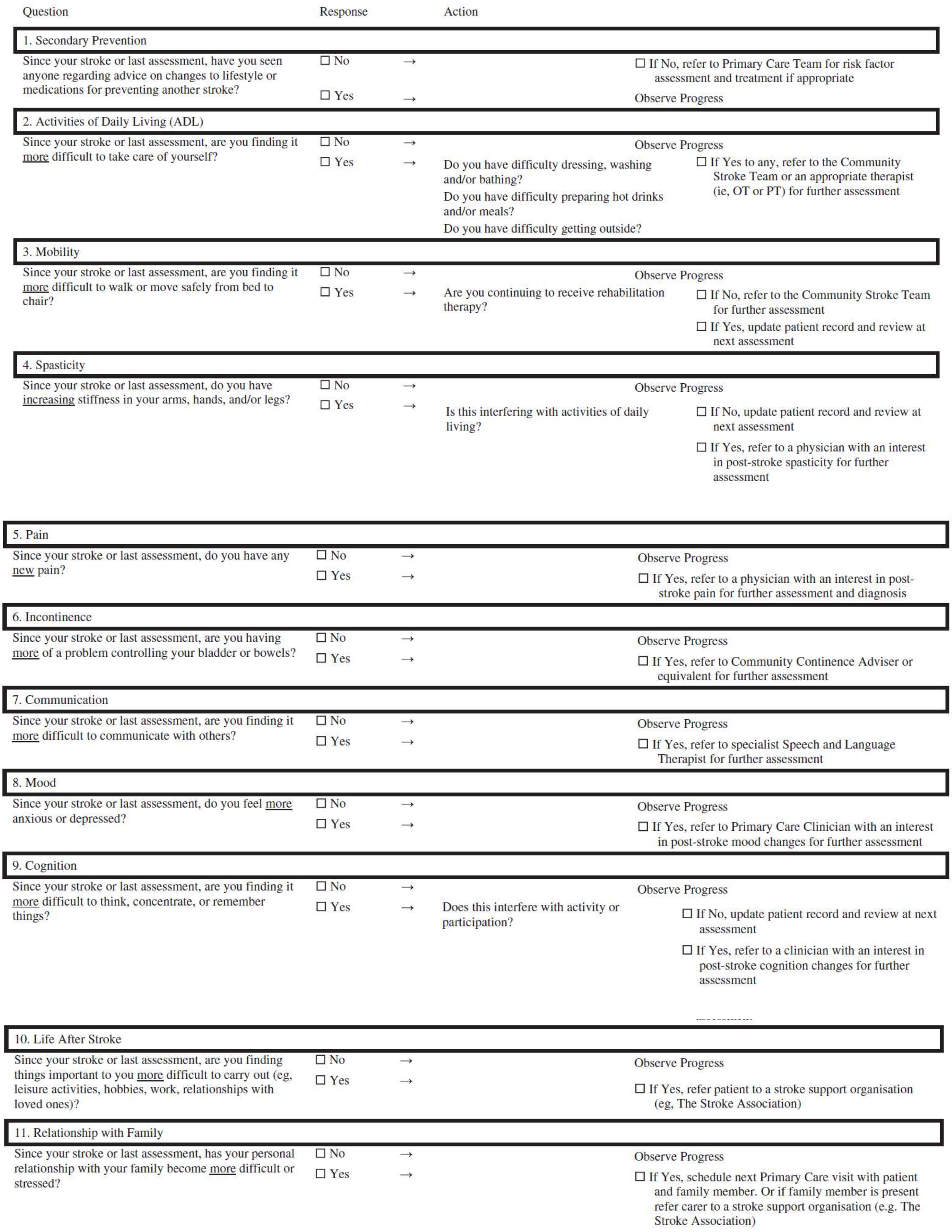
		YES	NO
1.	I would like more information about my stroke (e.g. what is a stroke, why it has happened to me and how to avoid having another one)	☐	☐
2.	I haven't had my medication/blood pressure checked for some time and would like a check up	☐	☐
3.	I regularly get pain and nothing seems to ease it	☐	☐
4.	My walking and general moving seems to be getting worse and I'm not getting any help with this	☐	☐
5.	I am worried that I might fall (again) and this is stopping me from doing my usual things	☐	☐
6.	I need additional aids (e.g. kitchen equipment) or adaptations (e.g. stair lift, grab rails) inside the home	☐	☐
7.	I need adaptations outside the home (e.g. ramp, rail) but they haven't been ordered yet or I've been waiting too long	☐	☐
8.	I need some help / advice about getting back to driving and / or getting a blue badge	☐	☐
9.	I would like to find out about travelling on buses, taxis and / or trains	☐	☐
10.	I would like outside help to get jobs done in my home (e.g. cleaning, cooking, ironing, fixing things)	☐	☐

Please Turn Over

		YES	NO
11.	I would like to look into the options for moving to another home	☐	☐
12.	I would like some advice about how to improve my diet (e.g. alcohol, sugar, fat and salt intakes)	☐	☐
13.	I need some advice to help me manage my money better (e.g. paying bills, getting my pension)	☐	☐
14.	I would like help to find out about, or to apply for benefits	☐	☐
15.	I would like advice on employment after stroke	☐	☐
16.	I need more help with things like cutting my toenails, washing myself or dental care (including dentures)	☐	☐
17.	I have problems with my bladder / bowel (accidents, constipation, diarrhoea) and would like some help with this	☐	☐
18.	I am concerned about my physical relationship with my partner and would like some advice or information	☐	☐
19.	I forget things quite a lot or find it hard to concentrate and would like some help with this	☐	☐
20.	I often feel quite low, angry or worried and would like to find out what help is available	☐	☐
21.	I would like to occupy my day better (e.g. social outings, home library, hobbies) but don't know how to go about it	☐	☐
22.	I would like to find out about holidays / breaks (including transport) that cater for people with disabilities	☐	☐

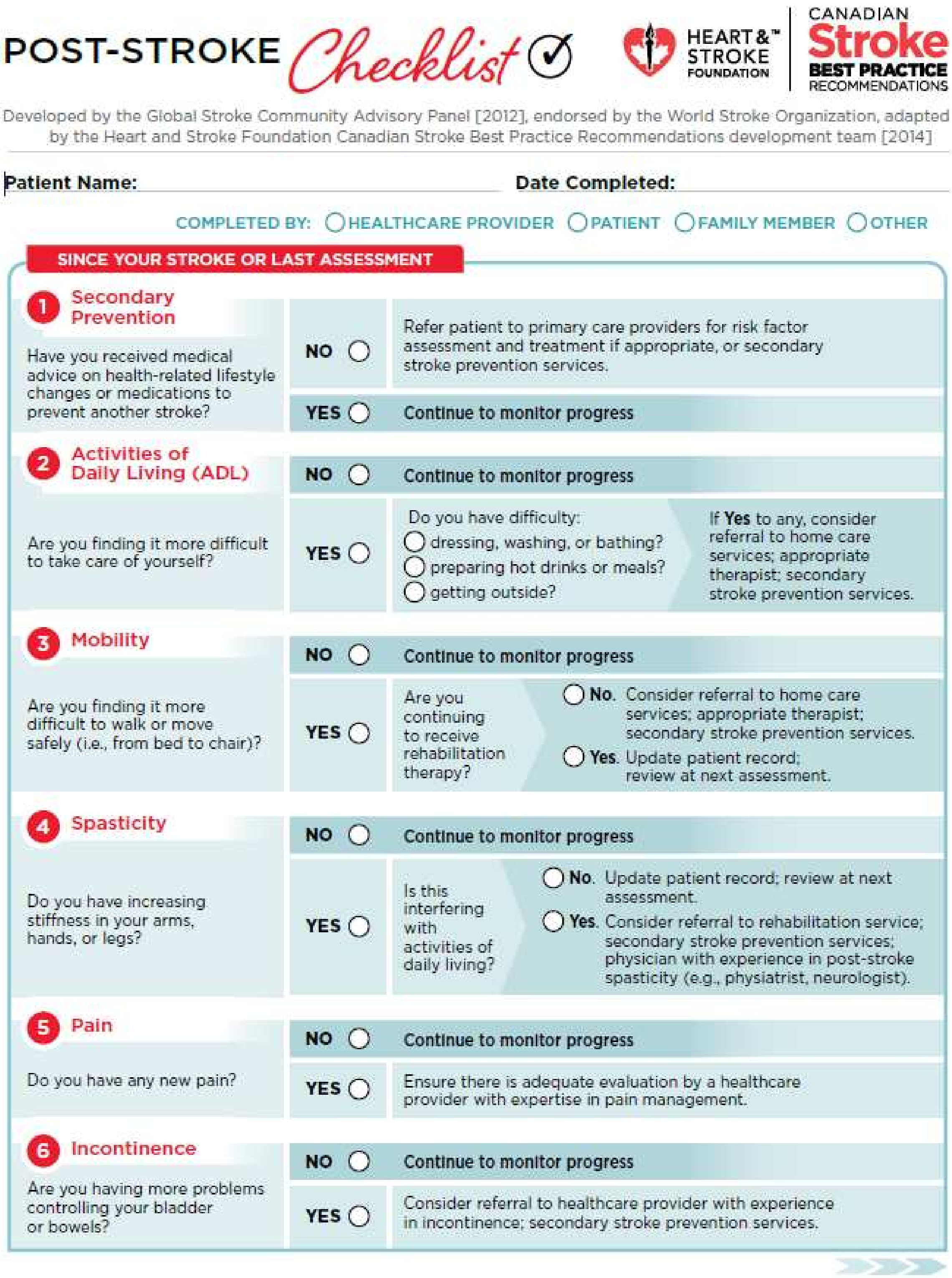
Appendix 8: Post-stroke checklist: original and updated version 2014

a) Original version (Philp et al. 2013)



Question	Response	Action	
1. Secondary Prevention			
Since your stroke or last assessment, have you seen anyone regarding advice on changes to lifestyle or medications for preventing another stroke?	☐ No →		☐ If No, refer to Primary Care Team for risk factor assessment and treatment if appropriate
	☐ Yes →		Observe Progress
2. Activities of Daily Living (ADL)			
Since your stroke or last assessment, are you finding it more difficult to take care of yourself?	☐ No →		Observe Progress
	☐ Yes →	Do you have difficulty dressing, washing and/or bathing? Do you have difficulty preparing hot drinks and/or meals? Do you have difficulty getting outside?	☐ If Yes to any, refer to the Community Stroke Team or an appropriate therapist (ie, OT or PT) for further assessment
3. Mobility			
Since your stroke or last assessment, are you finding it more difficult to walk or move safely from bed to chair?	☐ No →		Observe Progress
	☐ Yes →	Are you continuing to receive rehabilitation therapy?	☐ If No, refer to the Community Stroke Team for further assessment ☐ If Yes, update patient record and review at next assessment
4. Spasticity			
Since your stroke or last assessment, do you have increasing stiffness in your arms, hands, and/or legs?	☐ No →		Observe Progress
	☐ Yes →	Is this interfering with activities of daily living?	☐ If No, update patient record and review at next assessment ☐ If Yes, refer to a physician with an interest in post-stroke spasticity for further assessment
5. Pain			
Since your stroke or last assessment, do you have any new pain?	☐ No →		Observe Progress
	☐ Yes →		☐ If Yes, refer to a physician with an interest in post-stroke pain for further assessment and diagnosis
6. Incontinence			
Since your stroke or last assessment, are you having more of a problem controlling your bladder or bowels?	☐ No →		Observe Progress
	☐ Yes →		☐ If Yes, refer to Community Continence Adviser or equivalent for further assessment
7. Communication			
Since your stroke or last assessment, are you finding it more difficult to communicate with others?	☐ No →		Observe Progress
	☐ Yes →		☐ If Yes, refer to specialist Speech and Language Therapist for further assessment
8. Mood			
Since your stroke or last assessment, do you feel more anxious or depressed?	☐ No →		Observe Progress
	☐ Yes →		☐ If Yes, refer to Primary Care Clinician with an interest in post-stroke mood changes for further assessment
9. Cognition			
Since your stroke or last assessment, are you finding it more difficult to think, concentrate, or remember things?	☐ No →		Observe Progress
	☐ Yes →	Does this interfere with activity or participation?	☐ If No, update patient record and review at next assessment ☐ If Yes, refer to a clinician with an interest in post-stroke cognition changes for further assessment
10. Life After Stroke			
Since your stroke or last assessment, are you finding things important to you more difficult to carry out (eg, leisure activities, hobbies, work, relationships with loved ones)?	☐ No →		Observe Progress
	☐ Yes →		☐ If Yes, refer patient to a stroke support organisation (eg, The Stroke Association)
11. Relationship with Family			
Since your stroke or last assessment, has your personal relationship with your family become more difficult or stressed?	☐ No →		Observe Progress
	☐ Yes →		☐ If Yes, schedule next Primary Care visit with patient and family member. Or if family member is present refer carer to a stroke support organisation (e.g. The Stroke Association)

b) Updated version available from http://www.worldstrokecampaign.org/learn/the-post-stroke-checklist-psc-improving-life-after-stroke.html



POST-STROKE *Checklist* ✓

HEART & STROKE FOUNDATION

CANADIAN Stroke BEST PRACTICE RECOMMENDATIONS

Developed by the Global Stroke Community Advisory Panel [2012], endorsed by the World Stroke Organization, adapted by the Heart and Stroke Foundation Canadian Stroke Best Practice Recommendations development team [2014]

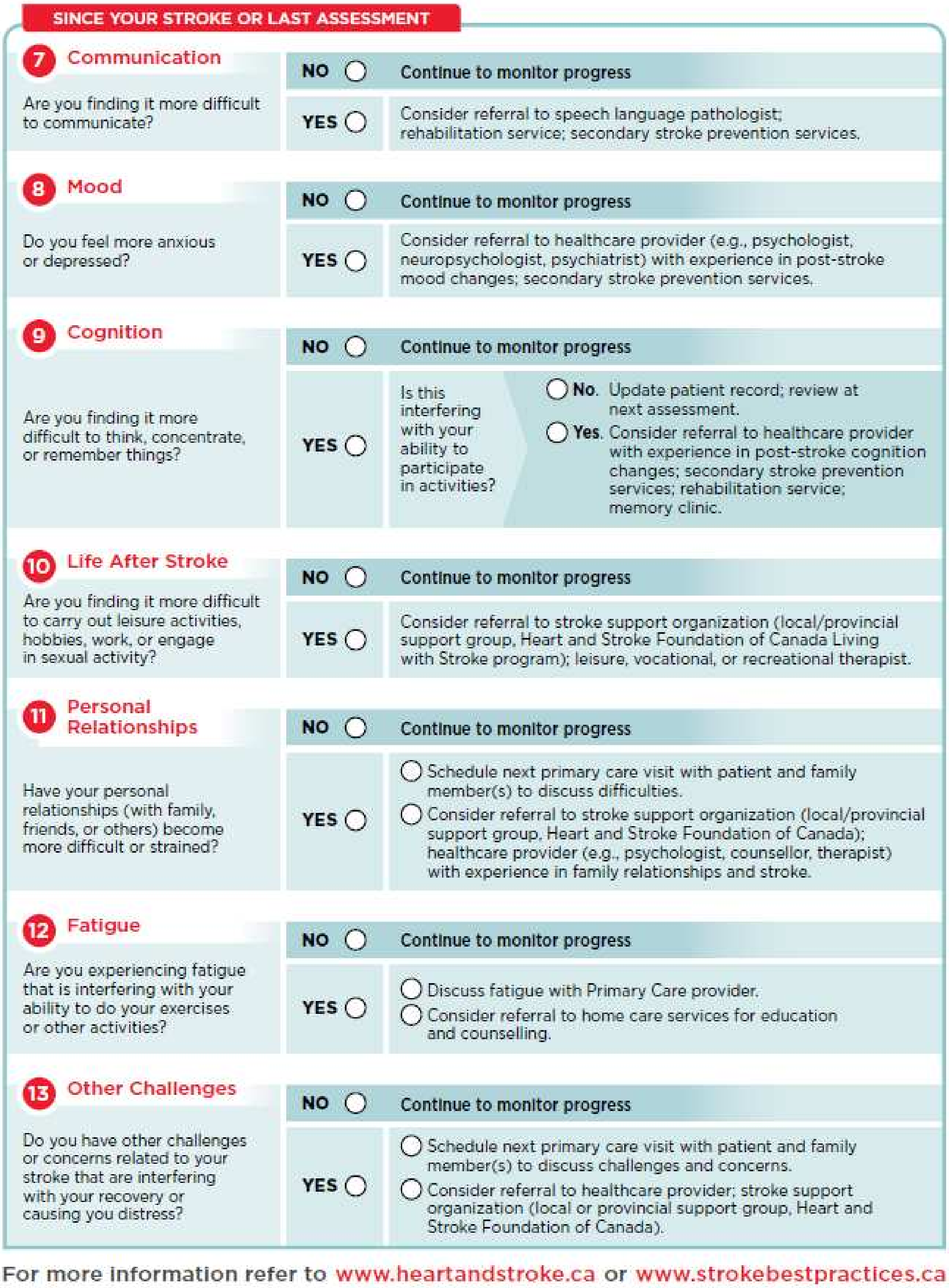
Patient Name:

Date Completed:

COMPLETED BY: ○ HEALTHCARE PROVIDER ○ PATIENT ○ FAMILY MEMBER ○ OTHER

SINCE YOUR STROKE OR LAST ASSESSMENT

1 Secondary Prevention Have you received medical advice on health-related lifestyle changes or medications to prevent another stroke?	**NO** ○	Refer patient to primary care providers for risk factor assessment and treatment if appropriate, or secondary stroke prevention services.	
	YES ○	**Continue to monitor progress**	
2 Activities of Daily Living (ADL) Are you finding it more difficult to take care of yourself?	**NO** ○	**Continue to monitor progress**	
	YES ○	Do you have difficulty: ○ dressing, washing, or bathing? ○ preparing hot drinks or meals? ○ getting outside?	If **Yes** to any, consider referral to home care services; appropriate therapist; secondary stroke prevention services.
3 Mobility Are you finding it more difficult to walk or move safely (i.e., from bed to chair)?	**NO** ○	**Continue to monitor progress**	
	YES ○	Are you continuing to receive rehabilitation therapy?	○ **No.** Consider referral to home care services; appropriate therapist; secondary stroke prevention services. ○ **Yes.** Update patient record; review at next assessment.
4 Spasticity Do you have increasing stiffness in your arms, hands, or legs?	**NO** ○	**Continue to monitor progress**	
	YES ○	Is this interfering with activities of daily living?	○ **No.** Update patient record; review at next assessment. ○ **Yes.** Consider referral to rehabilitation service; secondary stroke prevention services; physician with experience in post-stroke spasticity (e.g., physiatrist, neurologist).
5 Pain Do you have any new pain?	**NO** ○	**Continue to monitor progress**	
	YES ○	Ensure there is adequate evaluation by a healthcare provider with expertise in pain management.	
6 Incontinence Are you having more problems controlling your bladder or bowels?	**NO** ○	**Continue to monitor progress**	
	YES ○	Consider referral to healthcare provider with experience in incontinence; secondary stroke prevention services.	



SINCE YOUR STROKE OR LAST ASSESSMENT

7 Communication Are you finding it more difficult to communicate?	**NO** ○	**Continue to monitor progress**
	YES ○	Consider referral to speech language pathologist; rehabilitation service; secondary stroke prevention services.
8 Mood Do you feel more anxious or depressed?	**NO** ○	**Continue to monitor progress**
	YES ○	Consider referral to healthcare provider (e.g., psychologist, neuropsychologist, psychiatrist) with experience in post-stroke mood changes; secondary stroke prevention services.
9 Cognition Are you finding it more difficult to think, concentrate, or remember things?	**NO** ○	**Continue to monitor progress**
	YES ○	Is this interfering with your ability to participate in activities? ○ **No.** Update patient record; review at next assessment. ○ **Yes.** Consider referral to healthcare provider with experience in post-stroke cognition changes; secondary stroke prevention services; rehabilitation service; memory clinic.
10 Life After Stroke Are you finding it more difficult to carry out leisure activities, hobbies, work, or engage in sexual activity?	**NO** ○	**Continue to monitor progress**
	YES ○	Consider referral to stroke support organization (local/provincial support group, Heart and Stroke Foundation of Canada Living with Stroke program); leisure, vocational, or recreational therapist.
11 Personal Relationships Have your personal relationships (with family, friends, or others) become more difficult or strained?	**NO** ○	**Continue to monitor progress**
	YES ○	○ Schedule next primary care visit with patient and family member(s) to discuss difficulties. ○ Consider referral to stroke support organization (local/provincial support group, Heart and Stroke Foundation of Canada); healthcare provider (e.g., psychologist, counsellor, therapist) with experience in family relationships and stroke.
12 Fatigue Are you experiencing fatigue that is interfering with your ability to do your exercises or other activities?	**NO** ○	**Continue to monitor progress**
	YES ○	○ Discuss fatigue with Primary Care provider. ○ Consider referral to home care services for education and counselling.
13 Other Challenges Do you have other challenges or concerns related to your stroke that are interfering with your recovery or causing you distress?	**NO** ○	**Continue to monitor progress**
	YES ○	○ Schedule next primary care visit with patient and family member(s) to discuss challenges and concerns. ○ Consider referral to healthcare provider; stroke support organization (local or provincial support group, Heart and Stroke Foundation of Canada).

For more information refer to www.heartandstroke.ca or www.strokebestpractices.ca

Appendix 9: Topic guides

9a: Topic guide for patients and carers first interview

RESEARCH TITLE: How does the review process support adults with long term need post-stroke?

Instructions

- Introduce self & project
- Make sure they've read & understood patient information sheet
- Revisit confidentiality, tape recording, anonymity, data storage
- Conversational style, no right/wrong answer, fine to say things they didn't like
- Any further questions
- Complete consent form

Notify participant that the recorder will now be switched on.

Questions for respondents	**Prompts for interviewer/areas to cover**
Background/introduction - Can you tell me a bit about yourself?	- **For patient (pt)**: age, living arrangements, family & friends; roles & routines prior to stroke (work, leisure, caring, ADLs); any other health conditions. - **For carer**: age; relationship to patient & role; working?
Recent experiences: impact of stroke - Can you tell me about your stroke? - How has the stroke affected you? - What was/is central to your life and is it still possible (or limited)? - What was it like coming back home? OR moving to this care home? - How have things changed? - Have things been different to what you expected? - Do you feel that you have any control/say in what is happening in your life now?	Probably some overlap with above but prompt re: - Pt: effect on **body functions** (e.g. mobility, cognition/ memory, speech & swallow, visual, perceptual, mood, fatigue) - Pt & carer: impact on **participation** (e.g. ADLs, work, driving) and **relationship** - Pt & carer: **transitions** between services especially inpatient to home & start of ICT/ESD. Any delays. What services are they getting? - Any differences between **expectations** & what's happened
Support and information - Can you tell me about what support and/or information you have had since the stroke? - What's been most helpful? Or missing? - Was the timing appropriate (to you/the giver)?	- Information at discharge? - Immediate difficulties post-discharge? - Are they using any support groups? - Still getting ICT/ESD?
Six week review (6WR) Describe it to jog memory - Can you tell me about the review? - What did you think about the questions you were asked? - What was helpful about the review? - What was missing? - How could it be improved?	- What do pt/carer think was purpose of 6WR? - Did they understand purpose in advance? - Did it answer problems identified above? - Had they thought about questions in advance? - Alternative content/format to 6WR? - Is there anything they found unhelpful, disliked or couldn't see the point of?
Is there anything else you'd like to tell me about that I haven't already asked you?	

Thank & close. Ask about observing 6MR.

9b: Topic guide for patients and carers after the 6MR

RESEARCH TITLE: How does the review process support adults with long term need post-stroke?

Instructions

- Introduce self & project
- Revisit confidentiality, tape recording, anonymity, data storage
- Conversational style, no right/wrong answer, fine to say things they didn't like
- Ask about observing 6MR
- Any further questions
- Complete consent form

Notify participant that the recorder will now be switched on.

Question	Prompts
Introduction/review - How have things been since we last met?	- Prompt pt & carer for changes, concerns, ongoing issues, services, return to work - Any support groups/information they are using
Progress - What's your daily routine now? - How do you want things to improve in the next few months? - What was/is central to your life and is it still possible (or restricted/limited)? - Do you feel that you have any control/say in what is happening in your life now?	- What they've achieved in last 6 months - Any goals for the next 6 months & how will achieve them (e.g. do they need prof support?)
Six month review (6MR) Describe it to jog memory - Can you tell me about the review? - What was helpful? - What was missing? - How could it be improved? - How else could you be supported? - Was the timing appropriate (to you/the giver)?	- What was the purpose of it? - Did they understand purpose in advance? - Did it answer their concerns/questions? - How was it different to 6WR? - Is there anything they found unhelpful, disliked or couldn't see the point of? - Would it be helpful to have another review? In about how long? For what purpose?
Is there anything else you'd like to tell me about that I haven't already asked you?	

Thank & close.

9c: Topic guide for professionals

RESEARCH TITLE: How does the review process support adults with long term need post-stroke?

Instructions

- Introduce self and project
- Check they have read and understood information sheet
- Revisit confidentiality, tape recording, anonymity, data storage
- Any further questions
- Complete consent form

Notify participant that the recorder will now be switched on.

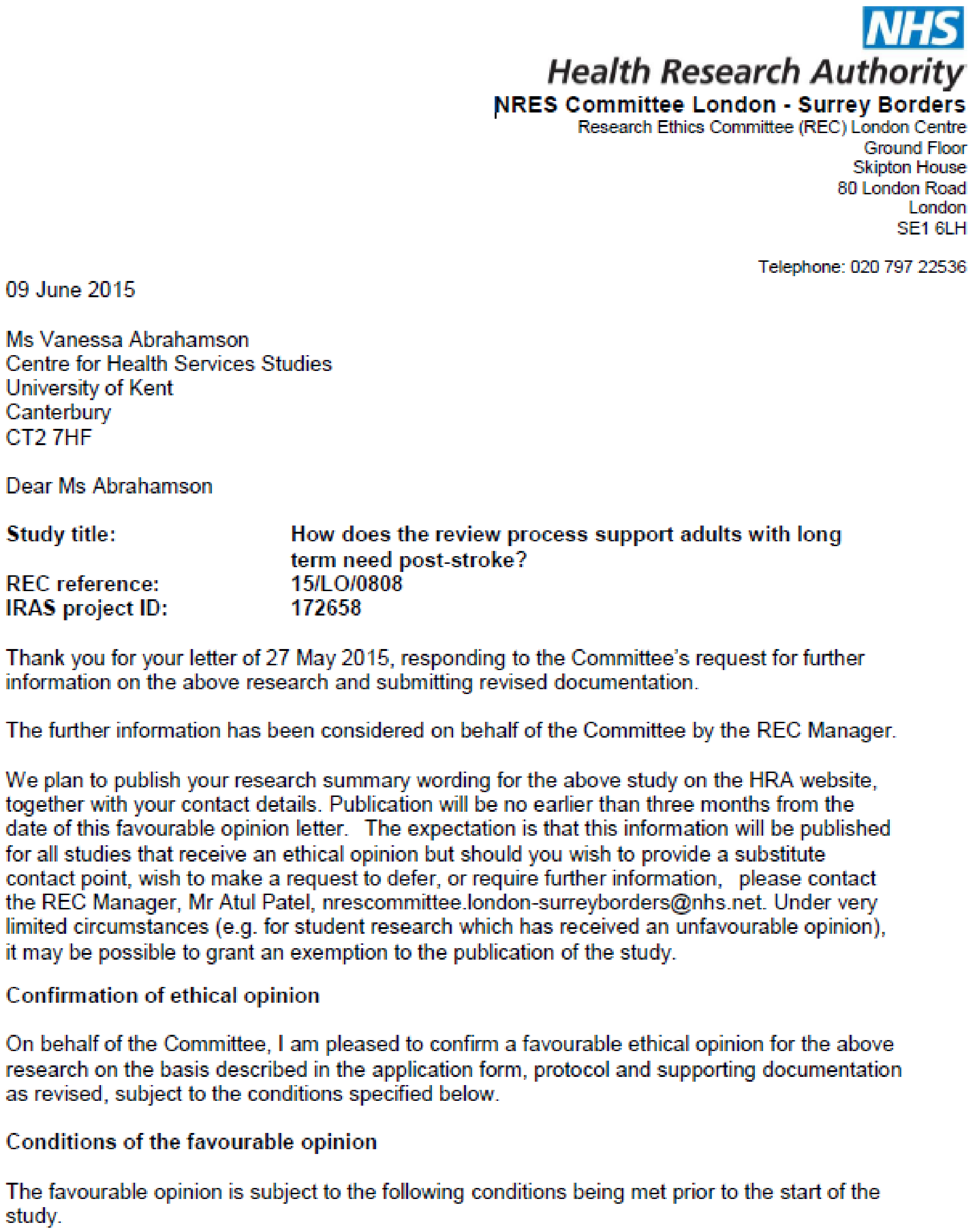
Questions for professionals	**Prompts for interviewer**
Introduction - Can you tell me a little about your role?	Will include: - Nurse specialists & the service managers - CCG reps - Care home manager/named nurse
Background to review process - Can you tell me about the background to initiating/commissioning the review process in your area? *(not policy background)*	**For CCGs & stroke nurse specialists.** - Why it was necessary to set up the service? - What problems/barriers did they encounter? - How did they prioritise it above other services? - Who did they consult with? E.g. SS/3rd sector
Purpose & mechanism - **What do you think is the purpose of the review process?** - How do you think it achieves this? - Is it an assessment of need or a complex intervention? - How does it contribute to or sit within a patient's overall recovery? - How does the 6MR fit with the ideal of providing long-term support? - Is self-management part of the equation? - How well is 2^0 prevention addressed including lifestyle factors? - Is it feasible or beneficial to provide yearly reviews, if you had the funding?	**For CCGs & stroke nurse specialists.** - Differentiate between 6 week review, 6MR, yearly and overall process - Is it meant to support carers? How? - Is there an end point or yearly reviews should roll on? What would be achieved? - How does it fit into the stroke care pathway?
Process - **Tell me a little about how you carry out the 6MR?** - What follow up work is involved? - How do you link with existing services? - What works well with the process? - What barriers have you encountered?	**For stroke nurse specialists only**. - What information do they have in advance? - Do they use GM-SAT or similar? - Clinical reasoning for where/how they carry it out (e.g. aphasia; care home resident; location) - Any barriers? - Who is responsible for what?

- What changes would you like to make if resources weren't an issue? - Do you think anyone else could carry out the 6MR, for example, the SA uses semi-trained staff?	- Can it be any professional? Or non-professional?
Outcomes - **What are the outcomes of the review process and/or 6MR?** - Can you measure these in any way? - Is there an endpoint?	- What are the problems with using outcome measures especially as it is Ax more than intervention. - Whose perspective e.g. patient, commissioner, provider? Each has different objectives e.g. QoL vs cost
Is there anything else you'd like to tell me about that I haven't already asked you?	

Thank & close.

Appendix 10: Research Ethics Committee approval letters

10a: Research Ethics Committee final approval letter



NHS
Health Research Authority
NRES Committee London - Surrey Borders
Research Ethics Committee (REC) London Centre
Ground Floor
Skipton House
80 London Road
London
SE1 6LH

Telephone: 020 797 22536

09 June 2015

Ms Vanessa Abrahamson
Centre for Health Services Studies
University of Kent
Canterbury
CT2 7HF

Dear Ms Abrahamson

Study title:	**How does the review process support adults with long term need post-stroke?**
REC reference:	**15/LO/0808**
IRAS project ID:	**172658**

Thank you for your letter of 27 May 2015, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the REC Manager.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this favourable opinion letter. The expectation is that this information will be published for all studies that receive an ethical opinion but should you wish to provide a substitute contact point, wish to make a request to defer, or require further information, please contact the REC Manager, Mr Atul Patel, nrescommittee.london-surreyborders@nhs.net. Under very limited circumstances (e.g. for student research which has received an unfavourable opinion), it may be possible to grant an exemption to the publication of the study.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at http://www.rdforum.nhs.uk.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

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

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database. This should be before the first participant is recruited but no later than 6 weeks after recruitment of the first participant.

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to request a deferral for study registration within the required timeframe, they should contact hra.studyregistration@nhs.net. The expectation is that all clinical trials will be registered, however, in exceptional circumstances non registration may be permissible with prior agreement from NRES. Guidance on where to register is provided on the HRA website.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Ethical review of research sites

NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	*Version*	*Date*
Covering letter on headed paper [covering letter]	1	15 April 2015
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Public liability]	1	31 July 2014
Interview schedules or topic guides for participants [Professionals]	2	14 April 2015
Interview schedules or topic guides for participants [Patients & carers 1st interview]	2	14 April 2015
Interview schedules or topic guides for participants [Patients & carers 2nd interview]	2	14 April 2015
IRAS Checklist XML [Checklist_17042015]		17 April 2015
Letter from funder [Email from ESRC]	1	06 May 2014
Letter from sponsor [ResGov 306]	1	08 April 2015
Letters of invitation to participant [Invitation letter]	1	14 April 2015
Letters of invitation to participant [Life after stroke group]	1	14 April 2015
Other [Tracking call to patients]	1	14 April 2015
Other [Professional Negligience]	1	19 September 2014
Other [Gantt chart]	2	26 March 2015
Other [Supervisors CV]		
Participant consent form [6MR Aphasia]	3	27 May 2015
Participant consent form [6MR]	1	27 May 2015
Participant consent form [Carer]	3	27 May 2015
Participant consent form [Patient Aphasia]	3	27 May 2015
Participant consent form [Patient]	3	27 May 2015
Participant consent form [Professionals]	3	27 May 2015
Participant information sheet (PIS) [Carer]	3	27 May 2015
Participant information sheet (PIS) [Professionals]	3	27 May 2015
Participant information sheet (PIS) [Patient Aphasia]	3	27 May 2015
Participant information sheet (PIS) [Patient]	3	27 May 2015
REC Application Form [REC_Form_17042015]		17 April 2015
Research protocol or project proposal [Protocol]	6	14 April 2015
Research protocol or project proposal	7	27 May 2015
Response to Request for Further Information		27 May 2015
Summary CV for Chief Investigator (CI) [Abrahamson_CV]	1	14 April 2015
Summary CV for supervisor (student research) [Wilson_CV]	2	15 April 2015

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document *"After ethical review – guidance for researchers"* gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website:
http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/

HRA Training

We are pleased to welcome researchers and R&D staff at our training days – see details at http://www.hra.nhs.uk/hra-training/

15/LO/0808 **Please quote this number on all correspondence**

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

Yours sincerely

pp

Sir Adrian Baillie
Chair

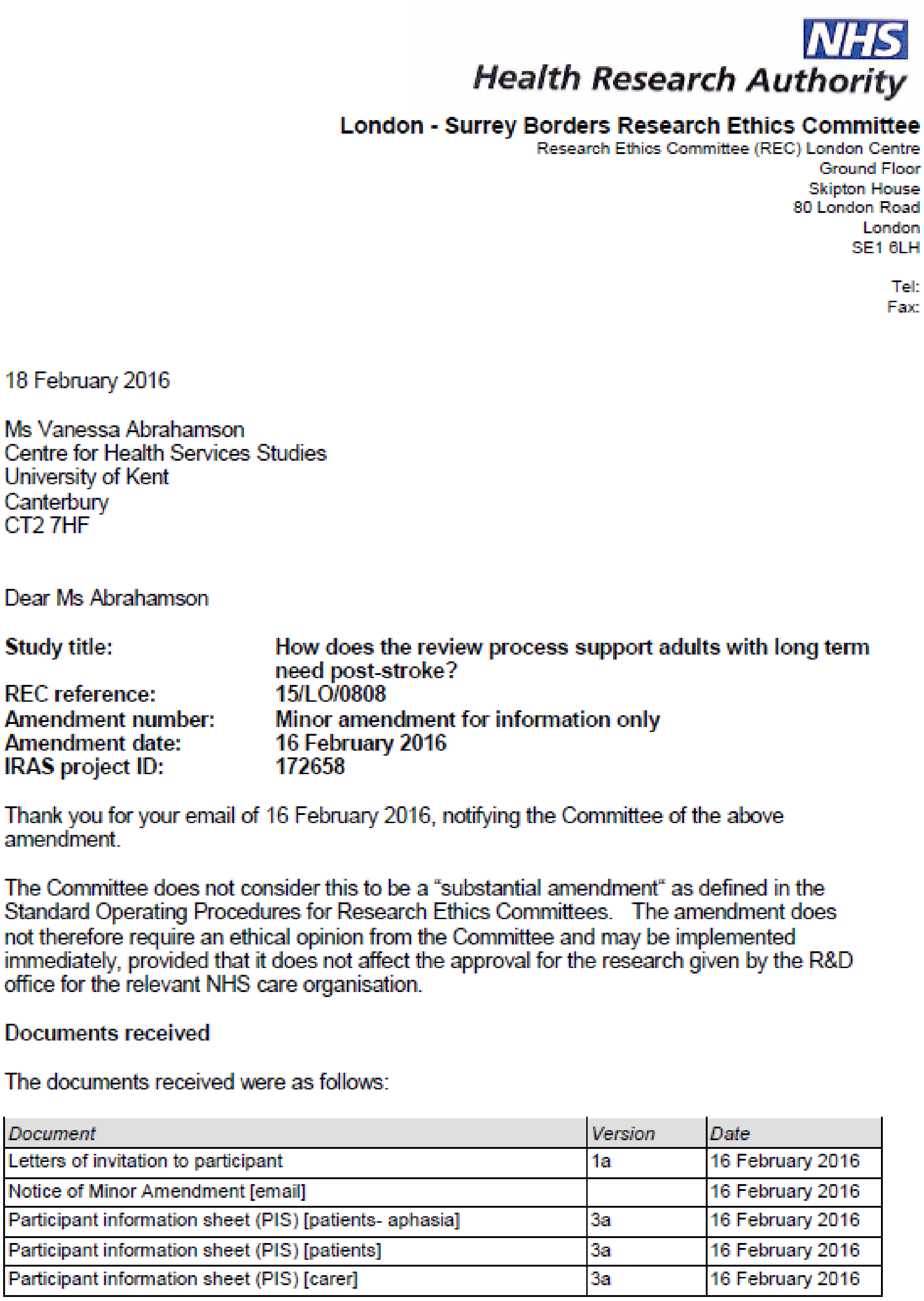
Email:nrescommittee.london-surreyborders@nhs.net

Enclosures: "After ethical review – guidance for researchers"

Copy to: *Nicole Palmer*

[Name of R&D Lead and Hospital Trust] - anonymised to protect confidentiality.

10b: Research Ethics Committee acknowledgement of minor amendments



NHS
Health Research Authority

London - Surrey Borders Research Ethics Committee
Research Ethics Committee (REC) London Centre
Ground Floor
Skipton House
80 London Road
London
SE1 6LH

Tel:
Fax:

18 February 2016

Ms Vanessa Abrahamson
Centre for Health Services Studies
University of Kent
Canterbury
CT2 7HF

Dear Ms Abrahamson

Study title: **How does the review process support adults with long term need post-stroke?**
REC reference: **15/LO/0808**
Amendment number: **Minor amendment for information only**
Amendment date: **16 February 2016**
IRAS project ID: **172658**

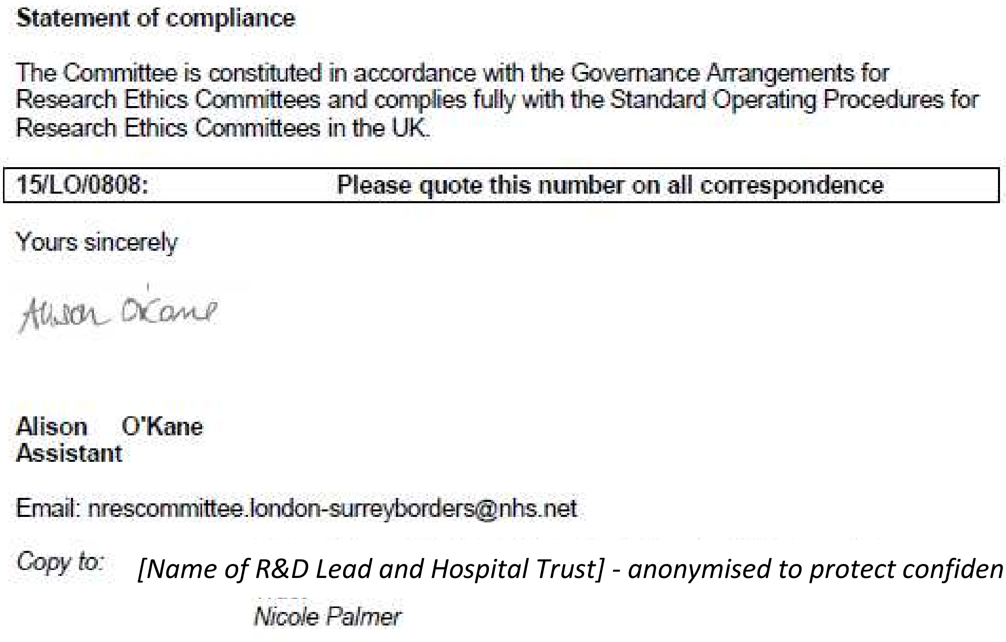
Thank you for your email of 16 February 2016, notifying the Committee of the above amendment.

The Committee does not consider this to be a "substantial amendment" as defined in the Standard Operating Procedures for Research Ethics Committees. The amendment does not therefore require an ethical opinion from the Committee and may be implemented immediately, provided that it does not affect the approval for the research given by the R&D office for the relevant NHS care organisation.

Documents received

The documents received were as follows:

Document	*Version*	*Date*
Letters of invitation to participant	1a	16 February 2016
Notice of Minor Amendment [email]		16 February 2016
Participant information sheet (PIS) [patients- aphasia]	3a	16 February 2016
Participant information sheet (PIS) [patients]	3a	16 February 2016
Participant information sheet (PIS) [carer]	3a	16 February 2016



Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

15/LO/0808:	**Please quote this number on all correspondence**

Yours sincerely

Alison O'Kane

Alison O'Kane
Assistant

Email: nrescommittee.london-surreyborders@nhs.net

Copy to: *[Name of R&D Lead and Hospital Trust] - anonymised to protect confidentiality.*
Nicole Palmer

Appendix 11: Patient invitation letter

PATIENT INVITATION LETTER

Study title: How does the review process support adults with long-term needs after a stroke?

We would like to invite you to take part in a research study being carried out at the University of Kent. The study plans to explore and understand how patients are supported by community services in the first year after a stroke.

We are asking you to take part because you have had a stroke. We would also like to talk to someone who helps you like your husband/wife or any other close relative. The research involves two interviews spread out over a year. We will visit you at home to talk about your experiences.

If you would like to learn more about this study please complete the response form and put it in the stamped envelope. You can either post it or return it to the doctor or nurse who gave you this letter.

If you have any questions about the study, please contact:

Vanessa Abrahamson, PhD student, University of Kent.

Email: va63@kent.ac.uk

Tel: 01227 827760 or 01227 827569

Thank you

RESPONSE FORM

I am interested in this research and would like to learn more about it. The researcher can contact me on the details below once I am home.

My details are as follows:

		I would prefer to be contacted by (tick which applies)
Telephone number:		
Mobile phone number:		
Email address:		
Postal address:		
I am also happy for you to contact my relative on:		

I would like aphasia friendly information: YES NO

Name: ____

Date: ______________________

Please return the form to the stroke nurse or post in the stamped addressed envelope

Appendix 12: Patient and carer information sheets

12a: Patient information sheet 1

PATIENT INFORMATION SHEET

Study: **How does the review process support adults with long-term needs after a stroke?**

We would like to invite you to take part in a research study that is being carried out by Vanessa Abrahamson who is a PhD student at the University of Kent. The other researcher is Professor Patricia Wilson who is supervising the research. The study will look at how people who have had a stroke are supported once they get home.

Before you decide whether to take part you need to understand why the research is being carried out and what it involves. Please take time to read the following information carefully. Please ask if anything is unclear or you would like more information; our contact details are at the end of this sheet. The study is being funded by the European Social Research Council.

What is the purpose of the research?

The study plans to explore and understand how patients are supported by community services in the first year after having a stroke. In the area that you live a stroke nurse reviews your progress at about 6 months after your stroke. This is known as a **six month review** and is a relatively new service. We want to find out how helpful you find this review and how it could be improved.

Why me?

You are being asked to take part because you have recently had a stroke. We would like to learn about your experiences once you are home. If you have a close relative who helps you we would also like to learn about their experiences. If you cannot identify someone we would still like to interview you.

How will I be involved in the project?

Taking part in the research means you will have the opportunity to tell the researcher about your experiences following your stroke. The researcher will visit you at home (or in your care home) to interview you. This is not formal but more like a discussion. The **first interview** will be once you have been home for 6-8 weeks. The **second interview** will be at about 9 months after your stroke. We will phone you in between these two interviews to see how things are going. Each interview will take 30-45 minutes with time either side for questions. The whole visit will take 1-1$^1/_2$ hours.

If you agree to take part, we will contact you once you are home to arrange the first interview on a day and time that suits. We also want to learn about your close relative's experiences. We will ask you if you are happy to talk together or are more comfortable speaking separately.

We would like to record the interview to help us remember what you say. Before we start recording we will ask you to sign a consent form agreeing to take part. The recording will be typed-up and all names will be removed. The recording will then be deleted. We may use direct quotes from the interview when writing up the research but any names will be removed.

We will ask a small number of participants whether we could sit in on your **six month review**. We can talk about this after the first interview. You are free to decide whether you are happy for the researcher to sit in on your review, or not.

Do I have to take part?

No. It is up to you whether or not to take part. If you decide to take part you can change your mind at any time without giving a reason. A decision not to take part will not affect your treatment in any way.

Are there benefits to taking part?

There are no immediate benefits of this research to you but it may help people in a similar situation to you in the future. What you say will contribute to our understanding and how to support people when they leave hospital; this may help us gain insights into how the service could be improved.

What might be difficult about taking part?

Whilst we do not anticipate any health risks from taking part you may find the interview tiring. You may find it upsetting to talk about your experiences. You can stop the interview at any time. We will provide you with information about local support groups, for example the Stroke Association.

Will my taking part in this project be kept confidential?

If you decide to take part all information collected from you will be kept strictly confidential. The recording of your interviews will be deleted after we have typed them. The paperwork will be stored in a protected way so that you cannot be identified. Only the researcher and her supervisor will have access to this information.

If you tell us something that indicates there is a risk of harm to yourself or someone else then we will need to consider telling someone about this risk. We will not speak to anyone without discussing with you first.

What will happen to the results of the research?

This study will help us understand your experiences and how to improve the service. The researcher will send you a summary of the findings and you are welcome to discuss them with her. The results will be fed back to the Trusts involved, particularly those involved in supporting you after your stroke. In order to reach a wider audience the results might be published in academic journals and presented at academic or professional conferences. You will not be identified in any way.

What next?

If you have any questions please feel free to contact the researcher, **Vanessa Abrahamson,** PhD student, University of Kent. Email: va63@kent.ac.uk**. Tel: 01227 827760.** Otherwise we will contact you within the next week to see if you agree to take part. If you do agree, we can make an appointment for the first interview.

Questions or concerns?

The study has been reviewed and ethically approved by NRES Committee London – Surrey Borders. The reference is **15/LO/0808**.

If you have any concerns/complaints please contact the **Customer Liaison and Communications officer**, Graham Tibble.

Tel: 020 8394 3843

Email: graham.tibble@nhs.net

You can also contact the researcher directly. If the issue is not resolved successfully please contact her supervisor, Professor Wilson, P.M.Wilson@kent.ac.uk, 01227 816093. Where this has not been successful, complaints should be addressed to the Director of Research Services, Dr Simon Kerridge, S.R.Kerridge@kent.ac.uk, 01227 823229.

12b: Patient information sheet 2 (aphasia friendly)

PATIENT INFORMATION SHEET

Study: **How does the review process support adults with long-term needs after a stroke?**

We would like to invite you to take part in a study about stroke

University of Kent 	It is being carried out by **Vanessa Abrahamson**, **PhD student,** University of Kent **Professor Patricia Wilson** is supervising the research The **European Social Research Council** is funding it.
	Please **read** the following **information** It **explains** the research and **why it is being carried out** Please **ask** if anything is unclear Our **contact details** are at the end of this sheet

Why are we doing the research?

	There are different **services** to help you manage at home after your stroke

 	About 6 months after your stroke a nurse will visit you at home. This is called a **6 month review.** We don’t know **how best to improve this review** The research will help us **learn more**

Why me?

 	You have had a stroke If you have a **close relative** who helps you we would also like to learn about **their experiences** We **still want to talk to you** if you do **not** have a close relative

How will I be involved in the project?

	You will have the opportunity to **tell the researcher** about **your experiences** following your stroke. This is like a **discussion** If you agree to take part, **we will contact you** once you are home.

	The researcher will **visit you at home** or in your **care home** for the interview **You will choose a** day and time that suits you
 	The **first interview** will be once you have been home for about **6 weeks** The **second interview** will be at about **9 months** after your stroke Each **interview** will take **30-45 minutes**. The **whole visit** will take **1-1$^{1}/_{2}$ hours**
	We also want to learn about **your close relative's experiences** We will **ask** you if you are happy to **talk together** or are more comfortable speaking **separately**
	We will take **sound recordings** This helps us to **remember** what you said **Only the researchers** will listen to the recording

 	The recording will be **typed** and all **names** will be **removed** The **recording** will then be **deleted** The information will be kept **safe** We will **not use your name**

Do I have to take part?

	**No.** You can decide. You **don't have to** take part If you don’t take part you will **still get your normal help**
	If you change your mind, **you can stop** at any time You **don't** have to **give a reason**

Are there benefits to taking part?

	You may **enjoy** taking part. You will **help** people in the **future** They may get **better help** You will help us to **learn**

What might be difficult about taking part?

 	You may find it **tiring** You may **get upset** talking about your stroke

Who will see the information about me?

	We will keep the **information** about you **safe** **Only** the **researchers** will see the **information about you** We will **take out your name** and **personal details**

Is the research safe?

 	A committee **decides if research can happen** This is the **ethics committee** They say that **this research** has been **planned properly** and **can go ahead** It has been **ethically approved** by the committee

	The **reference** is **15/LO/0808**
	If you tell us something that suggests there is a **risk of harm** to yourself (or someone else) we will need to **consider telling someone** We will **discuss** this **with you** before telling anyone
  	**If you are not happy with the research** you can **tell us**, or ask someone to tell us for you: 1) Tell the **researcher**, Vanessa Abrahamson Tel: 01228 827760 Email: va63@kent.ac.uk 2) Tell her **supervisor**, Professor Wilson Tel: 01227 816093 Email: P.M.Wilson@kent.ac.uk 3) Tell the **Director of Research Services**, Dr Simon Kerridge Tel: 01227 823229 Email: S.R.Kerridge@kent.ac.uk 4) Tell the **Customer Liaison and Communications Officer**, Graham Tibble Tel: 020 8394 3843 Email: graham.tibble@nhs.net

What will happen to the results?

	We will **give you the results** of the research
 	We will **share the results** with **services in your area** And with **other researchers** at **conferences** and **meetings** And through **newsletters** and in **academic journals**
 	The results will **not use your name** The results may include **what you said** but **not who said it**

What next?

 	Do you **want** to **take part? You** need to **decide** Does your **close relative** want to **take part**?

	You can **contact the researcher** for **more information:** **Vanessa Abrahamson,** Email: **va63@kent.ac.uk** **Tel: 01227 827760.** **And you can tell us** if you and your relative want to take part.
 	If you decide to take part you will need to **sign a consent form** This says that **you understand** the research and **you agree** to take part
  	We will **contact you** and ask for **your decision** **Yes** I want to **No** I don't want to I have a **close relative** who **wants to take part**

	If you decide to take part we will make **a time for the first interview** You can **choose** what **day and time** suits you

Thank you for taking the time to read this

12c: Carer information sheet

CARER INFORMATION SHEET

Study: **How does the review process support adults with long-term needs after a stroke?**

We would like to invite you to take part in a research study that is being carried out by Vanessa Abrahamson who is a PhD student at the University of Kent. The other researcher is Professor Patricia Wilson who is supervising the research. The study will look at how people who have had a stroke and their carers are supported once they get home. By carer we mean anyone who helps look after the person who has had a stroke.

Before you decide whether to take part you need to understand why the research is being carried out and what it involves. Please take time to read the following information carefully. Please ask if anything is unclear or you would like more information; our contact details are at the end of this sheet. The study is being funded by the European Social Research Council.

What is the purpose of the research?

The study plans to explore and understand how patients and carers are supported by community services in the first year after having a stroke. In the area that you live a stroke nurse visits the person who had the stroke about 6 months later. This is known as a **six month review** and is a relatively new service. We want to find out what you think about this review and how it could be improved.

Why me?

You are being asked to take part because you are married to, live with, or are a close relative of the person who has had a stroke. We would like to learn about your experiences alongside those of the person who had the stroke.

How will I be involved in the project?

Taking part in the research means you will have the opportunity to tell the researcher about your experiences looking after a person who has had a stroke. The researcher will visit you both at home for the interview which is more like an informal discussion. If the person you care for is in a care home we can visit you there or in your home. The **first interview** will be once the person you care for has been home for 6-8 weeks. The **second interview** will be at about 6 months later. We will phone you in between these two interviews to see how things are going. Each interview will take 30-45 minutes with time either side for questions. The whole visit will take 1-$1^1/_2$ hours.

If you agree to take part, we will contact you once the person you care for is home to arrange the first interview on a day and time that suits. We will ask you if you are happy to talk together or are more comfortable speaking separately.

We would like to record the interview to help us remember what you say. Before we start recording we will ask you to sign a consent form agreeing to take part. The recording will be typed-up and all names will be removed. The recording will then be deleted. We may use direct quotes from the interview when writing up the research but any names will be removed.

Do I have to take part?

No. It is up to you whether or not to take part. If you decide to take part you can change your mind at any time without giving a reason. A decision not to take part will not affect your treatment in any way.

Are there benefits to taking part?

There are no immediate benefits of this research to you but it may help people in a similar situation to you in the future. What you say will contribute to our understanding and how to support people and their carers in the first year post-stroke; this may help us gain insights into how the service could be improved.

What might be difficult about taking part?

You may find it upsetting to talk about your experiences. You can stop the interview at any time. We will provide you with information about local support groups, for example the Stroke Association.

Will my taking part in this project be kept confidential?

If you decide to take part all information collected from you will be kept strictly confidential. The recording of your interviews will be deleted after we have typed them. The paperwork will be stored in a protected way so that you cannot be identified. Only the researcher and her supervisor will have access to this information.

If you tell us something that indicates there is a risk of harm to yourself or someone else then we will need to consider telling someone about this risk. We will not speak to anyone without discussing with you first.

What will happen to the results of the research?

This study will help us understand your experiences and how to improve the service. The researcher will send you a summary of the findings and you are welcome to discuss them with her. The results will be fed back to the Trusts involved, particularly those involved in supporting you after your stroke. In order to reach a wider audience the results might be published in academic journals and presented at academic or professional conferences. You will not be identified in any way.

What next?

If you have any questions please feel free to contact the researcher, **Vanessa Abrahamson,** PhD student, University of Kent. Email: **va63@kent.ac.uk** **. Tel: 01227 827760.** Otherwise we will contact you within the next week to see if you agree to take part. If you do agree, we can make an appointment for the first interview.

Questions or concerns?

The study has been reviewed and ethically approved by NRES Committee London – Surrey Borders. The reference is **15/LO/0808**.

If you have any concerns/complaints please contact the researcher directly. If the issue is not resolved successfully please contact Professor Wilson, P.M.Wilson@kent.ac.uk, 01227 816093. Where this has not been successful, complaints should be addressed to the Director of Research Services, Dr Simon Kerridge, S.R.Kerridge@kent.ac.uk , 01227 823229.

Appendix 13: Patient and carer consent forms

13a: Consent form for patients 1

CONSENT FORM FOR PATIENTS

Title of Project: How does the review process support adults with long-term needs after a stroke?

Name & contact details of researcher: Vanessa Abrahamson, CHSS, George Allen Wing, University of Kent, Canterbury, Kent CT2 7NF. Tel: 01227 827760. Email: va63@kent.ac.uk

Participant Identification Code for this study:

Please initial box

1. I confirm that I have read and understand the information sheet dated ….. (version…..) for the above study and have had the opportunity to ask questions. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason. ☐
3. I understand that everything I say is confidential unless I tell you something that indicates that I, or someone else, is at risk of harm in which case you would discuss this with me before telling anyone else. ☐
4. I understand that data collected during the study may be looked at by individuals from the research team, from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. ☐
5. I understand and agree that the interview will be audio-recorded. ☐
6. I agree to take part in the above study. ☐
7. I agree that you can approach my carer to participate in this study. ☐

☐

8. I understand that if the researcher attends my six month review she will formally request my consent.

Name of Participant _______________ Signature _________________ Date_________

Name of Researcher ______________ Signature _________________ Date_________

Copies: 1 for participant, 1 for researcher

13b: Consent form for patients 2 (aphasia friendly)

CONSENT FORM FOR PATIENTS

Title of Project: How does the review process support adults with long-term needs after a stroke?

Name & contact details of researcher: Vanessa Abrahamson

Tel: 01227 827760

Email: va63@kent.ac.uk

Participant Identification Code for this study:

Please **mark** yes ☐ no ☐ **for each statement**

	I have **read** the **information** about the **research**	yes ☐ no ☐
	I have had the **chance** to **ask questions**	yes ☐ no ☐
	I am **happy** with the **answers** to my questions	yes ☐ no ☐
	I understand that **information** about me will be **kept safe.**	yes ☐ no ☐

	It will not be shared with **anyone outside** the research team	
	I know that when **results** are shared the researcher will **not use my name**	yes ☐ no ☐
	I understand that **I can stop being in the research** at any time. **If** I stop I **don't** have to **give a reason.** **I will still get normal care**	yes ☐ no ☐
	In very rare cases people **tell the researcher** something that suggests that **they**, or someone else, **are at risk of harm.** **If this happens** the researcher would **discuss this with me before telling anyone** else.	yes ☐ no ☐
	I understand and **agree** that the interview will be **audio-recorded**.	yes ☐ no ☐
	**I agree to take part** in the research	yes ☐ no ☐

	I agree that you can approach **my carer** to **participate** in this study.	yes ☐ no ☐
	I understand that **if** the researcher attends my **six month review** she will formally request **my consent**.	yes ☐ no ☐

Name of Participant ________________________________

Signature ____

Date_________

Name of Researcher ________________________________

Signature ____

Date_________

Copies: 1 for participant, 1 for researcher

13c: Consent form for carers

CONSENT FORM FOR CARERS

Title of Project: How does the review process support adults with long-term needs after a stroke?

Name & contact details of researcher: Vanessa Abrahamson, CHSS, George Allen Wing, University of Kent, Canterbury, Kent CT2 7NF. Tel: 01227 827760. Email: va63@kent.ac.uk

Participant Identification Code for this study:

Please initial box

1. I confirm that I have read and understand the information sheet dated ….. (version…..) for the above study and have had the opportunity to ask questions. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason. ☐
3. I understand that everything I say is confidential unless I tell you something that indicates that I, or someone else, is at risk of harm in which case you would discuss this with me before telling anyone else. ☐
4. I understand that data collected during the study may be looked at by individuals from the research team, from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. ☐
5. I understand and agree that the interview will be audio-recorded. ☐
6. I agree to take part in the above study. ☐

Name of Participant ______________ Signature ________________ Date_________

Name of Researcher _____________ Signature ________________ Date_________

Copies: 1 for participant, 1 for researcher

Appendix 14: Information sheet for professionals

INFORMATION SHEET for PROFESSIONALS

Study: How does the review process support adults with long-term needs post- stroke?

We would like to invite you to take part in a research study that is being carried out by Vanessa Abrahamson, PhD student, University of Kent. The research is being supervised by Professor Patricia Wilson. The study will explore how patients and carers are supported in the first year post-stroke with particular reference to the six month review as part of the review process.

Before you decide whether to take part please take time to read the following information. Please ask if anything is unclear or you would like more information; our contact details are at the end of this sheet. The study is being funded by the European Social Research Council.

What is the purpose of the research?

The study plans to explore and understand how patients and carers are supported by community services in the first year post-stroke with particular reference to the six week, six month and annual review where available. We are interviewing patients, and their carers, after the six week and six month review as well as observing how the reviews are carried out and interviewing staff.

Why me?

We want to talk to all professionals who are involved in the review process including: clinicians who carry out the review and their managers; those who commission the service; and care home managers where residents receive the six month review.

How will I be involved in the project?

We would like to carry out one interview of around 30 minutes with time either side for questions; the maximum time it would take is 1-$1^1/_4$ hours. Interviews can be face to face, in which case we will visit you at a time and place that suits, or by telephone/Skype. We would like to record the interview to ensure we have an accurate record of what was discussed. Before we start recording we will ask you to sign a consent form agreeing to take part. The recording will be typed-up and all names will be removed. The recording will then be deleted. We may use direct quotes from the interview when writing up the research but any names will be removed.

Do I have to take part?

No. It is up to you whether or not to take part. If you decide to take part you can change your mind at any time without giving a reason.

Are there benefits to taking part?

There are no immediate benefits of this research to you. What you say will contribute to our understanding of how to support people post-stroke and may contribute to the development of your service.

What might be difficult about taking part?

We realise that you are busy and finding time for an interview is difficult. We are flexible with when and how we carry out interviews.

Will my taking part in this project be kept confidential?

If you decide to take part all information collected from you will be kept strictly confidential. The recording of your interview will be deleted after we have typed it. The paperwork will be stored in a protected way so that you cannot be identified. Only the researcher and her supervisor will have access to this information. Very rarely, researchers may hear about practice that causes concern. They are obliged to report this but would inform the interviewee that this is being done.

What will happen to the results of the research?

This study will help us understand your perspective and the overall findings may be used to support service development. We would like to share our findings in whatever format you and your service find most helpful. For example, we would be happy to do a presentation as well as provide written feedback. In order to reach a wider audience the results may be published in academic journals and presented at academic or professional conferences. You will not be identified in any way.

What next?

If you have any questions please contact **Vanessa Abrahamson,** PhD student, University of Kent. Email: **va63@kent.ac.uk** **. Tel: 01227 827760.** Otherwise we will contact you within the next week to see if you agree to take part. If you do agree, we can make an appointment.

Questions or concerns?

If you have any concerns/complaints please contact the researcher directly. If the issue is not resolved please contact Professor Wilson, P.M.Wilson@kent.ac.uk, 01227 816093. Where this has not been successful, complaints should be addressed to the Director of Research Services, Dr Simon Kerridge, S.R.Kerridge@kent.ac.uk, 01227 823229. You may also wish to contact the study sponsor, Nicole Palmer, Research Ethics & Governance Officer, N.R.Palmer@kent.ac.uk, 01227 824797. You can also discuss any concerns with your line manager.

Appendix 15: Consent form for professionals

CONSENT FORM FOR PROFESSIONALS

Title of Project: How does the review process support adults with long-term needs after a stroke?

Name & contact details of researcher: Vanessa Abrahamson, CHSS, George Allen Wing, University of Kent, Canterbury, Kent CT2 7NF. Tel: 01227 827760. Email: va63@kent.ac.uk

Participant Identification Code for this study:

Please initial box

1. I confirm that I have read and understand the information sheet dated ….. (version…..) for the above study and have had the opportunity to ask questions. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason. ☐
3. I understand that everything I say is confidential and no personal information about me or my client group will be recounted unless I report practice that causes concern. We would discuss this with you before reporting any concerns. ☐
4. I understand that data collected during the study may be looked at by individuals from the research team, from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. ☐
5. I understand and agree that the interview will be audio-recorded. ☐
6. I agree to take part in the above study. ☐

Name of Participant _______________ Signature _________________ Date__________

Name of Researcher ______________ Signature _________________ Date__________

Copies: 1 for participant, 1 for researcher

Appendix 16: Summary of all respondents per site

Explanation of codes used to identify participants:

Identifier	Refers to:
CS1, R18, F, 87yrs:	Case study (or site) 1, respondent 18, female, 87 years old
CS1, R9, M, 79yrs:	Case study 1, respondent 9, male, 79 years old
CS2, C3:	Case study 2, the carer of respondent 3
CS2, M2:	Case study 2, the second manager interviewed
CS1, GP1:	Case study 1, the first GP interviewed
CS1, CCG3:	Case study 1, a commissioner within a Clinical Commissioning Group
CS1, SNS1:	Case study 1, a Stroke Nurse Specialist
CS3, SA3:	Case study 3, a Stroke Association co-ordinator
CS2, OT2:	Case study 2, an occupational therapist
CS2, PT2:	Case study 2, a physiotherapist
N.B. Those not prefixed by CS1-3 are not site specific; for example, Or1 refers to an orthoptist.	

Codes relevant to all case study sites:

Respondent no.	Role
M1	South East Coast Strategic Clinical Network, Quality Lead
M5	Member of Royal College of Physician's Intercollegiate Stroke Working Party
Or1	Academic and clinical orthoptist
SA4	Stroke Association: Regional director
SA5	Stroke Association: Regional director
SA6	Stroke Association: Services performance and delivery

16a: Case study 1 (CS1)

Patients: respondent no.	M: Male F: Female	Age	Who did they live with?	Did they have other long-term conditions? Y: Yes; N: No	Were they working pre-stroke?
1	F	77	Lived alone (widowed)	Y	Retired
2	F	50	Husband and son	Y	Not working due to ill health
9	M	79	Wife	Y	Retired
12	F	69	Husband	N	Retired
13	F	37	Husband and 2 children	N	Working full-time
14	M	85	Wife	Y	Retired
15	M	57	Mother (with dementia)	N	Retired to care for mother
16	M	64	Lived alone (divorced)	Y	Not working due to ill health
18	F	87	Friend/carer	Y	Retired
20	M	51	Lived alone (divorced)	Y	Not working due to ill health
21	F	67	Husband	N	Retired
24	F	34	Partner	Y	Long-term sick leave
25	M	78	Wife	Y	Retired
26	M	72	Partner	Y	Retired
27	M	88	Wife	N	Retired
28	F	66	Husband	N	Retired
30	M	73	Wife	N	Retired
32	M	68	Landlady (with dementia)	N	Retired
33	F	56	Lived alone	Y	Self-employed, part-time
34	M	28	Partner	N	Working full-time
35	F	72	Husband	N	Retired
36	M	58	Wife	N	Working full-time
37	M	77	Lived alone (wife in care home)	Y	Retired
38	M	54	Wife	N	Working full-time
39	M	73	Wife and daughter	Y	Retired
41	F	63	Lived alone (divorced)	N	Recently retired

Clinicians, managers and commissioners:

Respondent no.	Work role
SNS1	Community Stroke Nurse Specialist
SNS3	Community Stroke Nurse Specialist
SNS4	Community Stroke Nurse Specialist
SA2	Stroke Association worker; did not carry out 6MRs
PT1	Community physiotherapist
GP1	General Practitioner (part-time)
GP2	General Practitioner (part-time)
M5	Community rehabilitation services manager
CCG1	Clinical Commissioning Group: Head of Programme Delivery
CCG2	Clinical Commissioning Group: Head of Planning and Delivery

16b: Case study 2 (CS2)

Patients: respondent no.	M: Male F: Female	Age	Who did they live with?	Did they have other health conditions pre-stroke? Y: Yes; N: No	Were they working pre-stroke?
3	M	76	Wife	Y	Retired
4	F	85	Lived alone (widowed)	Y	Retired
5	M	72	Wife	Y	Retired
6	M	36	Parents	N	Worked full-time
7	F	85	Husband	N	Retired
8	M	31	Fiancé	N	Worked full-time
10	M	55	Lived alone	Y	Early retirement due to illness
11	F	63	Son	N	Worked full-time
17	F	68	Husband	Y	Retired
19	M	63	Wife	N	Retired
22	F	80	Daughter	N	Retired
23	M	61	Wife	N	Worked part-time
29	M	91	Wife	Y	Retired
31	M	63	Wife	N	Worked full-time
40	F	76	Husband	N	Retired

Clinicians, managers and commissioners:

Respondent no	Role
SNS2	Community Stroke Nurse Specialist for 6MRs and Early Supported Discharge team
SNS5	Service Manager/Stroke Nurse Specialist
SNS6	Stroke Nurse Specialist in the Acute Stroke Unit
SA1	Stroke Association worker; did not carry out 6MRs
PT2	Community physiotherapist/therapy lead
OT1	Community occupational therapist
OT2	Community occupational therapist
M3	Community rehabilitation services manager
M4	Community stroke co-ordinator

16c: Case study 3 (CS3)

Patients: respondent no.	M: Male F: Female	Age	Who did they live with?	Did they have other health conditions pre-stroke? Y: Yes; N: No	Were they working pre-stroke?
42	M	73	Wife	N	Retired
43	F	80	Husband	Y	Retired
44	F	79	Lived alone (divorced)	N	Retired
45	M	79	Wife	Y	Retired
46	M	67	Wife	Y	Retired due to ill health

Clinicians, managers and commissioners:

Respondent no.	Role
SA3	Stroke Association co-ordinator; carried out 6MRs
M2	Project manager, County Council
CCG3	Clinical Commissioning Group: Head of Planning and Delivery

Appendix 17: Description of respondents

Figure 1: Age range of respondents by site

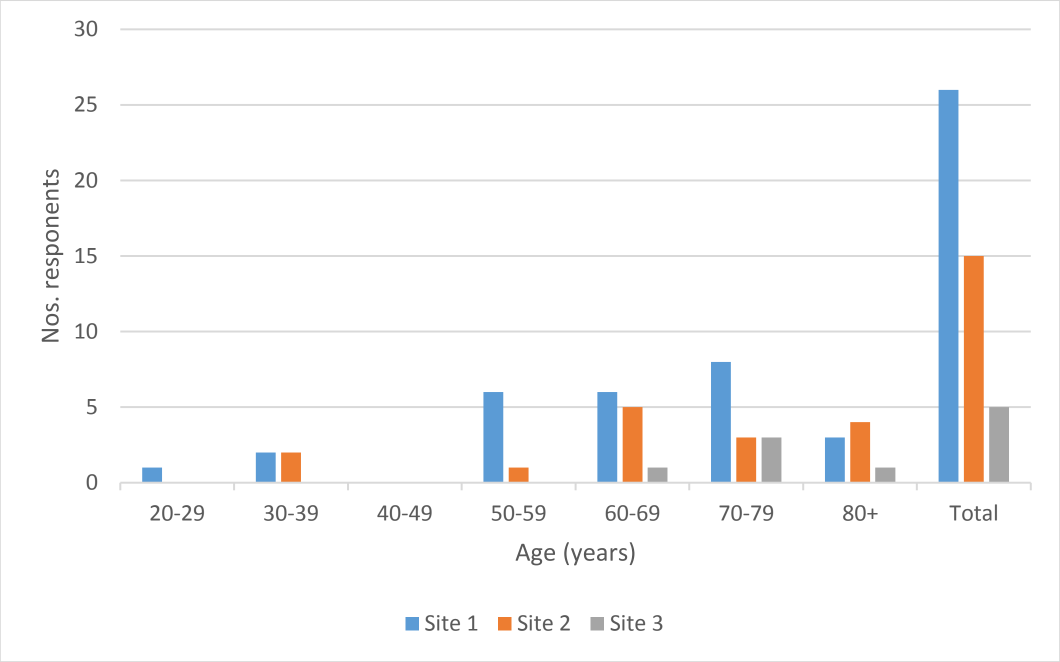
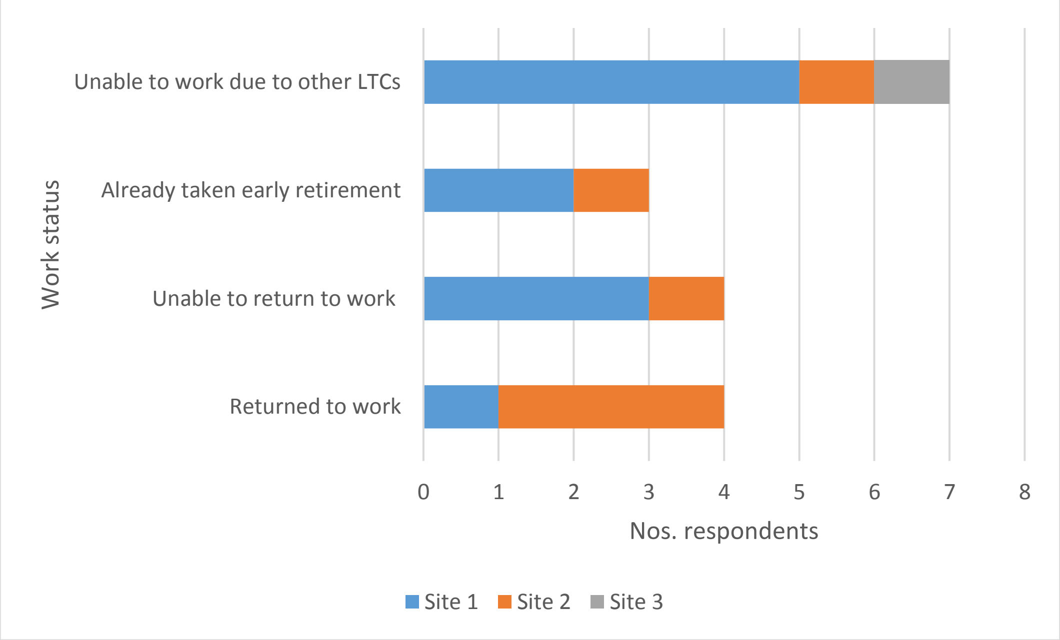


Figure 2: Working age respondents and return to work during the study period



Appendix 18: Site 2, letter sent with Life After Stroke invitation

Research study: How does the review process support adults with long-term needs after a stroke?

We would like to tell you about a research study that is being carried out by the University of Kent. The study is being carried out by PhD student, Vanessa Abrahamson, who is being supervised by Professor Patricia Wilson, University of Kent.

What is the purpose of the research?

The study plans to explore and understand how patients are supported by community services in the first year after having a stroke. In the area that you live a stroke nurse reviews your progress at about 6 months after your stroke and you are invited to attend the **'Life After Stroke' Group**. We want to learn more about stroke services and how to improve them. Some of you may already have been asked to take part in an interview as part of this study.

What is involved?

You do not need to do anything. The researcher will occasionally sit in on the Life After Stroke Group so we want to be sure that you feel comfortable with this. The purpose is for the researcher to learn about the content and format of the group and no personal information will be recorded.

The study has been reviewed and given ethical approval by The National Research Ethics Committee London - Surrey Borders. The reference is 15/LO/0808.

If you have any questions about the study, please contact: Vanessa Abrahamson, CHSS, University of Kent. Email: **va63@kent.ac.uk**. Tel: **01227 827760**.

Thank you

Appendix 19: Site 1 and 2, SNS clinic invitation for 6MR

19a: Site 1

[headed paper]

Our ref:
Date:

Address

Dear

You have been referred to the Stroke Specialist Nurse as you are due for your post-stroke review. I would like to offer you an appointment to see me in the clinic.

Venue:
Date:
Time:

Please bring your medications or new prescription with you to your appointment

The purpose of this appointment is to review your overall health and liaise with other relevant professionals if needed on your behalf. I will discuss stroke risk factors e.g. blood pressure, cholesterol and health promotion. I will explain the results of any relevant tests/investigations completed. During this review, you and/or your carer will also have an opportunity to discuss any worries that you may be experiencing that are directly related to the stroke.

If you wish to change the appointment date/time or you do not require it, please telephone XXX and ask for XXX. Thank you.

Yours sincerely

On behalf of the Stroke Specialist Nurse

19b: Site 2

[headed paper]

Our ref:
Date:

Dear

You have been invited to attend your 6 Month Stroke Review. You will be seen by XXX and she will discuss:

- Your recovery
- Your Stroke risk factors and how to address them
- Review your stroke prevention medications - **Please bring along any medication that you are currently taking.**
- If appropriate, returning to work

She will also check your blood pressure.

At the end of the consultation a letter will be sent to your GP about the discussions and, if any, recommendations that are made.

Date :
Time :
Venue:

Please call and leave us a message on xxx to confirm or decline your appointment. There are many patients on the waiting list and we would like to reallocate your appointment if you cannot attend. Please do not hesitate to contact us if you require any more information.

Yours sincerely

Stroke Co-ordinator and Nurse Specialist

Appendix 20: Site 3, SA invitation for 6MR

Date:

Dear

6 Month Stroke Review

The Stroke Association has been commissioned by XXX County Council, in conjunction with local NHS services, to **review the progress** of people who have had a **stroke**, six months after being **discharged from hospital**.

The review usually takes place in your **home** and is an opportunity to identify any **unmet needs**. It usually takes about **60-90 minutes**.

I have made an appointment to visit you at home on …………………………..

at ……………………………..

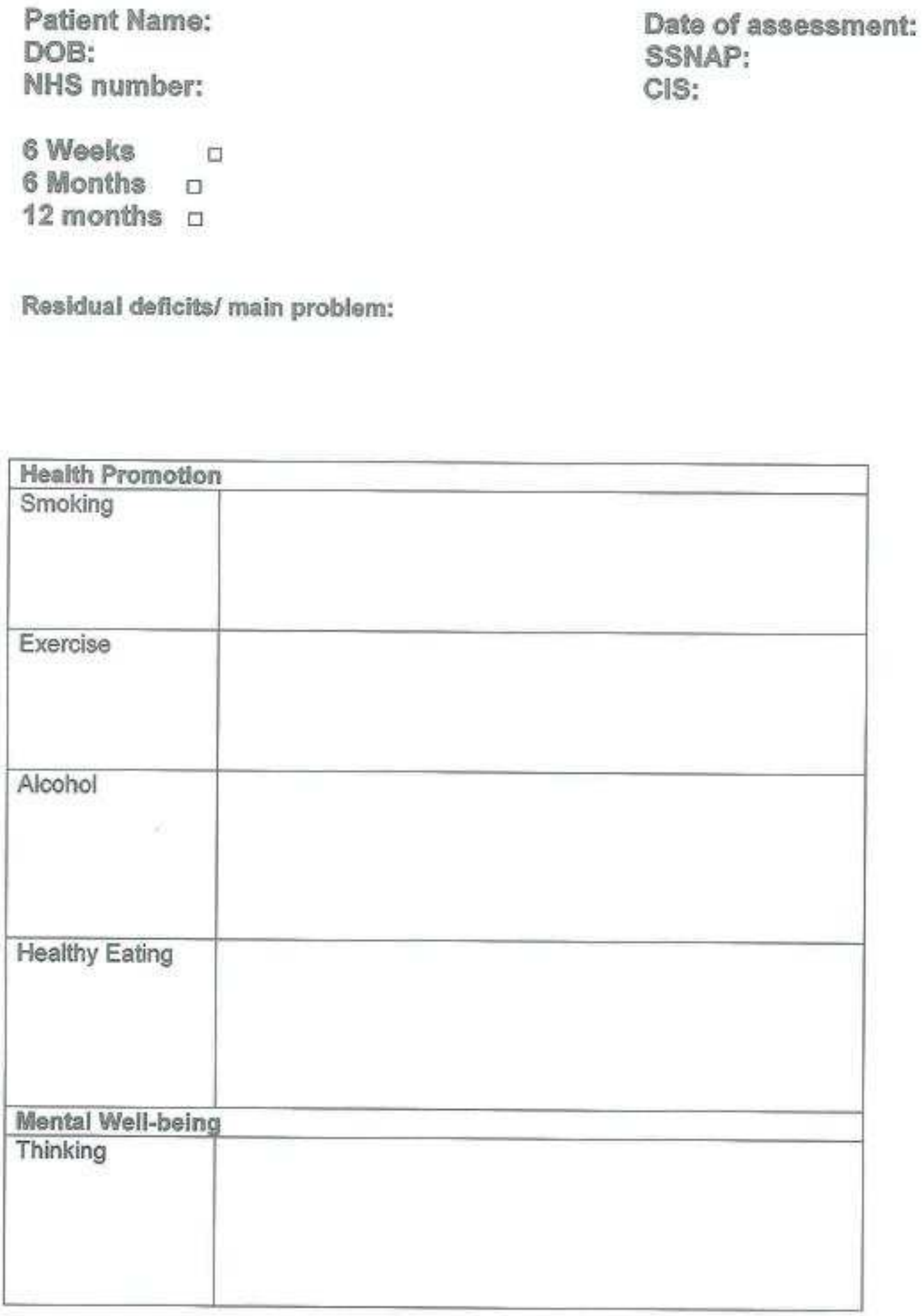
If this is not convenient please contact me in advance of the appointment date on [Tel].

I hope that all is going well.

Yours sincerely

Information, Advice and Support / 6 Month Review Coordinator
[Name & details]

Appendix 21: Site 1 template for 6MR



Patient Name:
DOB:
NHS number:

Date of assessment:
SSNAP:
CIS:

6 Weeks ☐
6 Months ☐
12 months ☐

Residual deficits/ main problem:

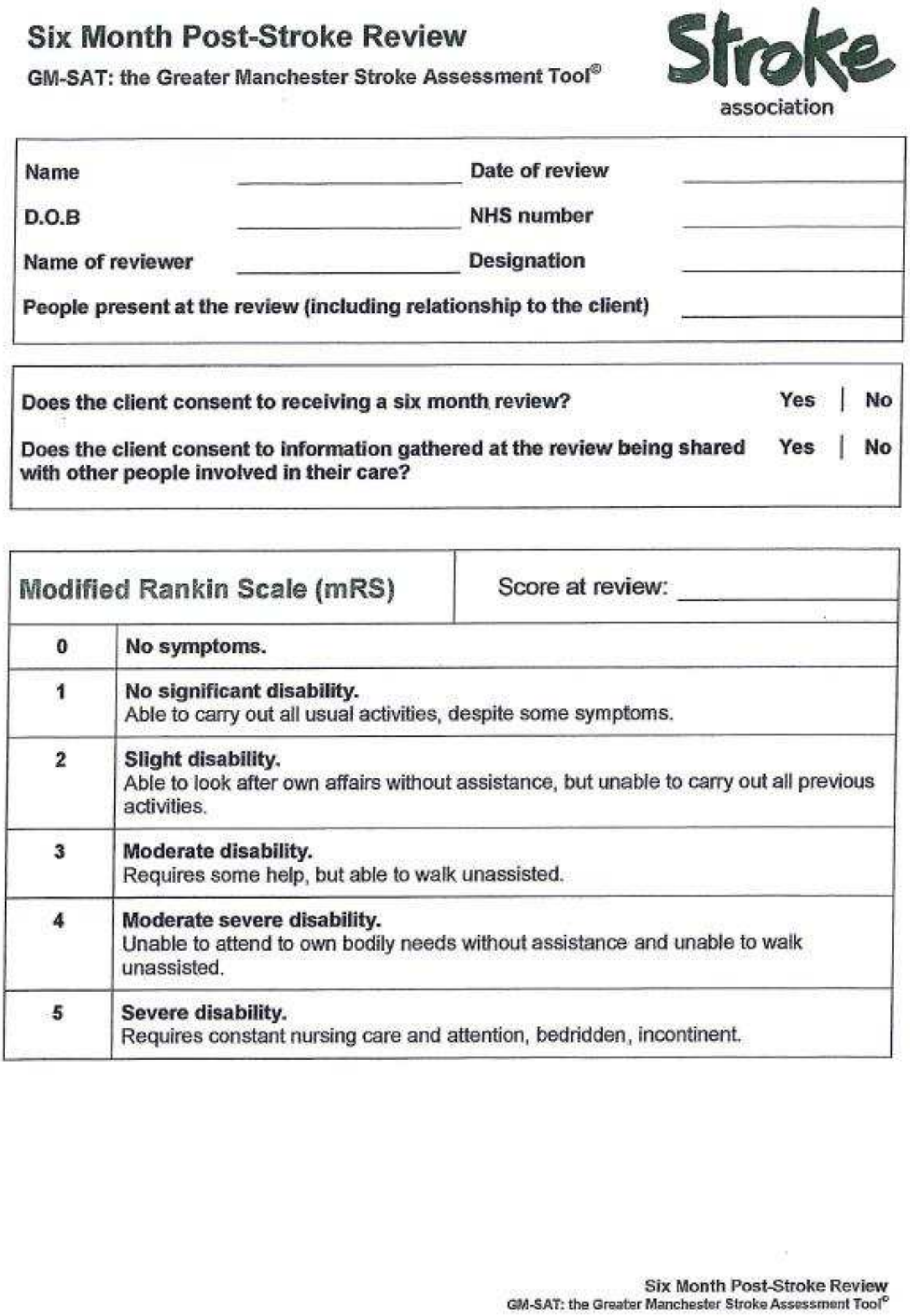
Health Promotion	
Smoking	
Exercise	
Alcohol	
Healthy Eating	
Mental Well-being	
Thinking	

Mood	
Anxiety	
Sleep	
Fatigue	
Emotions	
No issues	
Daily Living:	
Social situation	

Personal care Skin integrity	
Mobility	
Falls	
Continence	Continent/Stress Incontinence/Urge Incontinence/Mixed/Functional)
Swallow	
Speech	
Vision	
Domestic	
Work/leisure	

Driving	
Relationships	
Referrals made	
SALT	
Stroke Association	
Dietician	
Bladder & Bowel	
Meds Man	
Social Services	
Intermediate CT	
Neuro	
Psych	
Stroke	
Consultant	
AF Nurse	
Other	
Local stroke group	(Contact details/written information given)

Appendix 22: Site 3 template for 6MR



Six Month Post-Stroke Review

GM-SAT: the Greater Manchester Stroke Assessment Tool©

Stroke association

Name ____________________ Date of review ____________________

D.O.B ____________________ NHS number ____________________

Name of reviewer ____________________ Designation ____________________

People present at the review (including relationship to the client) ____________________

Does the client consent to receiving a six month review?	Yes	No
Does the client consent to information gathered at the review being shared with other people involved in their care?	Yes	No

Modified Rankin Scale (mRS)	Score at review: ____________________
0	**No symptoms.**
1	**No significant disability.** Able to carry out all usual activities, despite some symptoms.
2	**Slight disability.** Able to look after own affairs without assistance, but unable to carry out all previous activities.
3	**Moderate disability.** Requires some help, but able to walk unassisted.
4	**Moderate severe disability.** Unable to attend to own bodily needs without assistance and unable to walk unassisted.
5	**Severe disability.** Requires constant nursing care and attention, bedridden, incontinent.

Six Month Post-Stroke Review
GM-SAT: the Greater Manchester Stroke Assessment Tool©

Blood Pressure **1st Reading** ____ / ____ **2nd Reading** ____ / ____
(Where required)

☐ **≥200/110 mmHg**
Advise client to see their GP as soon as possible. **DO NOT IGNORE.**

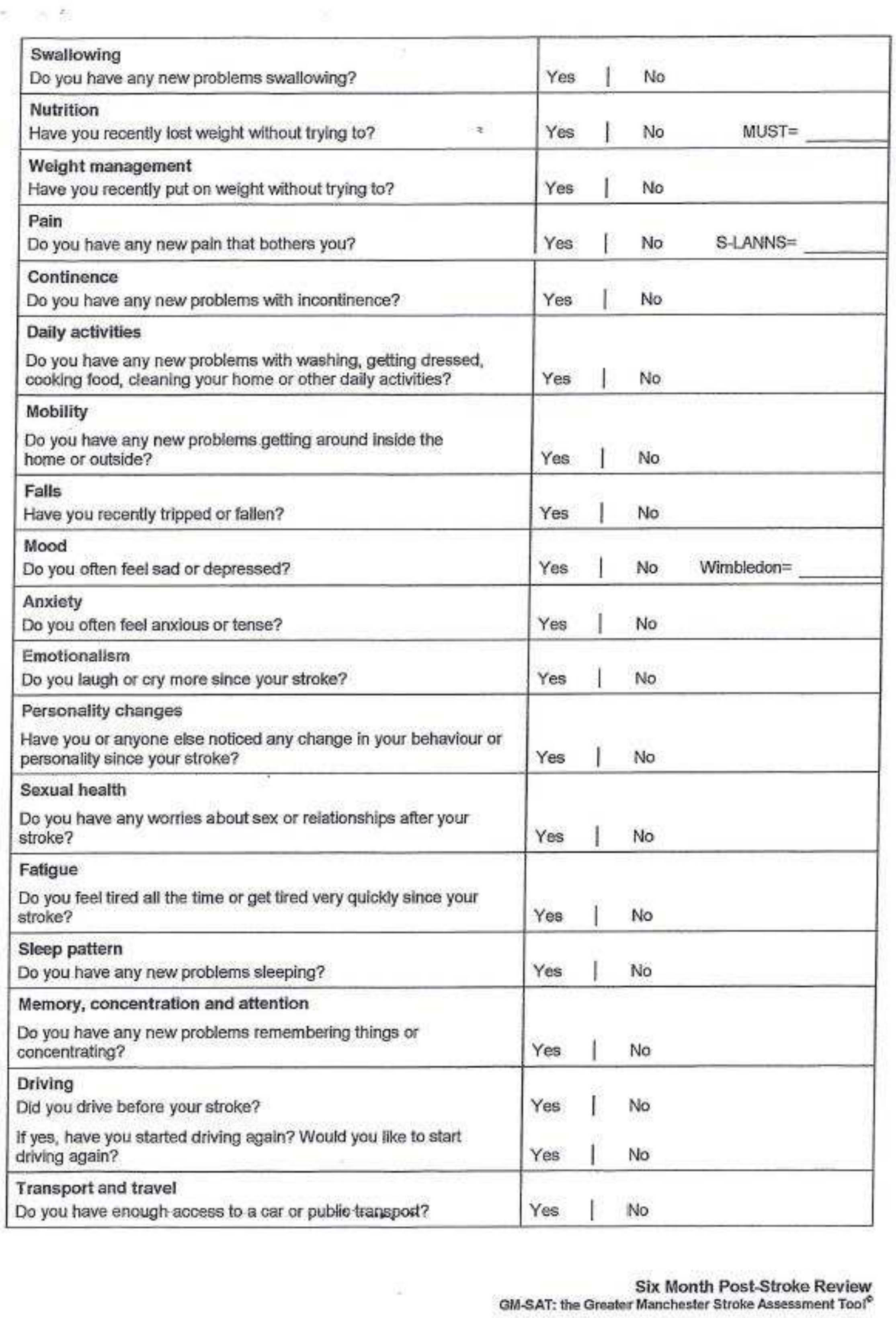
☐ **140/90 – 199/109 mmHg (if client has diabetes 130/80 – 199/109 mmHg)**
Advise client to see their GP within the next two weeks. Give lifestyle advice. DO NOT IGNORE.

☐ **<140/90 mmHg**
Give lifestyle advice and advise client to continue having their blood pressure checked on a regular basis.

☐ **<90/60 mmHg with symptoms such as fainting and dizziness**
Advise client to see their GP within the next few days. **DO NOT IGNORE.**

The purpose of today's review is to find out how you have been getting on since your stroke and to see how we can help you with any problems you may have. It is also a chance for you to talk about any worries or concerns you may have.
So, how have things been recently?

Question	**Notes**
Medicine management	
Do you have problems getting your medicine?	Yes | No
Do you have problems taking your medicine?	Yes | No
Medicine compliance	
Do you always take your medicine as prescribed?	Yes | No
Do you get side effects from your medicine?	Yes | No
Alcohol	
Do you drink alcohol?	Yes | No
If yes, how much do you drink and how often?	Yes | No
Smoking	
Do you smoke?	Yes | No
If yes, do you want to stop smoking?	Yes | No
Healthy eating	
Do you eat a balanced diet?	Yes | No
Exercise	
Do you exercise regularly? Do you keep active?	Yes | No
Vision	
Do you have any new problems with your sight?	Yes | No
Hearing	
Do you have any new problems with your hearing?	Yes | No
Communication	
Do you have any new problems with your speech, reading or writing?	Yes | No



Swallowing Do you have any new problems swallowing?	Yes	No	
Nutrition Have you recently lost weight without trying to?	Yes	No	MUST= ______
Weight management Have you recently put on weight without trying to?	Yes	No	
Pain Do you have any new pain that bothers you?	Yes	No	S-LANNS= ______
Continence Do you have any new problems with incontinence?	Yes	No	
Daily activities Do you have any new problems with washing, getting dressed, cooking food, cleaning your home or other daily activities?	Yes	No	
Mobility Do you have any new problems getting around inside the home or outside?	Yes	No	
Falls Have you recently tripped or fallen?	Yes	No	
Mood Do you often feel sad or depressed?	Yes	No	Wimbledon= ______
Anxiety Do you often feel anxious or tense?	Yes	No	
Emotionalism Do you laugh or cry more since your stroke?	Yes	No	
Personality changes Have you or anyone else noticed any change in your behaviour or personality since your stroke?	Yes	No	
Sexual health Do you have any worries about sex or relationships after your stroke?	Yes	No	
Fatigue Do you feel tired all the time or get tired very quickly since your stroke?	Yes	No	
Sleep pattern Do you have any new problems sleeping?	Yes	No	
Memory, concentration and attention Do you have any new problems remembering things or concentrating?	Yes	No	
Driving Did you drive before your stroke?	Yes	No	
If yes, have you started driving again? Would you like to start driving again?	Yes	No	
Transport and travel Do you have enough access to a car or public transport?	Yes	No	

Six Month Post-Stroke Review
GM-SAT: the Greater Manchester Stroke Assessment Tool©

Activities and hobbies		
Do you take part in any leisure activities and hobbies?	Yes	No
Are there any hobbies and activities you would like to do?	Yes	No
Work		
Do you work?	Yes	No
If no, would you like to work?	Yes	No
Money and benefits		
Do you need any information about benefits or money?	Yes	No
House and home		
Do you have any new problems with where you live?	Yes	No
Carer needs		
Do you have a carer or someone who helps you?	Yes	No
If yes, is there anything they need help with?	Yes	No
Is there anything else you would like to talk about today that we haven't covered?		

Notes

Appendix 23: 6MR summary reports for GP

23a: Site 1

[Headed paper with GP’s address and date]

Dear Dr

Name:

DOB:

NHS No:

Address:

I saw at his/her home/ in clinic on 2015 for a 6 week/6 month/12 month stroke review.

Mr/ Mrs suffered on presenting with

He has the following risk factors:

Blood pressure: mmHg (Please aim for Target 130/80mmHg)

Total Cholesterol: HDL: (Please check annually aiming for Target Total Cholesterol < 3.5mmol/l)

Medication:

A review includes:

- Medications review, including concordance, storage, side effects
- Checking appropriate investigations have been ordered and liaising with the stroke consultant.
- Stroke recovery; mobility, cognition, mood, fatigue*, speech, swallow, vision, activities of daily living, continence, skin integrity
- Health promotion; smoking, alcohol consumption, exercise/activity, healthy eating, driving.
- Health education; explanation of stroke, debriefing of stroke event, secondary stroke prevention, and other health issues
- Obstructive Sleep Apnoea screening using the Epworth Sleepiness Scale.
- Life after Stroke; promoting support networks and long term social inclusion.

Residual effects:

Current Barthel Score:

Modified Rankin Score:

I will contact in 6 months' time to check on progress. He has my contact details.

I have not arranged to see again but he/she has my contact details should he/she need my support at any time.

Please contact me for any further information.

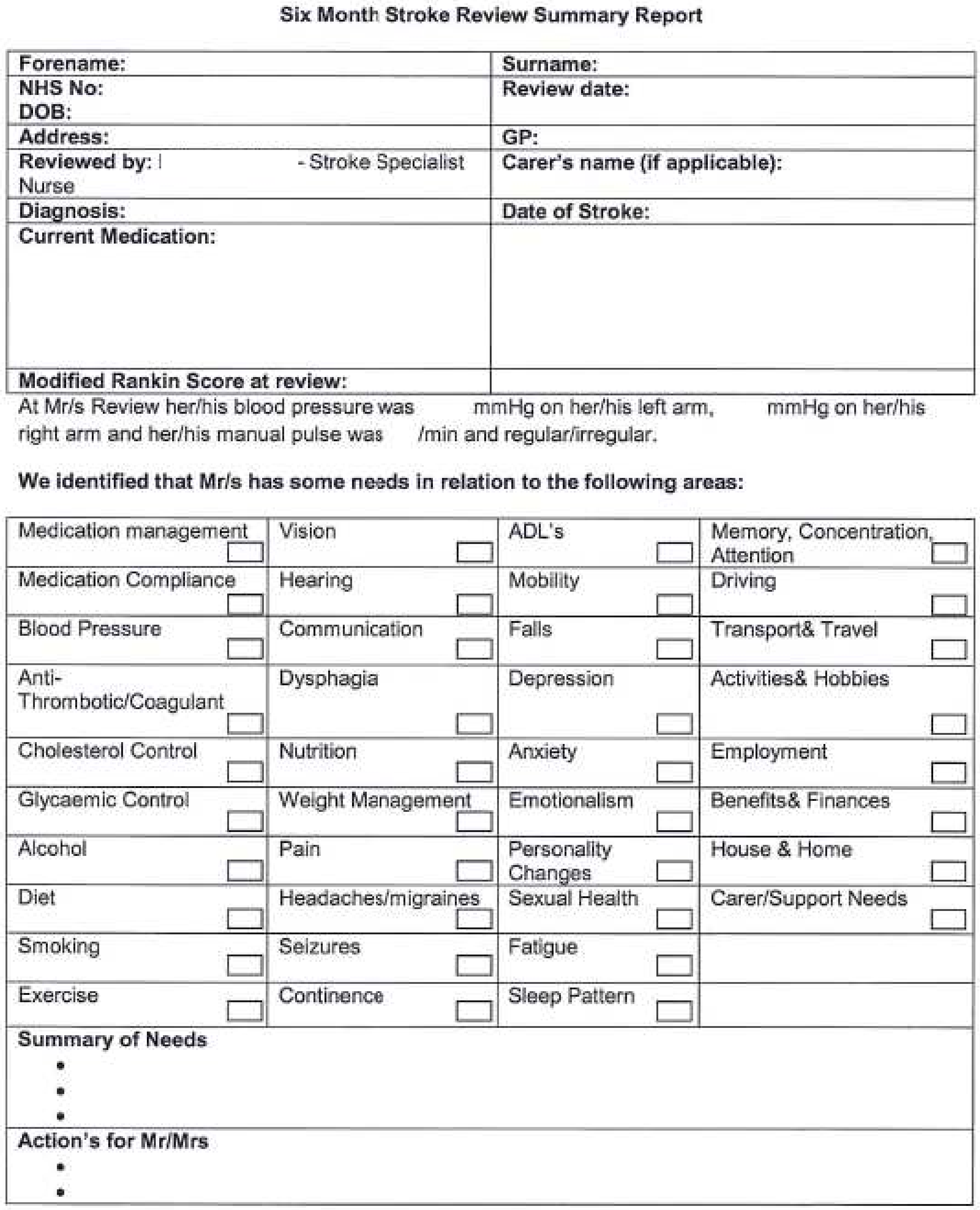
Yours Sincerely

Stroke Specialist Nurse

Cc:

23b: Site 2

[Headed paper with GP's address and date]



Six Month Stroke Review Summary Report

Forename:	**Surname:**
NHS No: **DOB:**	**Review date:**
Address:	**GP:**
Reviewed by: I - Stroke Specialist Nurse	**Carer's name (if applicable):**
Diagnosis:	**Date of Stroke:**
Current Medication:	
Modified Rankin Score at review:	

At Mr/s Review her/his blood pressure was mmHg on her/his left arm, mmHg on her/his right arm and her/his manual pulse was /min and regular/irregular.

We identified that Mr/s has some needs in relation to the following areas:

Medication management ☐	Vision ☐	ADL's ☐	Memory, Concentration, Attention ☐
Medication Compliance ☐	Hearing ☐	Mobility ☐	Driving ☐
Blood Pressure ☐	Communication ☐	Falls ☐	Transport& Travel ☐
Anti-Thrombotic/Coagulant ☐	Dysphagia ☐	Depression ☐	Activities& Hobbies ☐
Cholesterol Control ☐	Nutrition ☐	Anxiety ☐	Employment ☐
Glycaemic Control ☐	Weight Management ☐	Emotionalism ☐	Benefits& Finances ☐
Alcohol ☐	Pain ☐	Personality Changes ☐	House & Home ☐
Diet ☐	Headaches/migraines ☐	Sexual Health ☐	Carer/Support Needs ☐
Smoking ☐	Seizures ☐	Fatigue ☐	
Exercise ☐	Continence ☐	Sleep Pattern ☐	

Summary of Needs

-
-
-

Action's for Mr/Mrs

-
-

Action's for Stroke Nurse • • •
Action's for GP • • •

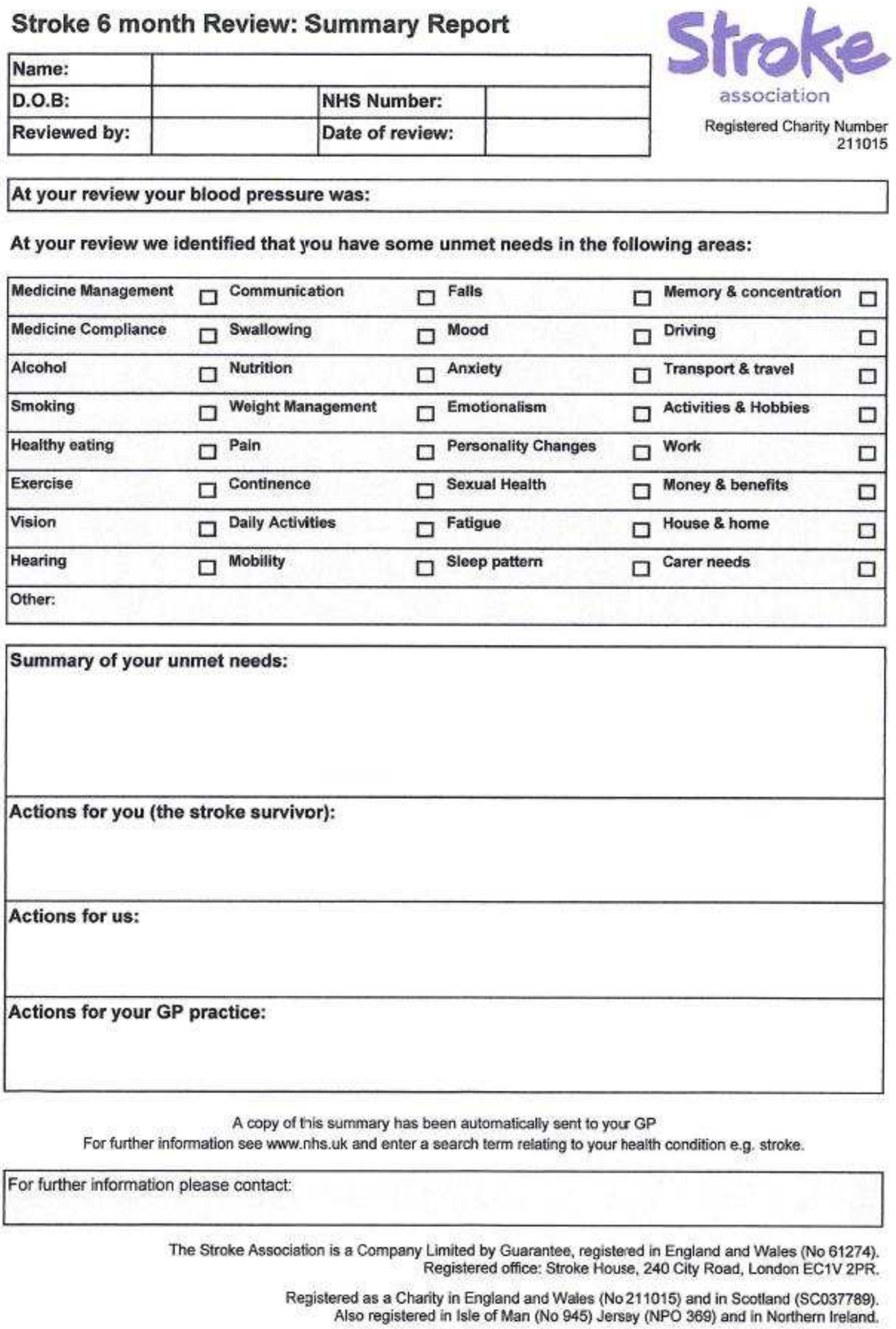
I have discharged Mr/Mrs from the six month review clinic today and would be happy to see him/her again should any stroke related matter arise.

Yours sincerely

Stroke Specialist Nurse

CC: GP, Patient, Stroke Team

23c: Site 3



Stroke 6 month Review: Summary Report

Stroke association

Registered Charity Number 211015

Name:			
D.O.B:		**NHS Number:**	
Reviewed by:		**Date of review:**	

At your review your blood pressure was:

At your review we identified that you have some unmet needs in the following areas:

Medicine Management ☐	Communication ☐	Falls ☐	Memory & concentration ☐
Medicine Compliance ☐	Swallowing ☐	Mood ☐	Driving ☐
Alcohol ☐	Nutrition ☐	Anxiety ☐	Transport & travel ☐
Smoking ☐	Weight Management ☐	Emotionalism ☐	Activities & Hobbies ☐
Healthy eating ☐	Pain ☐	Personality Changes ☐	Work ☐
Exercise ☐	Continence ☐	Sexual Health ☐	Money & benefits ☐
Vision ☐	Daily Activities ☐	Fatigue ☐	House & home ☐
Hearing ☐	Mobility ☐	Sleep pattern ☐	Carer needs ☐
Other:			

Summary of your unmet needs:

Actions for you (the stroke survivor):

Actions for us:

Actions for your GP practice:

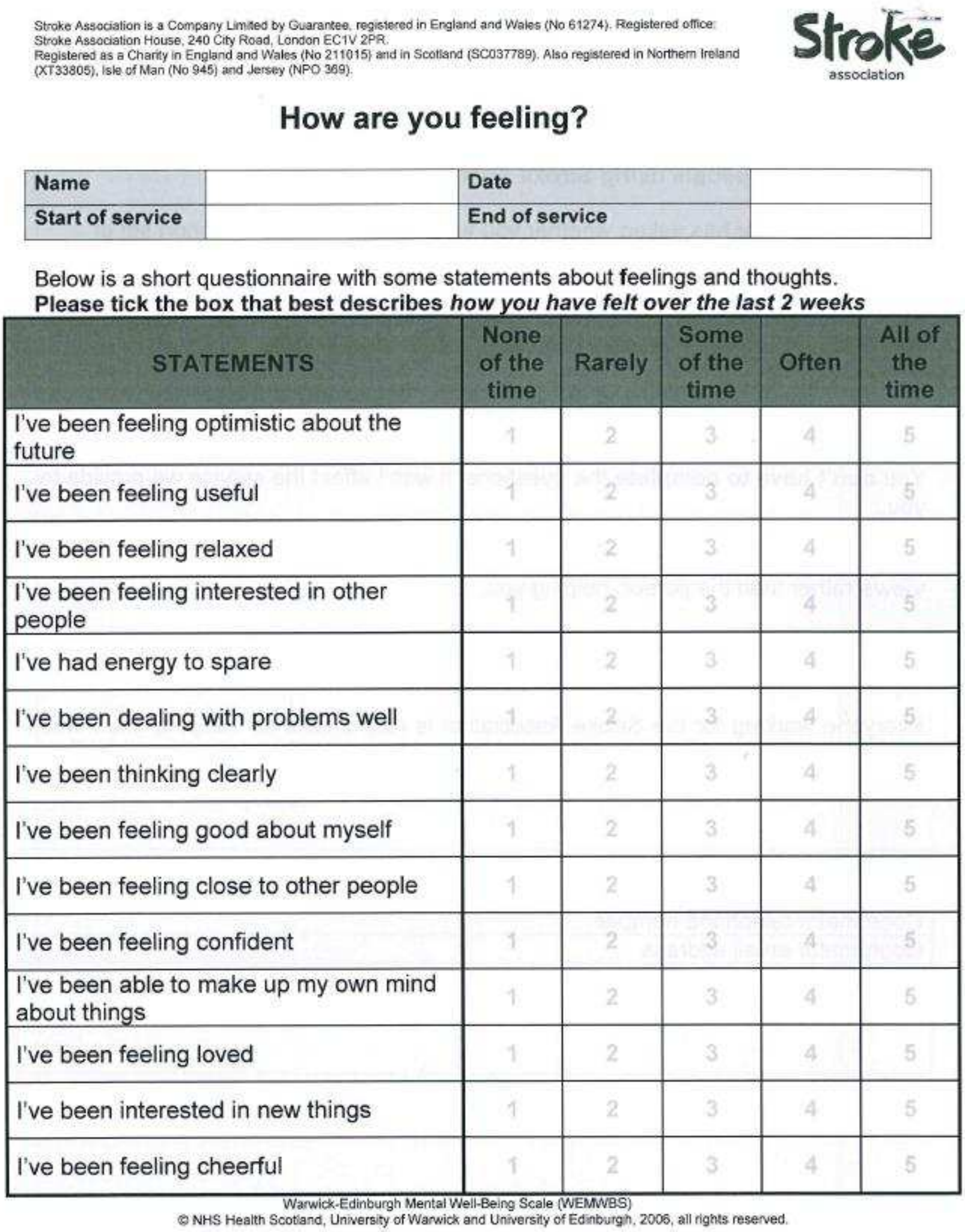
A copy of this summary has been automatically sent to your GP
For further information see www.nhs.uk and enter a search term relating to your health condition e.g. stroke.

For further information please contact:

The Stroke Association is a Company Limited by Guarantee, registered in England and Wales (No 61274).
Registered office: Stroke House, 240 City Road, London EC1V 2PR.

Registered as a Charity in England and Wales (No 211015) and in Scotland (SC037789).
Also registered in Isle of Man (No 945) Jersey (NPO 369) and in Northern Ireland.

Appendix 24: Warwick-Edinburgh Mental Well-being scale



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Registered as a Charity in England and Wales (No 211015) and in Scotland (SC037789). Also registered in Northern Ireland (XT33805), Isle of Man (No 945) and Jersey (NPO 369).

How are you feeling?

Name		**Date**	
Start of service		**End of service**	

Below is a short questionnaire with some statements about feelings and thoughts.
Please tick the box that best describes *how you have felt over the last 2 weeks*

STATEMENTS	None of the time	Rarely	Some of the time	Often	All of the time
I've been feeling optimistic about the future	1	2	3	4	5
I've been feeling useful	1	2	3	4	5
I've been feeling relaxed	1	2	3	4	5
I've been feeling interested in other people	1	2	3	4	5
I've had energy to spare	1	2	3	4	5
I've been dealing with problems well	1	2	3	4	5
I've been thinking clearly	1	2	3	4	5
I've been feeling good about myself	1	2	3	4	5
I've been feeling close to other people	1	2	3	4	5
I've been feeling confident	1	2	3	4	5
I've been able to make up my own mind about things	1	2	3	4	5
I've been feeling loved	1	2	3	4	5
I've been interested in new things	1	2	3	4	5
I've been feeling cheerful	1	2	3	4	5

Warwick-Edinburgh Mental Well-Being Scale (WEMWBS)