DEVELOPING A MODEL OF PEOPLE'S NEEDS AFTER TRANSIENT ISCHAEMIC ATTACK

by

Laura-Jane Gleave

A thesis submitted in partial fulfilment for the requirements for the degree of Doctor of Philosophy,
at the University of Central Lancashire

October 2017

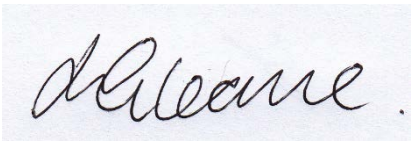
STUDENT DECLARATION FORM

Concurrent registration for two or more academic awards

I declare that while registered as a candidate for the research degree, I have not been a registered candidate or enrolled student for another award of the University or other academic or professional institution

Material submitted for another award

I declare that no material contained in the thesis has been used in any other submission for an academic award and is solely my own work



Signature of Candidate _____

Type of Award Doctor of Philosophy

School School of Nursing

Abstract

Transient ischaemic attack (TIA) is a condition which is typified by stroke symptoms that resolve quickly and completely. It could be expected that patients' needs following TIA would be limited to secondary stroke prevention strategies. However, in clinical practice, it has been observed that people appear to have many unexpected needs following TIA.

The overall aim of this research is to answer the question 'What are people's needs following TIA?' This was achieved by the development of a comprehensive list of potential needs and a model that describes commonly reported needs and how needs change over time. The methodology of this research was pragmatic, using mixed methods within seven inter-linked studies over three distinct phases. A needs assessment framework guided the research and an initial literature search revealed no previous needs assessment following TIA. There has since been limited research looking onto the experience of TIA.

Phase 1 used survey methods to explore TIA service provision at a national level to provide context for the subsequent studies. This comprised an email survey of British Association of Stroke Physicians' members asking about their services. A total of 73 responses were received from 59 of a possible 213 acute secondary care TIA services (some services provided more than one response). There was variability in access, content and personnel involved in TIA services across the United Kingdom. 97% were run by stroke specialist staff. Only 41% of sites offered routine follow-up, 29% offered investigations and results during first clinic attendance. 29% offered a seven-day service. Only 2 sites (3%) met all four of the above 'best practice' criteria devised for this study.

Phase 2 used an existing needs mapping for stroke as a starting point, on the basis that TIA and stroke are part of the same continuum of cerebrovascular disease. Patients were interviewed (n=11), or participated in focus groups (n=10). Health care staff were asked to complete a questionnaire based on the stroke needs mapping (n=96) or were interviewed (n=11). Carers of people who had a TIA, were also asked to complete a questionnaire (n=6). The findings from Phase 2 demonstrated that although many needs previously identified post-stroke are relevant, there are others that appear unique

following a TIA diagnosis. There were also mis-matches between staff and carers' views as compared to the views of patients, suggesting that efforts might be made to meet needs not actually felt by patients. Phase 2 showed that common needs were likely to be identified and addressed, but less common needs might be overlooked and therefore remain unmet. The findings of Phase 2 were combined to develop a draft model of needs following TIA.

Phase 3 aimed to validate the draft model of needs using an expert panel focus group comprising professionals (n=4), patients (n=3) and carers (n=1). The expert panel refined the draft model. Four time-points were identified over which needs changed. These time-points were defined as; onset of symptoms, diagnosis, early (0-28 days), and later (29 days or more).

The research showed the mis-matches between staff and patients' views of needs following TIA highlight common misconceptions on the part of healthcare professionals. The production of a comprehensive list of potential needs will help professionals to be more open to unexpected, or less obvious needs. The model of needs could be used when planning future services, to ensure needs are identified and where possible met. There were several needs identified following TIA that are not found in the stroke needs mapping, in particular, around recognition of the event and diagnosis of the condition.

The needs assessment framework used to structure the research has not previously been used in a healthcare setting, but it provided an excellent road-map through the needs assessment process. Lee's framework has previously been used in education but was selected for its compatibility with mixed methods and the focus on the individual rather than using a framework with a more bio-medical slant.

This is the first research to comprehensively explore needs and problems experienced following TIA, rather than reporting specific issues or parts of the TIA experience. TIA is not the benign condition which it was historically thought to be. A range of problems and needs can result from a TIA, some not previously identified in relation to TIA, such as hypervigilance and concern regarding diagnostic uncertainty.

Table of contents

Abstract ..... **ii**
Table of contents ..... **iv**
Table of tables ..... **viii**
Table of figures ..... **x**
Acknowledgements ..... **xii**
Abbreviations ..... **xiii**

1. INTRODUCTION AND OVERVIEW OF THESIS

1.1 Background **1**
UK context, policy and guidelines 1
Definition of TIA 5
Diagnosis of TIA 6
The TIA pathway and experience 9
1.2 Rationale for research **12**
1.3 Overview of thesis **14**

2. LITERATURE REVIEW PERTAINING TO THE EXPERIENCE OF TIA

2.1 Introduction **17**
2.2 Methods **17**
Search strategy 17
Data extraction 18
2.3 Results **19**
Narrative synthesis 25
2.4 Discussion **30**
2.5 Conclusion **31**
2.6 Summary **31**

3. METHODOLOGY AND OTHER UNDERPINNINGS OF THE THESIS

3.1 Introduction **33**
3.2 What are needs? **35**
3.3 Development of a model of needs following TIA **36**
3.4 The use of a stroke needs mapping to structure the research **37**
3.5 Needs Assessment **40**

3.6 Methodological approach 45
Phase 1 45
Phase 2 46
Phase 3 47
Other research 48
3.7 Summary 49

4. PHASE 1 – SETTING THE CONTEXT OF TIA SERVICE PROVISION AT THE START OF THE RESEARCH
4.1 Introduction 50
4.2 Background to Phase 1 50
Phase 1 Aims 54
Phase 1 Objectives 54
4.3. Development of the survey 54
Rationale 54
Purpose and survey design 55
Objectives of the survey 55
Survey development 55
Pre-testing (1) 56
Pre-testing (2) 57
4.4 Survey method 58
Setting 58
Subjects and sampling 58
Ethics 58
Survey 58
4.5 Results 59
Response rates and distribution of responses 59
Organisation 60
Personnel 62
Activity 66
What was available at one-stop services? 66
Follow-up characteristics 69
Features of best practice 70
4.6 Discussion 72
Study limitations 72
Survey development 73

Main survey subjects and sampling 73
Survey results 75
Key features of best practice 77
Identification of distinct service models 78
4.7 Conclusion 79
Implications for practice 79
Implications for this research 79
4.8 Summary 79

5. PHASE 2: STAFF, PATIENTS' AND CARERS' VIEWS ABOUT NEEDS FOLLOWING TIA BASED ON NEEDS IDENTIFIED FOLLOWING STROKE
5.1 Background 81
Phase 2 Aims 81
Phase 2 Objectives 81
Phase 2 study conduct overview 82
5.2 Methods 82
Phase 2a Survey of nurses and other healthcare staff 82
Phase 2b – Patients' and carers' views 86
Phase 2c – Professional interviews 93
5.3 Analysis 96
5.4 Findings 98
Phase 2a 98
Free text comments 109
Phase 2b 110
TIA specific needs 132
Phase 2c Staff interviews 153
5.5 Discussion 163
Summary of findings 163
Recruitment / response rate 164
Findings in relation to SNM 167
Findings in relation to needs not found in SNM 172
Strengths 174
Limitations 176
Implications for creating a model of needs 181
5.6 Synthesis 181
Relevance of SNM and mismatches between groups 182

Exploration of specific needs which are unique to TIA 190
Development of a draft model of needs following TIA 197
5.7 Summary..... 206

6. PHASE 3: REFINEMENT OF A PREVIOUSLY DEVELOPED MODEL OF NEEDS FOLLOWING TIA USING FOCUS GROUP METHODS WITH AN EXPERT PANEL
6.1 Introduction..... 207
6.2 Background to Phase 3..... 207
Phase 3 Aim 207
Phase 3 Objectives.....207
6.3 Methods..... 208
Sampling and recruitment.....209
Data analysis.....213
6.4 Results..... 214
Newly identified needs.....215
6.5 Discussion..... 219
6.6 Conclusions 224
Implications for Practice 224
Implications for further research 225
6.7 Summary..... 226

7 PRESENTATION OF A MODEL OF NEEDS AFTER TIA AND SUMMARY OF RESEARCH
7.1 Introduction..... 227
7.2 Summary of research..... 227
7.3 Presentation of final model..... 229
7.4 Discussion..... 233
Process 233
Personal development.....236
7.5 Contribution to knowledge 237
7.6 Further research..... 238
7.7 Recommendations for practice 240
7.8 Conclusion 241

8 REFERENCES 242
9 APPENDICES 264

Table of tables

Table 1 Demographic details of papers identified in the literature review.....21
Table 2 Summary of the evaluation of identified papers.....22
Table 3 Synthesis of research findings.....25
Table 4 Evaluation of potential needs assessment tools.....41
Table 5 Mapping of the programme of research onto the five steps of Lee's framework.....44
Table 6 The staff groups and frequency of responses within TIA services.....64
Table 7 The background of consultant medical practitioners running TIA services.....65
Table 8 Shows the reported activity at initial clinic attendance.....66
Table 9 Comparison of TIA service provision between three surveys of BASP members.....68
Table 10 Activities occurring at follow-up contact.....69
Table 11 The Four Key Features of Best Practice.....70
Table 12 Flow diagram showing the components of Phase Two.....82
Table 13 The range of 'other' roles as identified by those who completed the survey.....99
Table 14 Nurses and healthcare staff assessment of the relevance of physical needs following TIA.....101
Table 15 Nurses and healthcare staff assessment of the relevance of psychological / emotional needs following TIA.....102
Table 16 Nurses and healthcare staff assessment of the relevance of communication needs following TIA.....103
Table 17 Nurses and healthcare staff assessment of the relevance of everyday living needs following TIA.....104
Table 18 Nurses and healthcare staff assessment of the relevance of re-enablement needs following TIA.....105
Table 19 Nurses and healthcare staff assessment of the relevance of social needs following TIA.....106
Table 20 Nurses and healthcare staff assessment of the relevance of financial / legal needs following TIA.....107
Table 21 Summary of participant characteristics.....111
Table 22 Summary of participant characteristics for focus groups.....112

Table 23 Results of the focus group card sorting exercise, showing group 'relevant' and 'might be relevant' issues....113
Table 24 Summary of elements of Stroke Needs Mapping (SNM) for which a positive response was given....115
Table 25 Showing a summary of top rated needs....122
Table 26 Showing stroke and TIA needs....139
Table 27 Demographic details of the carers....141
Table 28 Carers' assessment of the relevance of physical needs following TIA....143
Table 29 Carers' assessment of the relevance of mental / emotional needs following TIA....145
Table 30 Carers' assessment of the relevance of communication needs following TIA....146
Table 31 Carers' assessment of the relevance of everyday living needs following TIA....148
Table 32 Carers' assessment of the relevance of re-enablement needs following TIA....149
Table 33 Carers' assessment of the relevance of social needs following TIA....150
Table 34 Carers' assessment of the relevance of Financial / Legal needs following TIA....151
Table 35 Professional views on high priority needs....160
Table 36 Details of participants in the expert panel....215
Table 37 Tabulated results of Group A discussions....216
Table 38 Tabulated results of Group B discussions....217
Table 39 Consolidated needs, initially based on the SNM, with TIA only needs added....218
Table 40 Listed needs identified using the blank timeline exercise....222

Table of figures

Figure 1 Comprehensive timeline of key research, developments and drivers that have impacted TIA management and care....4
Figure 2 Flow Diagram showing the research pathway through the thesis....16
Figure 3 Showing a flow diagram of evaluation of the search strategy....19
Figure 4 Stroke Needs Mapping (French et al., 2008)....39
Figure 5 Demonstrates the movement from quantitative to qualitative research methods throughout the research....45
Figure 6 Geographical Distribution of Responses....59
Figure 7 The range of TIA service provision....60
Figure 8 The range and frequency of duration of initial clinic contacts....61
Figure 9 Duration of follow-up contact....62
Figure 10 Venn diagram showing the numbers of services offering combinations of four key features of best (evidence-based) practice....71
Figure 11 Venn diagram summarising staff views on the relevance of stroke needs to people following TIA....108
Figure 12 Key themes identified....114
Figure 13 Venn diagram showing the relationship between stroke and TIA needs as determined by patients following TIA during interviews....131
Figure 14 Venn diagram summarising Focus Group views on the relevancy of stroke needs to people following TIA....140
Figure 15 Venn diagram summarising carers views on the relevancy of stroke needs to people following TIA....152
Figure 16 Shows the snowball recruitment process for professional interviews....153
Figure 17 A draft model summarising the themes that came from the professional interviews about people's needs following TIA....162
Figure 18 Venn diagram summarising all needs from the SNM that are thought to be potentially relevant following TIA....184
Figure 19 Venn diagram summarising needs from the SNM that are thought to be definitely relevant following TIA....186
Figure 20 Summary of needs from the SNM that are commonly identified as important following TIA Phase 2 a & b....189
Figure 21 SNM with TIA specific needs added....193

Figure 22 Venn diagram showing needs regarded as highly important or TIA specific from Phase 2 of the research 196
Figure 23 Shows the draft model of TIA needs based on key time points following TIA.....205
Figure 24 Final model of common needs following TIA.....231
Figure 25 Summarising final research findings relating to the relevance of stroke needs to people following TIA.....232

Acknowledgements

I must start by thanking Dr Jo Gibson for her continued support throughout this process. She has shown me kindness and support and offered 'reality checks' where needed. Professor Dame Caroline Watkins, Dr Michael Leathley and Dr Stephanie Jones complete my supervisory team and I cannot express the importance of the whole team's contribution to this research and my training.

Thanks, must be given to BASP, NSNF and SSNF for allowing me to contact their members. I also own a debt of gratitude to all the lovely people who were prepared to participate in my research and gave willingly of their time to enable me to follow my passion.

My work colleagues have my sincere thanks for supporting me and putting up with my unreasonable demands to have off duty planned months in advance. Special mentions must go to Val Horn; I couldn't have had a better manager, good luck with your retirement. Dr Suzanne Ragab for access to her patients; Jacqui Leggett who has enabled me to do so much and is an inspiration; Christine Dickson, who has been prepared to spend countless hours acting as my sounding board, and Beth Clark for being willing to go to very loud concerts with me when I need to blow off steam.

Friends have helped me throughout this process, particularly Heather Hazzard, who has supported me throughout my studies and let me stay with her whenever I've needed to break the long journey from Dorset to Lancashire. Tammy Sargeant has also offered moral support and cake when needed.

Finally, I must thank my family. Brian, my husband has given me the freedom to study whenever I'm not working. He has patiently understood the missed trips, parties and other events over the years and continues to look after me, the cats, and the house. My parents and sister have got used to me wanting to plan my life at least a year ahead and no longer think it unusual for me to be discussing plans for Christmas in April !!

You have all played an important part in the creation of this thesis. I couldn't have done it without you all.

Abbreviations

AF	Atrial Fibrillation
BASP	British Association of Stroke Physicians
BMA	British Medical Association
BP	Blood Pressure
CASP	Critical Appraisal Skills Programme
CCG	Clinical Commissioning Group
CT	Computer Tomography
DH	Department of Health
DVLA	Driving and Vehicle Licencing Agency
ECG	Electrocardiogram
F	Female
FAST	Face Arm Speech Test
FHEC	Faculty of Health and Social Care Ethics Committee
GCP	Good Clinical Practice
GP	General Practitioner
IRAS	Integrated Research Application System
ISWP	Intercollegiate Stroke Working Party
IT	Information Technology
M	Male
MeSH	Medical Subject Headings
MRI	Magnetic Resonance Imaging
n	Number
NAO	National Audit Office
NICE	National Institute for Health Care Excellence
NHS	National Health Service
NOK	Next of Kin
NRES	National Research Ethics Service
NSNF	National Stroke Nursing Forum
NSS	National Stroke Strategy
PTSD	Post Traumatic Stress Disorder
QM	Quality Markers
REC	Research Ethics Committee
SAE	Stamped Addressed Envelope
SNM	Stroke Needs Mapping
SSEF	Stroke Specific Educational Framework
SSNF	Scottish Stroke Nurses Forum
TIA	Transient Ischaemic Attack
UCLAN	University of Central Lancashire
UK	United Kingdom
USA	United States of America
WHO	World Health Organisation

1. INTRODUCTION AND OVERVIEW OF THESIS

1.1 Background

In this chapter, the background to this thesis will be explored. This will be achieved by looking specifically at: incidence of Transient Ischaemic Attack (TIA); service and policy changes over time; the changing definition of TIA; difficulty with TIA diagnosis; recognition of TIA; the relationship between TIA and stroke; and the experience of TIA. Finally, the rationale for the programme of research will be presented, together with an overview of the thesis.

TIA can be a warning sign of an imminent stroke. Up to 20% of all people who experience a TIA go on to have a stroke within 90 days; half of those strokes are likely to occur within the first 48 hours after a TIA (Johnston, 2007a; 2007b). Stroke is the leading cause of adult disability and is in the top three causes of death in England (Newton *et al.,* 2015). Each year approximately 80,000 people are hospitalised in England and Wales following a stroke (Intercollegiate Stroke Working Party [ISWP], 2016a). Over 300,000 people are living with disability in England and Wales following a stroke (Townsend *et al*., 2012; Krishnamurthi *et al.,* 2013; Wang, Rudd & Wolfe, 2013; Stroke Association, 2015).

To minimise the risk of stroke following TIA, urgent assessment and preventative treatment is needed. In England, it was estimated that approximately 46,000 people had a TIA in 2015 (Stroke Association, 2015). It is difficult to be sure of the incidence of TIAs in any population regardless of which definition is used, due to a lack of public awareness of TIA, which can lead to significant numbers of undiagnosed TIAs (Kelly *et al*., 2001). If all suspected TIAs and minor strokes were referred for assessment and management, the true number of clinic attendances might be closer to 150,000 a year (Giles & Rothwell, 2007a).

UK context, policy and guidelines

The National Stroke Strategy (NSS) for England and Wales (Department of Health [DH], 2007) covered all aspects of cerebrovascular disease and management. It was produced as a ten-year plan, and presented 20 Quality Markers (QM). Two of the markers (5 & 6) related to the assessment, and

management respectively, of patients following TIA. This document explicitly identified TIA as an emergency condition requiring urgent specialist diagnosis and treatment; it was also the first document to explicitly identify the need for TIA follow-up. Some of these requirements were reiterated in the third edition of the National Clinical Guideline for Stroke (ISWP, 2008b), and the National Institute for Health and Care Excellence (NICE) guidelines for the management of acute stroke and TIA (NICE, 2008), but neither document backed up the requirement for four-week follow-up following TIA.

NICE produced guidelines (2008) on the management of stroke and TIA in collaboration with the ISWP, who produce the National Clinical Guidelines for Stroke. In both the NICE guidance and the National Clinical Guidelines for Stroke, clear recommendations for how services should be structured to ensure timely access to TIA assessment and treatment, which supported QM 5 (Mant, Wade & Winner, 2004; Giles & Rothwell, 2007b; Rothwell *et al*., 2007). This together with the NSS, offered a robust platform upon which to build TIA services. This was strengthened by the Department of Health (DH) providing an additional three years of service development funding allocated to support the NSS. There were, however, no recommendations were made about TIA follow-up, again demonstrating the paucity of research in this area, and the lack of awareness of potential ongoing problems and needs.

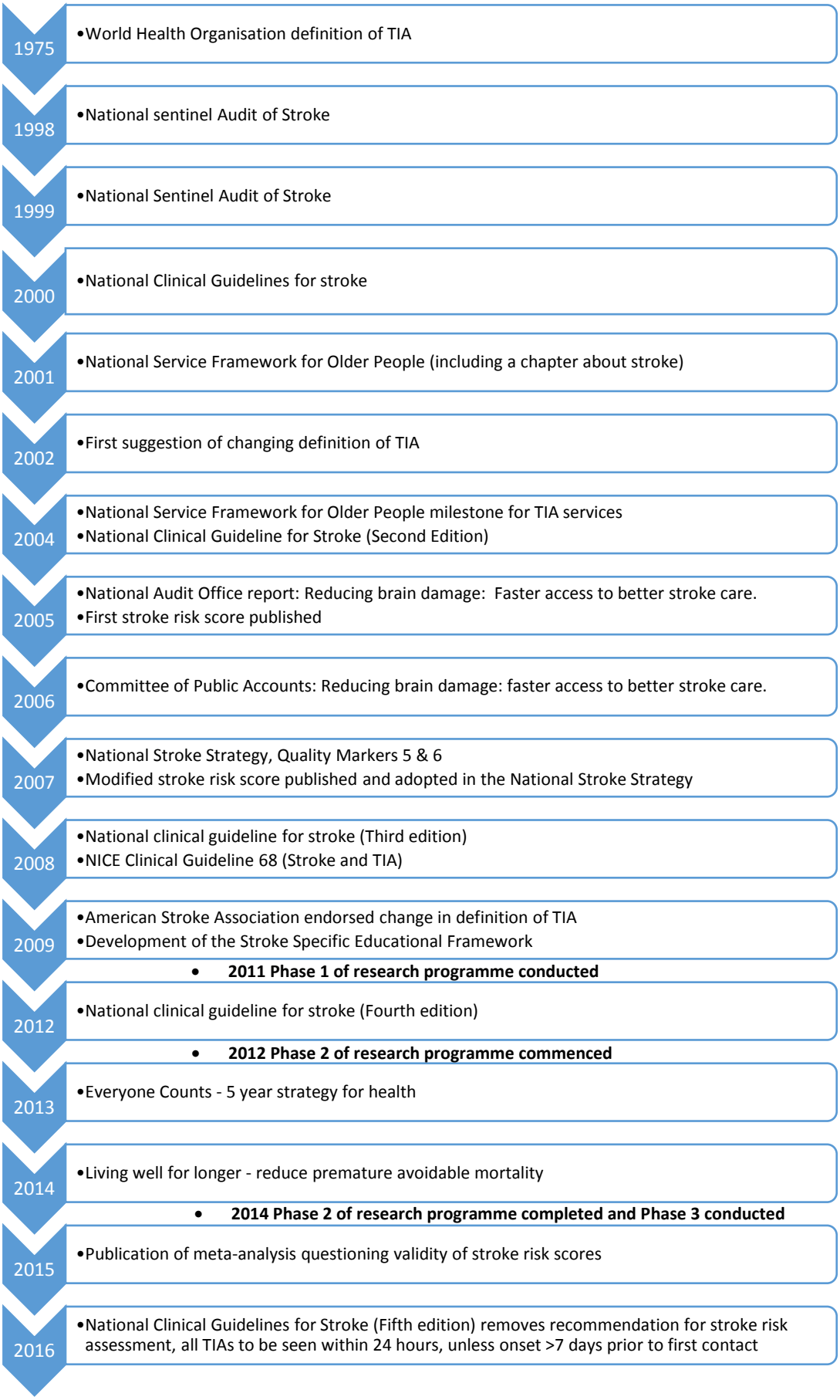
Local Health and Well-being Boards, set up across England and Wales, and seated within the Clinical Commissioning Groups, were tasked with reducing mortality from preventable causes. The strategy for the following five years was laid out in a DH document, Everyone Counts (DH, 2013). This led to a further policy document in 2014, 'Living Well for Longer: National Support for Local Action to Reduce Premature Avoidable Mortality' (DH, 2014). This was aimed at improving mortality by means of better primary and secondary prevention strategies, and earlier detection and treatment of disease. The focus of this initiative was empowerment and changing the behaviour of the population by influencing healthy choices. An element of empowerment is the ability to make informed choices, thus patients need to understand their situation.

In terms of the patient experience and understanding, having a TIA has changed from being seen as a ‘little blip’, or ‘one of those funny things’ (Stroke Association, 2014) to being viewed as a medical emergency, with clinicians changing from an un-hurried response, to aiming to see patients within 24 hours of symptom onset. The way in which the response to the event is experienced is likely to give rise to needs, since needs are contextualised by the service provided. The foreshortening of the TIA pathway has caused the focus to be firmly on speed of access, which has resulted in time-pressured clinics. The focus on rapid access to services may have resulted in a less patient-focused response (Christiansen, 2014). It is not clear whether the patient’s needs are considered following a diagnosis of TIA at initial contact, or whether follow-up offers an opportunity for needs to be considered, but it is recognised that during the acute episode and diagnosis, patients are less able to absorb and assimilate information (Lawrence *et al.,* 2010).

One response to changing services has been the development of the Stroke-Specific Educational Framework (SSEF), which has looked at workforce development and produced clear levels of competence for various staff who care for people with stroke (Watkins *et al.,* 2011; Leathley *et al.,* 2012; Watkins *et al.,* 2012). There is specific guidance for staff who care for people who have had a TIA within the SSEF. This is important in terms of awareness, training and encouraging staff to be vigilant in identifying needs in all patients with cerebrovascular disease.

Figure 1 shows the key drivers and developments that have shaped TIA services, from the initial World Health Organisation (WHO) definition (1975) to the most recent National clinical guidelines for stroke (ISWP, 2016b).

Figure 1 Comprehensive timeline of key research, developments and drivers that have impacted TIA management and care



Definition of TIA

The definition of TIA has evolved over time. TIA was defined by WHO (1975) as *'a sudden, focal neurological deficit that lasts for less than 24 hours, is of presumed vascular origin, and which is confined to an area of the brain or eye perfused by a specific artery.'* There must be complete recovery within 24 hours, with no residual deficit. Both TIA and stroke were wholly clinical diagnoses prior to the availability of radiological imaging such as Computer Tomography (CT) and Magnetic Resonance Imaging (MRI). This definition was re-used by the WHO task force on stroke (WHO, 1989).

The standard definition for TIA was based on the underpinning theory that TIA represented a reversible syndrome, with no subsequent permanent cerebral damage or functional impairment. This was refined in 2002 by the TIA Working Group who published a new definition:

> "TIA is a brief episode of neurologic dysfunction caused by focal brain or retinal ischemia, with clinical symptoms typically **lasting less than one hour** and **without evidence of acute infarction.**"

Albers *et al*., (2002). *NEJM,* 347, Page 1715.

In 2009, the American Stroke Association endorsed the new definition of TIA as:

> *"Transient Ischemic Attack (TIA): a transient episode of neurological dysfunction caused by focal brain, spinal cord, or retinal ischemia, without acute infarction [on MRI scan]."*

Easton *et al.,* (2009). *Stroke,* 40, Page 2281.

There is no temporal element to the new definition, since the diagnosis is based on the absence or presence of a lesion on MRI. This is a major change and may result in inaccuracies in the calculation of incidence unless the incidence specifies which definition is used. It moves the diagnosis of TIA from a clinical judgement to a radiological determination and therefore requires that all patients with possible TIA have an MRI scanned to rule out infarction

(Easton *et al.,* 2009). This change in usage of the term TIA, particularly in the United States of America (USA), requires that all research published after this time is explicit about which definition of TIA is used in participant selection, as this is likely to impact outcomes.

However, in the United Kingdom (UK), where there is less extensive use of early MRI imaging, the ISWP, authors of the National Clinical Guideline for Stroke advised that the choice of TIA definition was not relevant in clinical practice (ISWP, 2016b). Their rationale was that all cerebrovascular events must be investigated and treated as a matter of urgency, and treatment, in terms of stroke prevention, is the same with or without a small acute lesion on brain imaging.

However, there are impacts for patients in terms of the diagnosis they are given and how this may affect the care they received. Patients who clinically have experienced a TIA based on the WHO definition (1989), but are found to have a small ischaemic lesion on MRI scanning, would be given a diagnosis of stroke. This might give them access to a range of services available for people following stroke that are not currently available for people following TIA, for example standard 6 month and annual reviews (DH, 2007).

As described, the choice of definition used in research studies is likely to impact on the participants included and therefore the outcomes reported. The definition used for subject selection in this thesis is the older temporal one, with focal neurological symptoms lasting less than 24 hours (WHO, 1989).

Diagnosis of TIA

Diagnosis of TIA can be difficult, symptoms are transient and may appear trivial to the individual (Gibson & Watkins, 2012). TIA can present with a wide range of symptoms (Brown, 2001; Albucher, Martel & Mas, 2005). Symptoms found most likely to represent TIA include visual field deficits, speech difficulties, facial weakness and hemiparesis (Murray *et al*., 2007; Amort *et al*., 2011). The bulk of the diagnostic burden is therefore based on negative signs during physical neurological examination, a detailed history of the event, previous medical history and investigations to rule out stroke ‘mimics’. There are rarely any objective signs or symptoms remaining by the time the patient is

seen in clinic, and no single confirmatory radiological or laboratory test that can demonstrate conclusively that someone has had a TIA.

TIAs resolve quickly, therefore retrospective diagnosis can be hindered by the inability of the patient to recount their symptoms accurately (Johnston, 2002). Since TIA typically has a rapid onset of symptoms, reaching maximum intensity within minutes, followed by a gradual recovery of function, the patient's or witness's description of the time-span of events is crucial (Prabhakaran *et al.,* 2008; Sonni & Thaler, 2013). The key to TIA diagnosis has always been obtaining a detailed accurate history (Martin *et al*., 1997). Patients often struggle to describe their TIA (Gibson & Watkins, 2012; Kirkpatrick *et al.,* 2013), and whilst some of the difficulty is due to them experiencing an altered neurological state (Kalsner & Kalsner, 1990; Johnston, 2002), the interviewing skills of the clinician can be an important factor in determining what information is obtained. A framework of 'mimics and chameleons' has been proposed to promote adequate history taking for patients with suspected TIA (Nadarajan *et al.,* 2014).

Furthermore, it is widely acknowledged that up to 50% of patients who are referred to a TIA service will not, in fact, have had a TIA, but one of the many mimics. It is recognised that in a non-specialist setting, up to half of the patients given a provisional diagnosis of TIA are subsequently reassigned a non-cerebrovascular diagnosis following specialist review (Calanchini *et al*., 1977; Dennis *et al.,* 1990; Martin *et al*., 1997; Kelly *et al.,* 2001; Murray *et al.,* 2007; Kessler & Thomas, 2009; Castle *et al*., 2010; Schrock *et al*., 2012).

Another difficulty in TIA diagnosis is a lack of awareness about TIA in healthcare professionals. Primary care physicians are a major source of referrals into TIA services. In one study, primary care doctors from across USA participated in a telephone questionnaire, showed that only 22% could identify five typical symptoms of TIA, together with an appreciation that symptoms should not last over 24 hours and only 43% were aware of the temporal cut off (Nguyen-Huynh *et al*., 2003). In a further study, primary care doctors in Poland also had difficulty identifying TIA, particularly when the symptoms included visual disturbance (Tomasik *et al*., 2003). There is also considerable disagreement between individual specialists about diagnosis as

seen in studies measuring inter-observer variation (Kraaijeveld *et al.,* 1984; Castle *et al*., 2010), although a systematic approach to diagnosis can reduce variation (Koudstaal *et al.,* 1986).

Diagnostic difficulties may be compounded by patients focusing on key features when they become aware of a functional deficit, for example an arm weakness or difficulty in talking. Upon resolution of that particular symptom, during a clinical consultation, when asked 'is your arm / speech back to normal?' the patient would then reply yes, but might not volunteer information about other, more subtle symptoms, that might possibly still be on-going. In some cases, these could be identified during the physical examination. In the researcher's experience in clinical practice, it is necessary to specifically ask about any other changes that are new since symptom onset, to ensure that other less prominent symptoms are not overlooked, although there is no specific research to support this observation.

In addition to being a warning sign for stroke, TIA is a condition in its own right. Whilst TIA has generally been considered a transient episode with no sequelae or ongoing needs, recent research shows this may not be the case (Arts*,* Kwa & Dahmen*,* 2008; Gibson & Watkins, 2012; Spurgeon *et al.,* 2013; Moran *et al.,* 2014). The impact of receiving a diagnosis of TIA may include an increase in the cost of travel insurance and the ability to access financial products (Life insurance) and employment (Gommans, Barber & Fink, 2009). Diagnosis may also impact on the needs and experiences of patients in terms of altered body image and sense of wellbeing (Gibson & Watkins 2012). If people experience new or persistent problems or altered states following a TIA, that is likely to give rise to needs. It is also important that patients are aware of their risks having experienced a TIA, and the steps that need to be taken to minimise those risks. A diagnosis of TIA increases the risk of unidentified and therefore unmet needs due to the perception that there are no residual symptoms following the event. However, we cannot assume that people do not have needs beyond diagnosis and secondary prevention. The focus of this thesis is to explore needs following TIA from the perspectives of patients, carers and professionals informing the development of an evidence based model of needs.

The TIA pathway and experience

To access the TIA pathway, it is necessary, following an episode of transient focal neurological abnormality, for patients to recognise that something is not right, and seek help from a healthcare professional, usually a general practitioner, paramedic or by attendance at the local hospital. However, patients often overlook TIA symptoms, and therefore TIA is under recognised and under-reported (Wester *et al.,* 1999; Kelly *et al*., 2001; Jones *et al.,* 2007; Gibson & Watkins, 2012). In a small study of 96 minor stroke or TIA patients, the characteristic that was most likely to prompt early contact was sudden onset of persistent stable symptoms, that is, symptoms that don't resolved immediately (Feldmann *et al*., 1993). A more recent study conducted in Japan looking specifically at people following TIA, found no association between recognition of symptoms and the urgency of action. Arm weakness or speech disturbance were found to be most likely to provoke early help-seeking behaviour (Uehara *et al.,* 2014).

Although significant work has been undertaken to raise the profile of stroke and TIA in the UK there still may be a limited association between knowledge of TIA symptoms and help-seeking behaviour (Hsia *et al.*, 2011). Patients often demonstrate a reluctance to report TIA symptoms and may fail to appreciate the gravity of the condition, expressing concerns about 'wasting the doctor's time' (Sprigg *et al.,* 2009; Hilsdon, Kersten & Kirk, 2013), or down-playing symptoms altogether (Gibson & Watkins, 2012). However, in patients who have had a TIA it may be possible, using a simple nurse-led knowledge-based intervention, to increase the likelihood that they respond to subsequent stroke symptoms as a medical emergency (Jones *et al.,* 2007). Generally, awareness and recognition of TIA among the lay public and patients remain poor (Stroke Association, 2014). Another important factor appears to be the presence of a witness or family member to validate the experience and prompt the patient to take action or seek help on behalf of the patient (Mandelzweig *et al*., 2006; Mosley *et al.,* 2007a, 2007b; Sprigg *et al*., 2009).

The window of opportunity to intervene before a stroke occurs after a TIA can be brief. Delay in presentation is multi-factorial including issues such as recognition of symptoms, awareness of stroke risk factors, lack of awareness of the risk associated with TIA and avoidance behaviours (Harper *et al*., 1992;

Feldmann *et al.,* 1993; Silver, 2003; Carroll *et al*., 2004; Giles *et al*., 2006; Kleindorfer *et al*., 2006; Chandratheva *et al.,* 2010). The most common help-seeking response to experiencing TIA symptoms is contact with a primary care physician (Sprigg *et al*., 2009; Chandratheva *et al*., 2010; Wilson *et al*., 2014). However, primary care physicians cannot always be relied upon to take urgent action: previous research has reported that between 20 and 40% of primary care physicians would not refer patients with their first episode of TIA symptoms to a specialist clinic (Jagaesham, Aparajita & Gough, 2008). A more prolonged delay was found if symptoms were experienced outside working hours i.e. evenings and weekends (Lasserson *et al*., 2008). However, a more recent study did not demonstrate this delay (Magin *et al.*, 2015), suggesting services and physician opinions are evolving in response to the change in perceived acuity of TIA. Initial delay during and after a TIA was also reported to be caused whilst the patient tried to make sense of the experience. This, coupled with the patient's own threshold of being 'sick enough' to require help, accounts for the bulk of the delay (Moloczij *et al*., 2008, Sprigg *et al.,* 2009).

During the event, the lived experience may be complex. One study explicitly asked participants about the experience of TIA, and uncovered a number of new experiences, including changes in spatial awareness and co-ordination, feelings of disconnection, disorientation and incomplete awareness of the deficit (Kirkpatrick *et al*., 2013; Croot *et al*., 2014). The research findings give rise to the potential for needs to be associated with the experience itself and the desire to make sense of the experience (Kirkpatrick *et al.,* 2013; Crowfoot, van de Reit, & Maguire, 2016).

From the patient's perspective, attendance at a specialist clinic is usually when the definitive diagnosis is given. At that consultation, the patient is subjected to a number of investigations (Solenski 2004a; 2004b), which may feel overwhelming. They typically may have brain and carotid artery imaging (Chang *et al.,* 2002), blood tests (Sandercock, 2003), Electrocardiogram (ECG) and echocardiogram (Flemming *et al.,* 2004), and be fitted with a Holter monitor to screen for paroxysmal atrial fibrillation (Kar *et al*., 2009a; 2009b; Gladstone *et al.,* 2009, 2014); in addition to a physical examination with

thorough neurological review (Tyrell, Swain & Rudd, 2010; Simmons, Cirignano & Gadegbeku, 2012).

Along with diagnosis of TIA, and stroke risk following TIA, there is a large evidence base for both pharmacological and surgical management following TIA. First, the patient requires investigations to identify the cause of the event, if possible (Flemming *et al.,* 2004). Then, based on both positive and negative findings, a treatment and secondary prevention plan is formulated for each individual. Medical treatment and secondary prevention strategies following TIA are based on addressing risk factors and the underlying cause of the event if known (Rothwell, Buchan & Johnston, 2006). Surgery focuses on carotid endarterectomy or stenting, which should be performed as soon as possible after the event, if appropriate (DH, 2007; Karkos *et al.,* 2007; ISWP, 2016b).

Secondary prevention strategies are based around initially optimising cerebral blood flow by early initiation of antiplatelet medications (Ross & Nahab, 2009), addressing modifiable risk factors, which include hypertension, smoking, diabetes, obesity, excess alcohol intake, atrial fibrillation, symptomatic carotid stenosis, mural cardiac thrombus, and raised serum cholesterol (NICE, 2008; ISWP, 2016b).

Potentially, from having felt fit and well, people will abruptly become ‘unwell’, with long-term medication, an expectation for them to address lifestyle change and behavioural issues (such as smoking and drinking alcohol), all as a consequence of what are often considered to be trivial brief symptoms (Gibson & Watkins, 2012). Patients may be extremely anxious and fearful of the future, requiring support to understand what has happened. On diagnosis, it is important to encourage the patient to consider lifestyle modification. Education about medication is vital to promote patient concordance (Marinker & Shaw, 2003; Courtnay & Griffiths, 2005; Chambers *et al.*, 2011). Patients need help to reframe their experience in a more positive light, in relation to the opportunity to address risk factors and reduce the risk of a completed stroke (Gibson & Watkins, 2012). A study looking at targeted interventions post discharge for minor stroke and TIA, demonstrated improved stroke risk knowledge and risk factor management for patients (Allen *et al*., 2002). It is

interesting to note that most of the missing data in that study was due to TIA patients who declined the 3-month home assessment, despite having similar problems at discharge to those with minor stroke, such as hypertension, depression or issues with medications. This suggests that patients may be less willing to engage with research following TIA, than after a stroke. This could have a bearing on recruitment into research following TIA. Regular telephone contact has been shown to improve concordance with medication and attendance in clinics (Sides *et al.,* 2012).

1.2 Rationale for research

There have been several publications relating to needs following stroke (Backe, Larsson & Fridlund, 1996; Boter, Rinkel & Haan, 2004; Talbot *et al.,* 2004; McKevitt *et al.,* 2010), but no published research about needs following TIA. This could be in part due to a belief that TIA is a wholly transient event, such that people return to their pre-TIA state. Patients would therefore not have any needs associated with the experience other than diagnosis and appropriate medical or surgical secondary prevention. Most research published about TIA relates to secondary prevention of stroke, or assessment of subsequent risk of stroke.

The emphasis in clinical practice has been on enabling patients to access TIA services for initial assessment in a timely manner, and having access to a range of imaging techniques; patient needs may not be seen as a priority and may only be considered during follow-up activities. The focus in service development has been on rapid access to services, refining the diagnosis, and timely treatment initiation, therefore, might result in needs and concerns being missed. The very rapid evaluation, diagnosis and treatment of TIA, whilst necessary, may induce anxiety in patients, particularly within the National Health Service [NHS], where patients typically expect to wait a number of weeks for appointments and tests (Gibson & Watkins, 2011; Christiansen, 2014). The NSS states that all patients following TIA should receive a further follow-up encounter four weeks after the initial event. The format of the four-week follow-up was not outlined within the document. Quality Marker 6, states:

> *"All patients with TIA or minor stroke should be followed up one month after the event, either in primary or secondary care*" and that "*Follow up should comprise review of medication and risk factors; screening for cognitive problems and subtle neurological impairment*".
>
> National Stroke Strategy. (DH, 2007), page 25.

A survey of TIA clinic provision published in 2007 demonstrated that there was wide variability across the country in terms of TIA service structure, access to investigations, and the types and numbers of personnel involved in clinic provision (Beech *et al.,* 2007). However, this survey pre-dates the publication of the NSS (DH, 2007), and the NICE guidance for management of acute stroke and TIA (NICE, 2008). There have been no subsequent publications or reviews of TIA services in the literature, although some TIA service data can be found in the National Sentinel Audit of Stroke (ISWP, 2011; ISWP, 2014; ISWP, 2016b), including the percentage of organisations in England, Wales and Northern Ireland that offer TIA services and how frequently they are available (daily, weekly).

There is little published data available about how TIA follow-up services are being delivered across England and no data about whether the services on offer are meeting the perceived needs of patients who have experienced TIA. Since this programme of research started there has been some research published relating to the experience of TIA (Arts *et al*., 2008; Pendlebury *et al*., 2011; Moran *et al.*, 2014). This research identifies some potential on-going problems following TIA, for example cognitive impairment, fatigue and depression, but all these studies included a mixed cohort of both TIA and stroke patients. Ongoing problems were identified as part of studies looking at programmes of care, or investigating single issues after minor stroke and TIA. There is some evidence that those who experience minor stroke and TIA may also experience anxiety, memory problems, and difficulty coming to terms with the change in their health status (Allen *et al*., 2002; Arts *et al*., 2008; Boter & Group, 2004; Boter *et al*., 2004). Research that has identified ongoing problems following TIA typically was focussed on the phenomenon concerned

rather than its association with TIA specifically and therefore can only present a fragmented picture. There has not been a report which comprehensively documents patients' needs following TIA.

There was a large body of evidence to support early assessment of TIA in the NSS, but there was little under-pinning evidence for TIA follow-up (DH, 2007). This appeared to be a pragmatic recommendation and not based on reported patient needs or expectations. There does not appear to be significant theoretical under-pinning to recommendations, with a general lack of literature relating to the experience of TIA and specifically to the needs of those who have the diagnosis. To date, no comprehensive needs analysis has been conducted with patients following TIA to underpin the determination of priorities for future TIA service provision. This evaluation is needed to ensure services meet patients' needs, rather than being based on assumptions of what their needs might be. The programme of research reported in this thesis aims to address this gap in the knowledge base.

For convenience and clarity throughout this thesis, people who have experienced TIA will be referred to as patients. People (non-professionals) who have offered informal support to someone who has experienced TIA (physical, emotional or practical) will be referred to as carers, and people who have been involved in this research due to their professional role will be referred to as staff or professionals.

1.3 Overview of thesis

The overall aim of this thesis is to explore needs following TIA from a range of perspectives and to develop a model of needs that might be used to guide clinical practice.

Chapter 1 has provided the background and wider context for the research, by means of introducing key literature and policy documents which have shaped current TIA services and the research presented here.

Chapter 2 will present literature relating to the experience of TIA.

Chapter 3 considers the methodology underpinning the programme of research. It will also contemplate the concept of needs in relation to the

research, identify the needs framework used to explore needs, justify the choice of framework, and finally, clarify what a model is, and why it might be useful to develop one.

Chapter 4 presents Phase 1 of the research programme, which is a nationwide survey of TIA services. The aim of this survey was to develop an understanding of TIA services, particularly in relation to follow-up available.

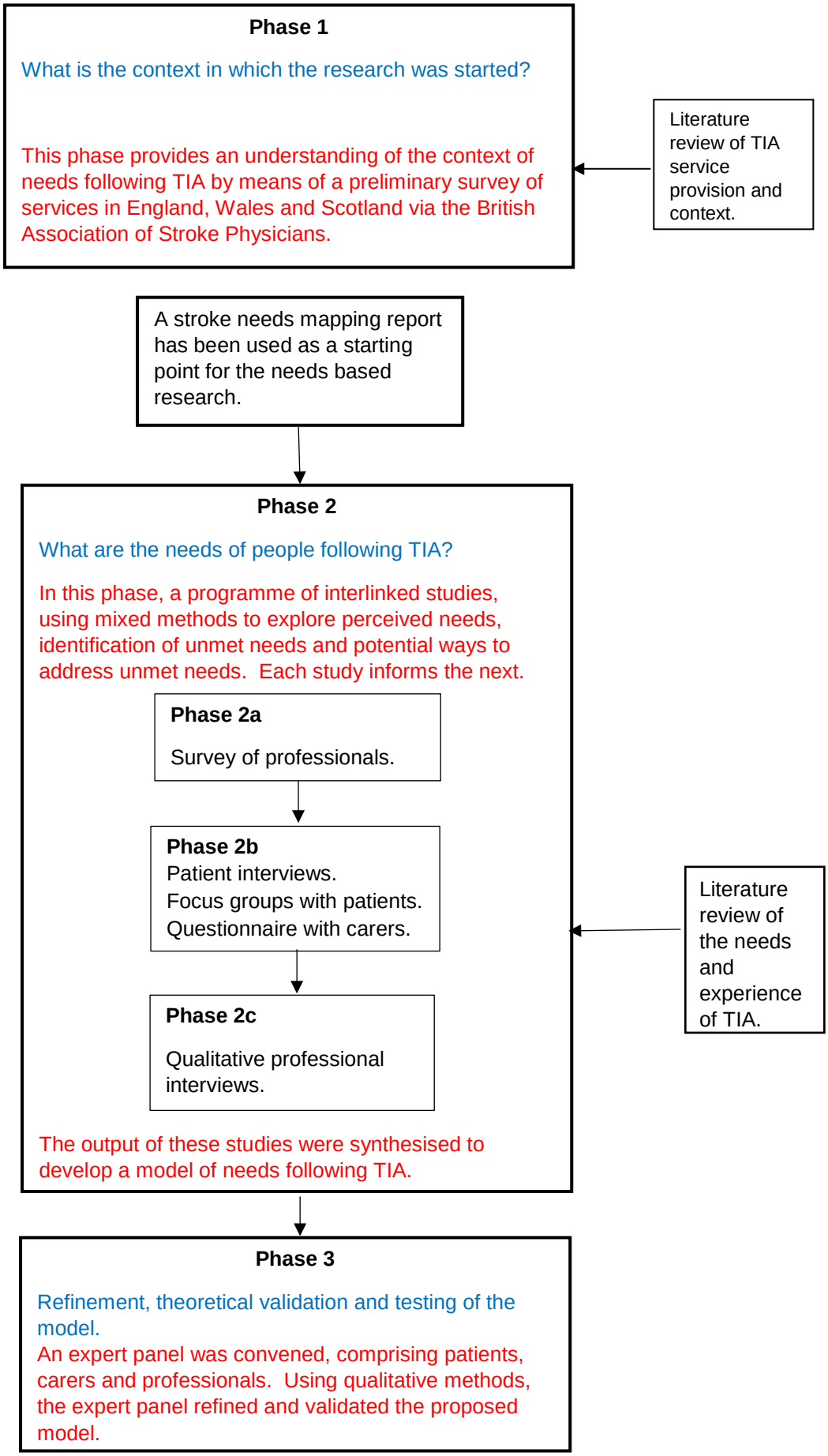
Chapter 5 describes Phase 2 of the research, which aimed to develop a comprehensive list of potential needs following TIA and to construct a draft model of needs. This phase used mixed methods and was based on the findings of a comprehensive stroke needs mapping report. Data from the stroke needs mapping were used as a starting point for exploring views about needs following TIA from the perspective of staff, patients and carers. This included a survey conducted predominantly with nurses, but including other staff involved in, or interested in, caring for patients with TIA and later interviews with staff in regular contact with people following TIA. Research with patients used interview and focus group methods. Carers were asked to complete a questionnaire that was based on the stroke needs mapping. A draft model of needs following TIA was developed.

Chapter 6 describes the validation of the draft model of needs by an expert panel comprising staff, patients and a carer, which provided some theoretical validation for the model and allowed refinement of the final model.

Chapter 7 presents the final model of needs, together with other key findings, the main strengths, limitations, potential impact on clinical practice, future research, original contribution to knowledge and recommendations.

A visual representation of the phases within the program of research can be found in Figure 2.

Figure 2 Flow Diagram showing the research pathway through the thesis



2. LITERATURE REVIEW PERTAINING TO THE EXPERIENCE OF TIA

2.1 Introduction

Chapter one has outlined some of the key issues in TIA diagnosis and management, together with the healthcare policies that have influenced TIA care in the UK. In chapter two a literature review will be reported in a systematic way to identify relevant research relating to needs following TIA. The overall aim of the literature review was to identify any needs following TIA. The literature review questions were:

1. What is the existing evidence relating specifically to needs experienced by people following TIA?
2. What categories of needs following TIA have been identified?
3. If there is no specific evidence relating to needs following TIA, what evidence pertaining to the experience of TIA can be found?

To answer these questions some assumptions were made. The first was to look at needs globally, in relation to the diagnosis. Needs might be un-met, and therefore experienced, or met and potentially not experienced. After-effects of TIA, if they existed, would be likely to give rise to needs, so in the absence of specific literature pertaining to needs, TIA experience would be explored. The second assumption was that research based in a qualitative paradigm, would illuminate the experience 'as a whole', rather than focusing on individual issues, such as cognitive impairment or fatigue, both of which have been reported following TIA (Arts *et al.,* 2008). Research looking at the prevalence of single issues or based in a positivistic paradigm were not, for this reason, included in the literature review. This was because the purpose of the review was to gain insight into how people experience needs after a TIA, not to count the number of people who reported a specific issue.

2.2 Methods

Search strategy

A systematic approach to the search was constructed, which included MeSH terms (Medical Subject Headings) for Transient Ischaemic Attack (TIA), and search terms for consequences, problems, impairment, experiences, dysfunction and personal narrative. The electronic databases searched

included: OVID Medline, psychINFO, CINAHL, and EMBASE. The searches were amended as necessary for each database. Citations were screened on title then abstract, any articles that met the inclusion criteria were read in full. Backward and forward citation searches were conducted to ensure a comprehensive search. The search strategy was constructed to identify research specifically relating to needs following TIA (See Appendix A1 for full search strategy).

Inclusion criteria

- TIA specific data.
- Primary research studies.
- Use of qualitative methodology or mixed method approaches.
- Relating to TIA need and / or experience.

Exclusion

- Abstract only data.
- Quantitative reports with no qualitative component.
- Subjects < 18 years.
- Non-English language publications.
- Non-human studies.
- Studies where data pertaining to TIA and minor stroke cannot be separated.

Data extraction

A data extraction form was created to summarise the identified research (Green, Johnson & Adams, 2001). Items included in the form were aligned to the Critical Appraisal Skills Programme (CASP) appraisal tool for qualitative research (CASP, 2013) and included:

- Study details (author, year of publication).
- Demography of participants.
- Aims stated.
- Methods used.
- Data analysis.
- Findings (themes).
- Bias (selection, credibility, transferability, reflexivity).

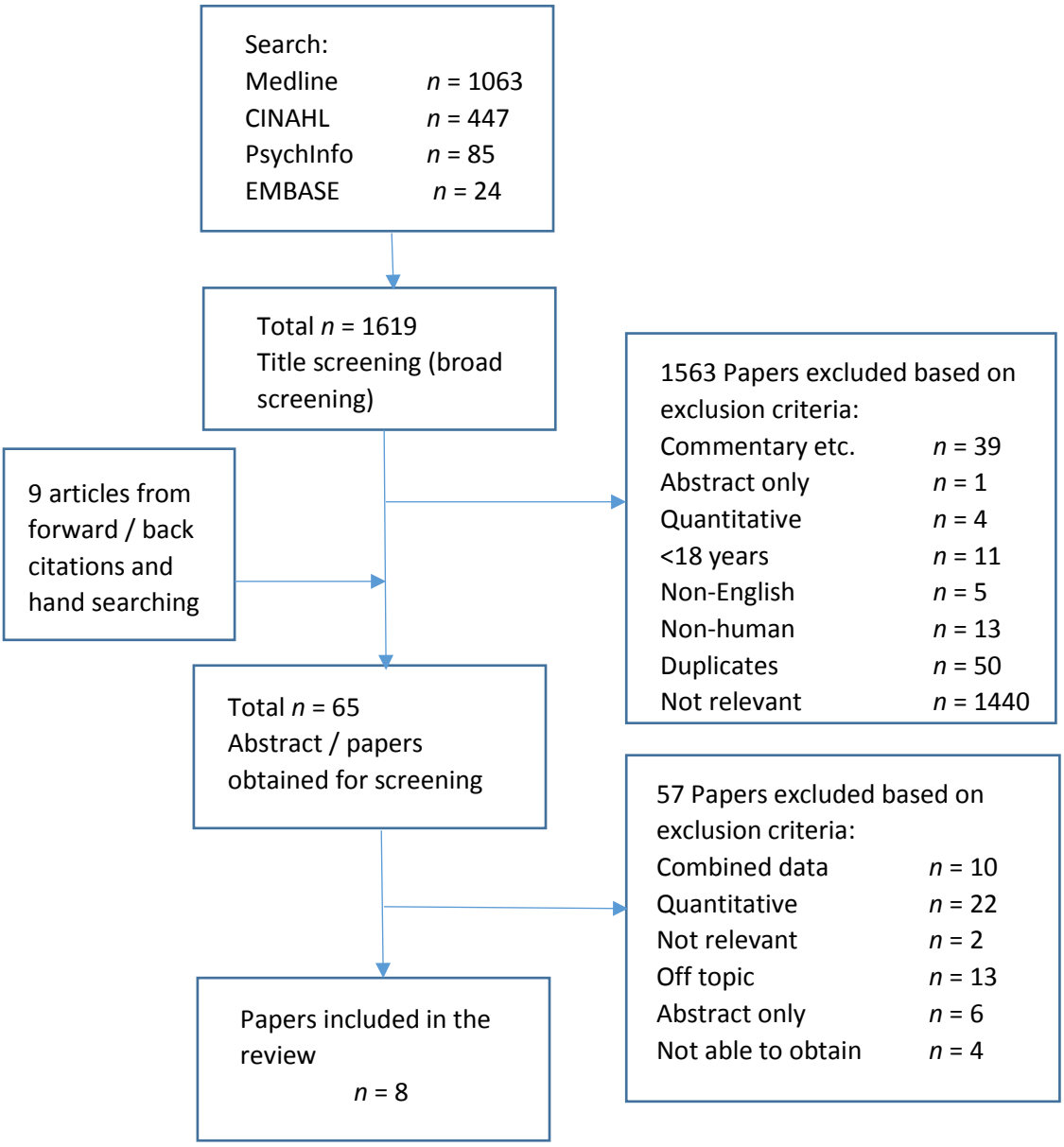
Study authors were not contacted for clarification or missing data.

Each item was considered for all included studies. Judgements were made based on the criteria outlined in the CASP appraisal tool and summarised in Tables 1 and 2. A narrative synthesis was completed including a summary of each study.

2.3 Results

The search strategy identified 1619 articles. Following screening of title, abstract or complete articles, 8 studies met the inclusion criteria (see Figure 3).

Figure 3 Showing a flow diagram of evaluation of the search strategy



The eight included studies reported on a total of 139 participants with an age range from 28 to over 94 years, although two studies did not provide information about the age of participants. There were more male participants in every study, where gender was reported, and overall 70% of participants were male. Six studies were conducted in the UK, with one from USA and one from Australia. The publication dates range from 2006 to 2016. All methods were qualitative or mixed methods in nature as required by the inclusion criteria, but a range of methods were used, including: narrative description; narrative enquiry, semi-structured and in-depth interview; Q-methodology, and repertory grid. Aims of the articles ranged from a focus on the experience of the TIA event itself to the long-term lived experience. Table 1 summarises the demography of the studies included, and Table 2 outlines the findings of the studies using the headings: Aims stated; Methods used; Data analysis; Findings (themes); Potential bias, and Importance in relation to needs.

Table 1 Demographic details of papers identified in the literature review

	Authors	Year of publication	Country	Number of participants	Mean age	% Male
1	Chardavoyne & Frechette	2006	USA	1	69	100%
2	Gibson & Watkins	2011	UK	20	70.2	65%
3	Gibson & Watkins	2012	UK	16	71.6 yrs (range 50-81)	69%
4	Spurgeon *et al.*	2012	UK	23	Not stated	Not stated
5	Kirkpatrick *et al.*	2013	UK	25	(Mode 50-70 yrs)	76%
6	Spurgeon, James & Sackley	2013	UK	12	71.5 (range 47-86)	58%
7	Croot *et al*.	2014	UK	39	31-89	54%
8	Crowfoot, van de Reit, & Maguire	2016	Australia	3	Not stated	67%

Table 2 Summary of the evaluation of identified papers

Authors	1. Aims	2. Methods	3. Analysis
Chardavoyne & Frechette	Clearly stated: - To recount the experiences of one man following TIA	Narrative description of one man's experiences following TIA, over nine-month period	There was no formal analysis, but comparison with other literature in PTSD and stroke cited
Gibson & Watkins	Clearly stated: - To examine how patients make decisions regarding medical treatment after TIA	In-depth interviews were used, in an iterative approach, where earlier interviews informed later ones	Constant comparative analysis of grounded theory
Gibson & Watkins	Clearly stated: - To report people's experiences of TIA and how that affects their perception of health and uptake of secondary prevention	Grounded theory was used to explore peoples' individual experiences, using purposive sampling and semi-structured interviews	Constant comparison methods (Glaser & Strauss, 1967)
Spurgeon *et al.*	Clearly stated: - To capture patients' experiences of TIA and its subsequent impact	Mixed methods. Q-methodology- reported to have the rigor of quantitative data with the richness of qualitative	Analysis of Q-set of data was positivistic, but linked to transcripts of the process giving qualitative data and illustrative quotes
Kirkpatrick *et al.*	Clearly stated: - To determine whether patients' experience of TIA would reveal additional deficits	Qualitative semi-structured interviews about the TIA experience itself	Framework analysis (Ritchie & Spencer, 1993)
Spurgeon, James & Sackley	Clearly stated: - To investigate the subjective psychological experiences of TIA	Based on the theory of personal constructs, the method used was a repertory grid	Analysis was via a bespoke computer programme which analyses responses derived from creating and individualised grid
Croot *et al.*	Clearly stated: - To explore the long-term lived experience of TIA	Semi-structured interviews with a narrative approach	Thematic analysis with a focus on content rather than structure (Riessman, 2002; Bold, 2012)
Crowfoot, van de Reit, & Maguire	Clearly stated: - To explore how experiencing TIA symptoms might lead to help seeking behaviour	Narrative enquiry valuing human experience and using the re-living and re-telling of experience	No formal analysis, but interpretation of individual stories by the researcher

Table 2 Summary of the evaluation of identified papers (cont)

Authors	4. Findings / themes identified	5. Potential bias	6. Importance
Chardavoyne & Frechette	Research describes a patient who was exhibiting symptoms of PTSD following TIA. Not been reported previously associated with TIA	Single subject who presented clinically to one of the authors. Potential that author might fit symptoms to the psychological disease rather than the fit being natural	This is the first report of PTSD following TIA, therefore raising awareness of the possibility in other patients. A single case report cannot be transferable, but identifies possibility of PTSD in TIA
Gibson & Watkins	Types of evidence used in decision-making in TIA. Empirical, pathophysiologic, experiential, patients' goals and values, system features	Purposive sample. Demonstrates how conflicting data was incorporated into findings	New information about how people make decisions about treatment, grounded in current practice. Small single centre study, but clearly states limitations and future application
Gibson & Watkins	Acknowledgement vs denial, out of the blue, ignoring symptoms, fear, seeking help, taking defensive action, changed perception of health, fortunate warning	Clear description of researcher's relationship to topic and participants, two people involved in analysis	Findings are considered in relation to current practice and policy and existing literature. Further research suggested. Implications for practice explored
Spurgeon *et al.*	Lack of knowledge, life impact of TIA, Anxiety, interpersonal impact, depression, impact of physical symptoms, cognitive avoidance / denial, constructive optimism	Risk of bias in construction of the concourse statements. Complex process might result in less robust data, however mitigated to an extent by supporting quotes	Mixed methods study. Findings considered in context of current practice with recommendations for future service development
Kirkpatrick *et al.*	Acute TIA resulted in problems with: spatial perception and coordination; feelings of disconnection or disorientation; incomplete awareness of deficit; visual disturbance; articulation / word-finding	Care in selecting only those with TIA diagnosis, however no ethnic heterogeneity of participants and unequal gender split reduce generalisability of findings. No clear description of symptoms at onset	The new findings in this research relate to experiences at TIA onset, however since the full range of symptoms for each patient were not presented, it is not clear how this could be used in clinical practice

Table 2 Summary of the evaluation of identified papers (cont)

Authors	4. Findings / themes identified	5. Potential bias	6. Importance
Spurgeon, James & Sackley	Constructs identified: Fear of future / role change; loss of confidence; frustration / personal restrictions; embarrassment; Anxiety re loss of normality; Wake-up call; sense of loss and its management; anxiety and disappointment; physical limitations	Retrospective. Patients 6-24 months after event, so memory might not be reliable. Highly complex process requires good communication skills, purposive TIA sample but all retired, 6 professional / managerial and 6 skilled / unskilled workers	Recommends the development of a positive affective response. Data prompts further research to validate findings and assess transferability
Croot *et al.*	Themes included: transience, or not; Physical sequelae; psychological consequences – permanence of uncertainty and anxiety; TIA can be transient	Potential of self-selection bias. 400 contacted 39 included. Research looked at long-term consequences of TIA range of time from onset was 2-24 months	First study looking at long-term experience of TIA. Outlines a case for ongoing support following TIA. Considers current service context and suggests further possible research
Crowfoot, van de Reit, & Maguire	Five main story lines were identified, these were: bodily disruption; time stasis; altered temporal perceptions; the role of others and help-seeking behaviours	Clear documentation of steps taken to minimise bias	Whilst this research is limited to three participants, parallels in their stories have been identified, that are suggestive of a trend. Not transferable

Table 3 Synthesis of research findings

Overall themes	Components	Study Number
TIA sequelae	Physical limitations, psychological consequences, loss of confidence, frustration / personal restrictions, sense of loss, altered perception of time, bodily disruption	*1, 2, 4, 5, 6, 7, 8.*
Negative emotional states	Post-Traumatic Stress Disorder (PTSD), anxiety, fear, depression, "out of the blue" – shock	*1, 3, 4, 5, 7*
Initial help seeking / acceptance	Acknowledgement / denial, cognitive avoidance, help-seeking, ignoring symptoms, role of others, TIAs can be transient – or not, time stasis	*2, 3, 4, 5, 8*
Positive interpretation of TIA	Fortunate warning, wake-up call, constructive optimism	*3, 4, 6*
The future	Changed perceptions of health, life impact of TIA, fear of the future / role change, anxiety & disappointment, loss of normality	*4, 6, 7*
Reducing risk	Decision making, defensive action, permanence of uncertainty and anxiety	*2, 7*

Narrative synthesis

In terms of the overall experience of TIA, there have been few recent studies which have looked at the subjective experience, and only eight studies have been identified in this review. There are a larger number of studies that look at single issues following TIA or stroke, such as fatigue (Winward *et al*., 2009; Eilertsen, Ormstad & Kirkvold, 2013), cognitive impairment (Bakker *et al.,* 2003; Fens *et al.,* 2013) or depression (Rao, Jackson & Howard, 2001; Luijendijk *et al*., 2011). Some of these studies focus specifically on participants following TIA (Guyomard *et al.,* 2011; Kiphuth *et al*., 2014; Sivakumar, Camicioli & Butcher, 2014b; van Rooij *et al.,* 2014), but most present data from a mixed group representing TIA and minor stroke (Arts *et al*., 2008; Kronish *et al*., 2012; Moran *et al*., 2014).

One of the early qualitative studies in relation to decision making after TIA, looked specifically at how people came to a decision regarding whether they would consent to carotid endarterectomy, if recommended by their surgeon

(Gibson & Watkins, 2011). Data was collected by in-depth interviews. The research identified a range of types of information that patients might use to come to a decision regarding future treatment. A possible limitation of this study was that it was based in a single hospital, and all 20 participants were seen by one surgeon. It is possible that results could be affected by that surgeon's manner or communication skills. A second qualitative study by the same team, looked at the experiences of TIA of 16 patients with carotid stenosis. Data was collected using interviews and grounded theory, and a number of themes emerged from the research. Themes included the tension between previously held beliefs about their health in the face of a TIA, and the need to acknowledge and deal with the new reality; difficulty describing and explaining the event; the perceived suddenness and shock involved; the tendency to down-play or minimise what was seen as trivial events; fear for the future; consulting with others before taking action; taking defensive action to avoid further problems; and a changed perception of health (Gibson & Watkins, 2012). This group of patients are a sub-group of the whole TIA population, and whilst they were thought by the research team to be representative of the wider TIA population, it is acknowledged that many TIA episodes are unrecognised and therefore unreported (Kelly *et al*., 2001; Giles *et al.*, 2006). It is not possible to know whether the group of patients that has not recognised a TIA, differs in any significant way from those that seek medical help.

A case of PTSD in a 69-year old man following TIA, was reported in 2006, as a case study (Chardavoyne & Frechette, 2006). This was the first time this type of anxiety, as well as depression, was linked to TIA. Whilst the experiences of the individual concerned were extreme, the types of emotional disturbance recounted had previously been clearly linked to stroke (Aybek *et al*., 2005; Bruggimann *et al.*, 2006), and have since been further described in the literature relating to TIA (Spurgeon *et al*., 2012; Verbraak *et al.,* 2012; Spurgeon *et al*., 2013). Between 18 and 30% of patients tested were found to be exhibiting signs of PTSD, most commonly found in the younger participants, women and those of lower socioeconomic group (Kiphuth *et al*., 2014). PTSD is a maladaptive coping behaviour in which the risk of stroke is over-stressed. One of the important behaviours in relation to PTSD appears to be a pattern of non-compliance with medication, which might result in patients having unnecessarily

high risk of subsequent stroke (Kiphuth *et al*., 2014). It is unclear whether this behaviour is related to associated depression, or avoidance of triggers which remind the person of the TIA (Kiphuth *et al*., 2014; Vickery & Williams, 2014). It is possible however that PTSD is under-reported, since patients experiencing the condition might avoid engaging with clinical care, or participating in research which requires them to think about the stressor (TIA).

A mixed methods study using a card sort Q-methodology (Akhtar-Danesh, Baumann & Cordingley, 2008) with 23 participants, identified 8 themes or concepts, three of which were felt to be new. These were anxiety, cognitive avoidance and constructive optimism (Spurgeon *et al.,* 2012). Patients in this study were diagnosed with TIA based on the newer 'tissue' definition (Easton *et al.,* 2009), so those with a cerebral lesion were excluded. A further study was published using a researcher administered questionnaire with patients following TIA or minor completed strokes, or patients following a brief admission or attendance at hospital following an episode of angina pectoris (Fens *et al*., 2013). This study revealed high levels of fatigue, and difficulties with memory, concentration and communication, (both spoken and written) in the TIA group.

A study published in 2013 reported subjective experiences in 12 people following TIA (Spurgeon *et al.,* 2013). This study used a repertory grid approach, from which emerged six themes: ‘deep-seated anxiety about future uncertainties / disruption’, loss of confidence’, frustration, ‘TIA as a wake-up call’, ‘a sense of loss and sadness’, and embarrassment. New themes have been added, but this research builds on that published the previous year in creating a picture of what a TIA might be like, and how it affects the individual.

The use of methods such as Q-methodology and repertory grid approaches have the advantage of combining the richness of qualitative enquiry with quantitative analysis(Akhtar-Danesh, Baumann & Cordingley, 2008). One difficulty with such methods is that they are highly structured processes which might be challenging for patients who could potentially have cognitive impairment following TIA. In the case of Q-methodology the researcher sets the agenda in terms of a concourse of potential cards, derived from previous literature and exploratory interview, it is possible that the process could limit responses with new information, as there is a potential for participants to feel

constrained by the contents of the cards. The above study using repertory grid methods confined the reporting to the 'construct' feelings of the subjects, which again might have constrained the responses of participants.

Two studies looked at the experience of TIA itself (Kirkpatrick *et al.,* 2013; Crowfoot *et al*., 2016). Both have findings relating to altered perception either in terms of spatial awareness, disconnection or disorientation (Kirkpatrick *et al*., 2013) or the passage of time (Crowfoot *et al*., 2016). These are important findings that remind us that the patient is often an unreliable witness (Kalsner & Kalsner, 1990) following TIA. Since diagnosis is predominantly based on the recounted history of the event, alteration of subjective awareness could impact on whether someone receives a diagnosis of TIA or not (Prabhakaran *et al.,* 2008; Sonni & Thaler, 2013).

One study aimed at exploring the long-term lived experience of TIA conducted semi-structured interviews with 39 participants. The time since TIA ranged from two to 24 months, which might make it more difficult to claim the findings are related to the long-term experience (Croot *et al.,* 2014). It is not clear how the experience has changed over time, and information relating to the acute phase following TIA might be difficult for some participants to recall accurately, particularly considering the body of evidence relating to memory or other cognitive impairment (Bakker *et al.,* 2003; Fens *et al.,* 2013).

The aims of the eight studies in this review include exploring the experience of the TIA event itself, identify new deficits following TIA, identify psychological impacts and implications for decision-making and to explore the long-term lived experience. Thus, the whole of TIA experience is covered within these identified studies, from the moment of onset to the longer-term impact. No single study looked at the whole pathway and some focussed on a small part of the overall experience (Crowfoot *et al.,* 2016), whereas others took a broader approach (Spurgeon *et al.,* 2012).

A range of methods were employed within the studies. Six studies used standard qualitative methods including interviews, and narrative enquiry, whereas two studies (Spurgeon *et al*., 2012; 2013), used more elaborate

methods which combined elements of both qualitative and quantitative research. In all cases, rich data relating to the experience of TIA were provided.

The analysis processes were varied in the identified studies, with two studies having no formal analysis reported (Chardavoyne & Frechette, 2006; Crowfoot *et al*., 2016). Of the remaining six studies, two used specific analyses related to Q-methodology and a bespoke computer programme based on repertory grid analysis (Spurgeon *et al*., 2012; 2013). The remaining four studies reported analysis using constant comparison (Gibson & Watkins, 2011; 2012), framework analysis and thematic analysis (Kirkpatrick *et al*., 2013; Croot *et al*., 2014).

The overall themes that appear to emerge from the studies include TIA sequalae, negative emotional states, issues around initial help-seeking and acceptance, positive interpretations of TIA, concern regarding the future and reducing risk. All studies identified at least two of these themes. One study (Spurgeon *et al*., 2012) identified five of the overall themes within their data.

Potential bias was addressed by all studies. The study most open to potential bias was the case study of a single individual following TIA (Chardavoyne & Frechette, 2006). All other studies acknowledged potential sources of bias and steps taken to minimise bias. All studies had small numbers of subjects, in keeping with qualitative research. However, there is still potential self-selection bias, with a possibility that those people who chose to participate in research might differ in some ways from those people who chose not to participate. One study specifically used the newer tissue based definition of TIA, which would exclude patients with early ischaemic damage in an MRI scan (Easton *et al.,* 2009), other studies either used the earlier WHO definition (1975), or did not clarify which definition of TIA was used. Patients who were included based on a diagnosis of TIA using the older definition may potentially include people who could have been demonstrated to have sustained visible damage on early MRI. This is relevant because it may result in slightly different cohorts of patients being selected.

2.4 Discussion

This literature review demonstrates a range of after-effects following TIA. Most of these experiences are perceived as negative for the individual concerned. The main themes that arose from the research were the on-going physical, psychological and cognitive impacts of TIA (See Table 3). There was also information about the experience of the TIA event itself. As the body of evidence about the impact of TIA expands, it is becoming apparent that TIA is clearly not the benign condition it was thought to be a mere 20 years ago, and as this realisation spreads through the stroke community, it challenges us to ensure that care for those who have had a TIA is targeted and appropriate.

Looking at the body of research identified in this review, it becomes apparent that for some people the experience of TIA is ongoing and might be extreme. Physical, mental, emotional and social domains of everyday life can be impacted, and whilst some people have been able to adopt a positive interpretation of the event, the overall impact of TIA appears to be residual problems, and increased uncertainty or anxiety for the future. This literature review has been limited to eight studies, but there appears to be growing interest in qualitative research in relation to TIA. All but one of the research articles presented were published since 2011. The presentation of TIA symptoms is highly variable and the individual, and their own coping strategies, appear to influence the experience.

The limitations of this literature review relate mainly to the risk of missing publications that should have been included. This might happen for a variety of reasons (Green *et al*., 2001). This review does not include papers that might be relevant, but were not published in English. All studies were from English speaking countries. The decision to include only publications written in English was based on this being post-graduate research with limited funds. Data from poster presentations and conferences were not included, since there was insufficient information to judge the quality of the research. Finally, the review only included published data, therefore it is possible there is material *in press*, that would also have been included, had it been available. It is recognised that there can be delay between publication and key word / MeSH headings being applied to the electronic databases.

The implication of the limitations is that there might be one or more research articles, that if accessed and evaluated might have been included within the review. It is unlikely that one or two additional articles would significantly change the overall finding that TIA is not an event that lasts for the duration of the main physical symptoms, but in some cases, may have persistent after-effects, that could give rise to needs following TIA.

The author's clinical experience of seeing patients regularly after TIA, was that of repeatedly being told about how life had changed for these individuals and their families. This prompted the research topic for this thesis. The literature review demonstrates supporting evidence for this view.

2.5 Conclusion

Gap in the knowledge base

It is clear that TIA is not an isolated event, but has lasting effects for many people, which potentially could give rise to needs over and above those associated with stroke risk reduction. To date there has not been a needs assessment undertaken and published for this patient group. The aim of this thesis is to address that gap in the knowledge-base.

This will be achieved by:

- Conducting a review of national service provision at the start of the research (2008).
- Develop a comprehensive list of possible needs and problems following TIA, based on the views of patients, healthcare professionals and carers.
- Construct a draft model of needs following TIA.
- Refine the draft model of needs with help from patients, healthcare professionals and carers.

2.6 Summary

In this chapter, some of the issues encountered during the research reported in this thesis have been explored. Evaluation of the available literature has enabled a narrative to be created in relation to a number of steps in the pathway through the experience of TIA. It is acknowledged that not everyone will have similar experiences, since the overall experience is based on symptoms

experienced, health beliefs and previous life experiences, coupled with the services received from health care providers and responses from significant others. In Chapter 4 we will look at the range of TIA services provided across the country at the start of this research.

3. METHODOLOGY AND OTHER UNDERPINNINGS OF THE THESIS

3.1 Introduction

In this chapter, the theoretical stance of the author will be explored as well as the choice of methodology. The concept of need will be introduced and its use in this thesis will be clarified. Needs assessment will be reviewed and the choice of needs assessment framework will be explained. The use of a stroke needs mapping will be explained in the context of the methodology selected. The concept of a model will be explored and the development of a model of needs following TIA justified. Finally, the methods used in each phase of this research will be reviewed.

A researcher needs to be reflexive and understand their own beliefs about the nature of knowledge and how it has impacted on the research question. The way the research is structured is the research paradigm, a framework that forms the basis of the research (Kuhn, 1996). Different types of research are based on different types of philosophical underpinning (Guba & Lincoln, 1994; Doyle, Brady & Byrne, 2009). There are two broad approaches to research, quantitative and qualitative (Bailey, 1997). Qualitative data (the "why or how") is more descriptive and explains findings rather than reporting them. This approach to research tends to help develop hypotheses. Quantitative data (the "what") describes knowledge or information that can be counted and relates to the type of data generated in Phase 1 of this research. Quantitative research is designed to test hypotheses that have been previously developed.

Methodology looks at how knowledge is acquired in a systematic way and varies in the degree of objectivity or subjectivity, based on the epistemological stance. It is a philosophical approach to obtaining knowledge, the methodology will determine which methods are congruent with the research question and should be used in the pursuit of specific knowledge (Flemming, 2007).

The research reported in this thesis is based on a mixed methods approach, that is, a mixture of both quantitative and qualitative research, where each paradigm when taken together illuminates the interpretation of all the findings. The research question '*What are people's needs following TIA?*' is highly complex and can be most fully answered using a combination of approaches. The philosophical underpinning of mixed methods is one of pragmatism

identifying suitable methods for each part of the investigation and conducting them in accordance with the appropriate paradigm and methodology (Bishop, 2014).

Using multiple methods, and a range of participants with different perspectives, will enable a richer understanding than would be achieved from either qualitative or quantitative paradigms alone. There are philosophical and epistemological tensions to be found in mixed methods research, but knowledge may be plural and uncertain allowing both paradigms to sit together (Foss & Ellefse, 2002). No one stance can be completely impartial, so it is important to have an appreciation of both paradigms. In this research, each step contributes to, and explains, findings and therefore set the stage for the next step.

There are claims that mixed methods research is merely positivism in disguise (Giddings & Grant, 2007), and does not value the qualitative data to the same extent as the quantitative. However, it can be argued that mixed methods enable the richness of qualitative data to be collected whilst providing the structure more commonly found in quantitative research, thus allowing direct comparison between disparate groups. Within mixed methods research, the whole is greater than the sum of its parts. Mixed methods can be 'mixed' in a variety of ways, either sequential or concurrent. Mixed methods can also refer to mixing qualitative and quantitative methods during study design and data collection or just during data analysis and synthesis.

In this thesis, there will be both elements of sequential and concurrent research. Firstly, there is a quantitative survey of TIA services, followed by concurrent surveys, interviews and focus groups with a range of participants with different experiences of TIA (Patients, Staff and Carers), and finally a qualitative focus group. The benefits of using mixed methods include more completeness of findings, a degree of triangulation of findings, and the offsetting of perceived weakness in either of the traditional paradigms (Foster, 1997; Foss & Ellefsen, 2002; Williamson, 2005). Data will be combined during interpretation, after it has been analysed in a manner compatible with its nature. The typology of mixed methods research (Creswell & Plano Clark, 2007) for this programme of research most closely fits a triangulation convergence model. Triangulation of

multiple data collection methods and analytical processes then enabled the production of more comprehensive results and therefore greater trustworthiness to the ultimate findings (Foss & Ellefsen, 2002).

It is recognised that although the use of mixed methods research has been growing in nursing research, there are many who believe that it is not possible to utilise two epistemologies simultaneously, and that qualitative and quantitative approaches are mutually exclusive (Smith & Heshusius, 1986; Guba, 1987). On a practical level, it may be difficult for both qualitative and quantitative research to be carried out simultaneously due to the necessary mind-set (Johnson & Onwuegbuzie, 2004; Ivankova, *et al*., 2006), and requires a good understanding of both paradigms before successfully attempting to combine them (Doyle *et al.,* 2009). However, there is also a view that mixing quantitative and qualitative research is seen to be a valid pragmatic approach to enquiry (Howe, 1988). Even if researchers have an understanding of both qualitative and quantitative paradigms, they tend to have a personal preference. The author's background is set in a positivistic paradigm, and so has required the development of both a new mind-set and skill-set to enable the richness of qualitative findings to illuminate the quantitative data. Mixed methods enable the combining of data from different sources in a way that allows them to be directly compared (Curry & Nunez-Smith, 2015). Needs represent a human experience, which cannot be adequately represented by numbers alone. However, the use of quantitative data enables comparisons and identifies mis-matches between groups. Justification for the individual methods used in each phase of the research will be provided later in this chapter.

3.2 What are needs?

To understand people's needs in relation to any medical condition it is necessary to acknowledge that need is a concept that lacks clarity of meaning and is subjective in nature (Bradshaw, 1994; Asadi-Lari *et al*., 2003a). Therefore, it is necessary to provide clarification. In this study, the focus is on the needs of the individual, rather than on other concepts of needs, e.g. philosophical, societal, economic, political or pragmatic needs (Bradshaw, 1994; Asadi-Lari *et al*., 2003a, 2003b). Need, in the context of this research, is based on the individual's perception of requirement or necessity. A need will often be

expressed as an unmet need, and is likely to be associated with problems or difficulties within the 'normal' daily life of the individual.

The Stroke Needs Mapping (SNM) also provided definitions of key terms, which have also been used in this research:

- ***Problem:*** *a condition, impairment or functional limitation acquired as a consequence of stroke;*
- ***Need:*** *an ability or aspect of life where support for either the stroke survivor or carer may be required to promote health and well-being, or to maximise activity / participation;*
- ***Unmet need:*** *an area of need which is perceived by the user to be unmet, or which does not meet specified standards.*

UK Stroke Survivor Needs Survey Information Mapping Exercise Final Report, (French *et al*., 2008), *Page 7*.

It can be difficult to separate needs, unmet needs and problems. It is likely that patients and carers will identify unmet needs and problems due to their perception. Staff may be more likely to talk about needs which they perceive to be common, so these may be potentially more commonly met. They perceive a need and perceive their intervention as being aimed at that need. For example, a patient may experience depression following a TIA. The need is likely to be identified in relation to how and when it is being addressed. However, it could be completely unrecognised as a need. Some unmet needs can be unrecognised and unrecognised. It might be unseen by the professional because the patient doesn't think that it is something they ought to bother the professional with. It might be unseen by the patient, in that they assume the problem is normal and that they just 'have to put up with it'. If identified, a need is potentially something that can be addressed.

3.3 Development of a model of needs following TIA

A model is a construct that simplifies and explains a complex phenomenon (Oxford English Dictionary, 2012). Need following TIA is a complex issue with a multitude of possible problems, needs, and unmet needs being identified by individuals or staff. Each person is likely to experience need in their own unique way, based on previous experience, personality and support network. The

development of a model of needs, in conjunction with a comprehensive table of potential needs will offer an insight into both the breadth of potential needs, and the more frequently experienced needs. It must be recognised that those needs more commonly experienced are also those more likely to be met, so less common needs may have a greater impact for those who experience them, specifically because they are less likely to be recognised and addressed.

3.4 The use of a stroke needs mapping to structure the research

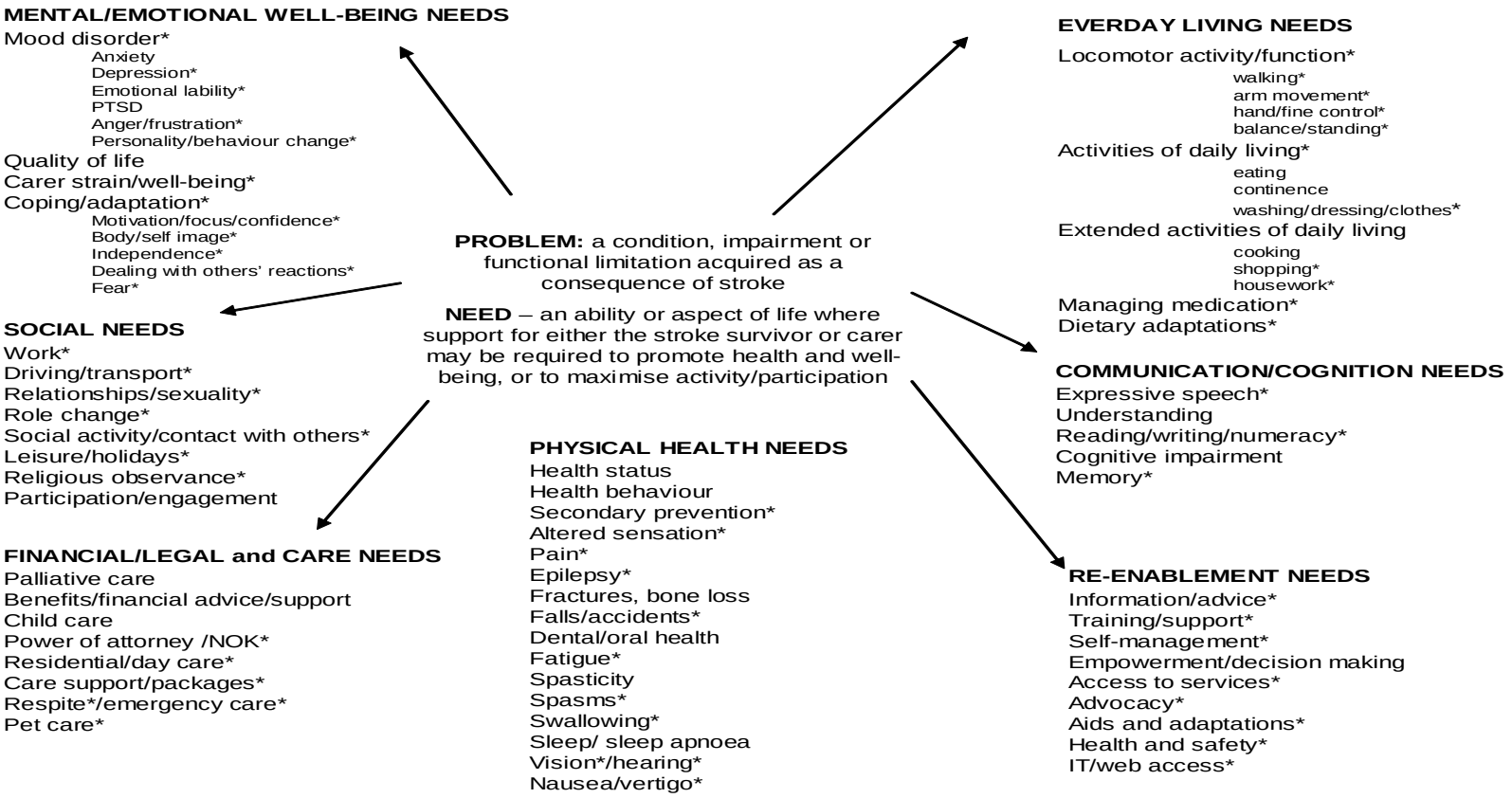
Cerebrovascular disease can be considered as a continuum, with TIA being placed at one end of the spectrum and severe stroke or death at the other. Both TIA and stroke share features of aetiology and risk factors (Dennis *et al*., 1989), although there are notable differences, particularly with haemorrhagic stroke. The shared aetiology of stroke and TIA suggests that people who have experienced a TIA might have at least some needs in common with those who have experienced a stroke. Some needs, post-stroke, are due to persistent symptoms such as physical or cognitive impairment. These might be expected to be less likely after a TIA. There are some needs which are likely to be common to both stroke and TIA, for example secondary stroke prevention. There may also be some novel needs which are unique to TIA and do not arise in stroke.

To focus the exploration of needs following TIA, a framework was used to structure the research and enable comparison of need perception between staff, patients and other groups. The framework adopted for this research was a model of needs and problems, identified by the UK stroke survivor needs survey information mapping exercise (French *et al.,* 2008) (see Figure 4). There had been previous publications related to stroke needs, but they were older (O'Mahony *et al*., 1999; Kersten *et al.,* 2002; Low *et al.,* 2003). The Stroke Needs Mapping (French *et al*., 2008) was judged to be the most up to date and relevant, and was selected to reflect recent changes in services. This was important because identified needs tend to relate to unmet need, and service provision impacts on perceived need. This document reported a review of a wide range of literature relating to stroke and described the output of a number of focus groups looking at needs following stroke. The report will be referred to as the 'Stroke Needs Mapping' or 'SNM'.

Seven domains of needs following stroke were identified for exploration, based on the SNM. Each domain contained a list of elements. The domains were:

1. **Communication / cognition**. e.g. Speech, understanding and processing of information.
2. **Mental / emotional well-being**. e.g. Mood disorders, personality / behaviour change, coping and adaptation.
3. **Everyday living.** e.g. Managing medication, mobility, personal care and home care.
4. **Physical health**. e.g. General health, stroke prevention, vision and hearing, dental and oral health.
5. **Re-enablement**. e.g. Information / advice, training / support, aids, adaptations, and equipment.
6. **Social**. e.g. Social activity, leisure, relationships and sexuality, work, transport and driving.
7. **Financial / legal / care needs.** e.g. Financial issues, respite day or residential care.

Figure 4 Stroke Needs Mapping (French *et al*., 2008)



3.5 Needs Assessment

Needs assessment can be conducted at many levels, depending on the type of need to be explored. Analysis of needs at a population or community level will necessarily be different in approach when compared to assessment of the needs of an individual. There is no definitive best method or framework identified for needs assessment (McEwen, Russell & Stewart, 1995). Using a variety of methods within a framework of needs assessment, including elements of quantitative and qualitative research, results in robust outcomes. This can be further strengthened by the inclusion of a range of sources of data (Murray & Graham, 1995; Asadi-Lari & Gray, 2005).

Needs assessment can be defined as "*a formal analysis that documents gaps between current results and desired results, arranges gaps (needs) in priority order, and selects the needs to be resolved*" (Kaufman, 1982, page 75). Needs assessment should have a systematic approach, with a defined population, it should be an active process rather than a passive response to demand, and should consider a range of views or perspectives (Jordan & Wright, 1997). There are a wealth of needs assessment tools and frameworks available in the literature, and some have been used previously with people following stroke or their carers (O'Mahony *et al*., 1999; Kersten *et al.,* 2002; Low *et al.,* 2003).

Since there is no previously published needs assessment of people following TIA, a wider search for needs assessment literature was reviewed and possible frameworks identified. Some needs assessment literature failed to clearly define the needs assessment tool used, those were excluded.

The tools that appeared to fit the requirements of the research were evaluated using a number of features including the focus of the research i.e. individual experience, versus support of service development; the methods used in data collection; whether the tool allowed for, or encouraged, the use of mixed methods; and / or a range of respondents, or sources. Suitability was determined based on these features. Only one framework met all the requirements, although it had not previously been used in a healthcare setting. The evaluation of needs assessment tools has been summarised in Table 4.

Table 4 Evaluation of potential needs assessment tools

Needs assessment tool	Focus	Methods of data collection	Mixed methods	Multiple sources	Suitability
Nottingham Health Needs Assessment (Asadi-Lari, Packham & Gray, 2003b)	Individuals	Self-completed questionnaires	✗	✗	✗
Southampton Needs Assessment Questionnaire, (Low *et al.,* 2003)	Individuals	Postal questionnaire	✗	✗	✗
Northwick Park Care Needs Assessment (Williams, Harris & Turner-Stokes, 2007)	Dependency / staffing numbers	Observation of care	✗	✗	✗
Case study method of needs Assessment (Cowley *et al.,* 2000)	Service quality	Focus groups	✗	✓	✗
Scottish Needs Assessment Programme (McEwen, Russell & Stewart, 1995)	Commissioning of services	Epidemiological data and group discussion	✓	✓	✗
Pharmaceutical needs assessment (Williams, Bond & Menzies., 2000)	Service provision	Interviews, postal survey, open forum, league table to prioritise care	✓	✓	✗
Lee's framework of needs (Lee, Altschuld, & White, 2007b)	Needs of individuals (learners not health related)	Mixed methods, interviews, surveys	✓	✓	✓

Of the seven tools identified, four did not focus on the needs or experience of the individual, and so these were not considered suitable, although in some cases multiple sources and mixed methods were used. Three tools did focus on the individual, but, two of those were based on questionnaires in isolation and therefore would not fit the requirement of the research. One tool met the above requirements, but, had not been used in healthcare previously. It was decided that the lack of clinical use was not a reason to exclude the tool, since people following TIA should have no residual focal neurology, and therefore, could be considered to be 'back to normal', without the need for a clinical slant

to the tool. The selected framework (Lee *et al.,* 2007b), appeared to fit best, and intuitively made sense for the author. It was easily aligned to the aims of the research reported in this thesis, and was selected as the needs assessment framework to underpin the process of investigation (Lee *et al.,* 2007b). For convenience and clarity, hereafter, the framework will be referred to as Lee's framework throughout the thesis.

Needs assessment at an individual level in healthcare, centres around functional ability, disability or health requirement (Robinson & Elkan, 1996; Asadi-Lari & Gray, 2005). There was no evidence in the literature to demonstrate that people following TIA experienced any change in function or health status, so a needs assessment framework that did not contain a health dimension seemed to fit the situation better. By selecting a needs assessment tool that moved away from the use of a biomedical model, it was possible to focus on people and their needs, rather than the condition.

Lee's framework was previously used in education. Needs assessment was considered as a five-step process (Kaufman & English, 1979; Witkin & Altschuld, 1995; White & Altschuld, 2012), where each step linked to a task within the programme of research and included a range of stakeholders, using a mixed methods approach. Each step forms an objective within this programme of research, see Table 5. The use of more than one type of stakeholder in this model demonstrates the inter-relatedness of views between groups. By including the views of more than one group a more comprehensive understanding of needs can be developed and therefore a more robust model developed.

Lee's framework for needs assessment (2007b), utilised a sequential mixed methods approach, first using quantitative methods followed by qualitative methods, as described by Creswell (2015). The quantitative element of Lee's needs assessment was a web-based survey using closed questions. The qualitative element of Lee's needs assessment used open-ended questions in a web based survey. His subjects were students (who were familiar with the services being investigated, and regularly used the Information Technology (IT) systems employed for the research) and faculty staff, who could also be expected to know about service provision and relevant IT. Analysis of the data

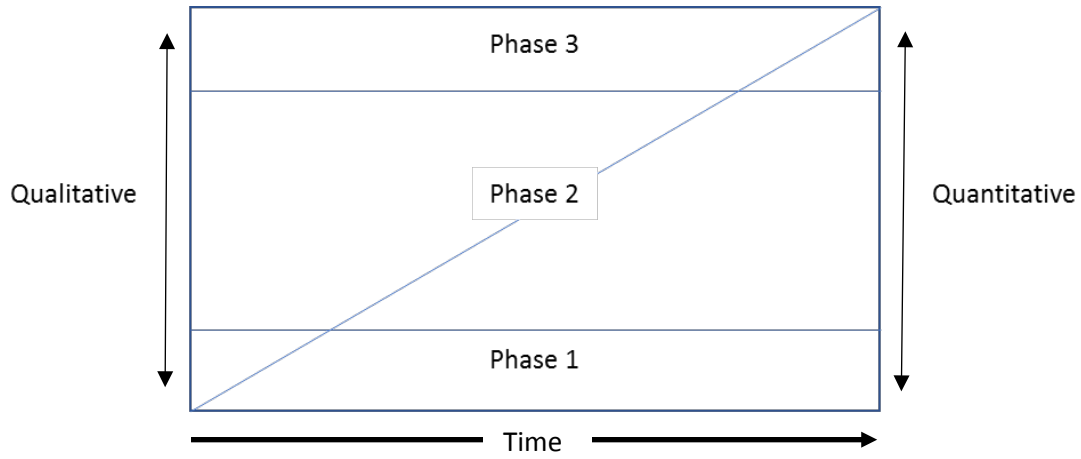
collected was initially based on group comparison using statistics. In the qualitative part of the needs assessment, the differences between groups were highlighted and participants were asked their views on why differences might be present. This was followed by thematic analysis of responses. Lee reports that although using mixed methods and a range of participants results in complex data, the benefit is that the findings are more complete and comprehensive.

Table 5 Mapping of the programme of research onto the five steps of Lee's framework

Lee's framework	Phase of research	Aim / methods
Step 1 **Ascertaining current status** *How are current services configured and run?*	Phase 1	Survey of service provision and models across mainland Britain
Step 2 **Identifying 'ideal' state** *What do stroke specific staff perceive as the needs of people following TIA?* *What needs and concerns are reported by those who have experienced a TIA?* *What are the views of 'carers' regarding peoples' needs following TIA?*	Phase 2a	Professionals' perceptions of needs shape the services that they deliver, but are likely to differ from those of the people experiencing the medical condition under scrutiny
Step 3 **Quantifying gaps between what should be and what is** *Which reported needs are perceived by patients as common / uncommon, met / unmet?*	Phase 2b	People who have received a diagnosis of TIA must be involved in identifying their own needs, because they are the only ones who have the lived experience. Carers were asked about both their perception of need on behalf of the person they supported, and their own perceived needs within that role. They were also asked to comment on whether, and how, needs were met
Step 4 **Analysing causes of discrepancy** *Which of the needs identified by people following TIA do health care professionals feel they meet?*	Phase 2c	Professionals who work in the field of TIA were asked about insights into how needs could be identified and met
Step 5 **Establishing priorities** *Is it possible to develop a model of needs following TIA? And how might those needs be met?*	Phase 3	Expert panel comprising staff, patients and carers, reviewed data from the on-going research to establish how needs can best be identified and met, enabling synthesis and validation of findings from previous steps

Over the course of the research, the methods move from Phase 1, which is predominantly quantitative, with some free text data, to Phase 2 which is mixed methods, using both quantitative and qualitative research methods to Phase 3, that uses almost exclusively qualitative research methods. See Figure 5.

Figure 5 Demonstrates the movement from quantitative to qualitative research methods throughout the research



3.6 Methodological approach

Phase 1

This phase of the research used primarily a positivistic approach having a quantitative paradigm. There were some free text responses to enable other responses and views to be shared. Although this is 'thin data' and could not be probed in more depth, it could inform later interviews and group discussions.

A survey was selected as the research method of choice for this study, because it offered a mechanism by which a wide range of participants from a wide geographical area could be sampled, using minimal resources, and taking a relatively short time (Kellerman & Herold, 2001; Edwards *et al*., 2002; Sahlqvist *et al.,* 2011). Another of the benefits of a survey method is the standardisation of questioning, which enables data to be readily grouped and compared (Moser & Kalton, 1971). Survey methods require significant planning to ensure the correct questions are asked and the optimum amount of information collected (Edwards *et al.,* 2009). The main drawback to survey methods is that poorly considered survey questions can be difficult to answer and deliver ambiguous data (Sahlqvist *et al*., 2011). There is also evidence that longer questionnaire s have a lower response rate (Edwards *et al.,* 2009). Low response rates can

make interpretation of results more difficult and can lead to bias in the data obtained (Murphy, 1993; Cook, Dickinson & Eccles, 2009; Fan *et al.,* 2010; Sahlqvist *et al.,* 2011). This is of particular concern when it is not possible to verify whether responders are representative of the population of interest (Cook *et al.,* 2009). This survey used a cross-sectional design, as data was being collected at a single contemporaneous point in time (Moser & Kalton, 1971).

Other methods considered and rejected were structured telephone surveys, or observed practice. These were considered impractical due to time and cost constraints. Observation would offer in-depth understanding of individual TIA service provision, but would not give an appreciation of wider services across the UK, also there would be a requirement to gain ethical consent for clinical observation, which would add considerable cost and time.

Phase 2

A mixed methods approach enabled in-depth insights into healthcare staff and patients' views of their needs following TIA. Basing the enquiry on the SNM allowed a uniformity of approach to be achieved with a quantitative dimension using surveys and questionnaires. A qualitative perspective was achieved through discussion in interviews and focus groups of the needs identified, both from the SNM and by clarifying needs that were unique to people following TIA.

In relation to qualitative data collection it is important to understand one's own beliefs and how they might impact on data collection and interpretation (Crotty, 2003; Walsh & Downe, 2006; King & Horrocks, 2010; Corbin & Strauss, 2015). The perspective adopted for this study is based in interpretivism (Crotty, 2003), which aims to establish an understanding of the issues rather than just cataloguing them. Much of Phase 2b methodology was based in the qualitative paradigm, where data collection and analysis are systematic and iterative in nature. Theory as a concept can be considered as the linking of two features, based on the experience of an individual, where the two features are linked by a relationship. As data are collected, they are reviewed and coded. Each code is associated with a concept, and as the concepts grow and develop, so theory can be built. This research was based on two pre-constructed frameworks, that of needs assessment, based on the work of Lee (Lee *et al*., 2007b), and also the Stroke Needs Mapping (French *et al*., 2008), which was used as a starting point for the content of the research in Phase 2. The aim was to use these

constructs to help shape the research, without allowing them to constrain the data obtained. This would allow the data to demonstrate where there was a good fit with the SNM, and not force data into pre-existing categories where the fit was less good. As the research developed through the various sub-studies in Phase 2, the SNM became less influential. The data led the enquiry as each interaction informed the following encounters.

Individual semi-structured interviews enabled exploration of the relevant issues and also allowed the participants the freedom to introduce information that they felt was relevant to the discussion. There were also benefits to using a focus group strategy for understanding needs and performing needs assessment, one of which being its interactive nature, allowing discussion between participants (Kruegar & Casey, 2009). Focus groups can tease out a variety of views and experiences in a way that individual interviews cannot by combining people who share characteristics to help the researcher understand the topic. These groups gathered the opinions of people who had experienced, or been given, the diagnosis of TIA. Focus groups are group discussions that are conducted in a non-threatening, permissive environment designed to promote self-disclosure to the degree the participant chooses. This method is thought to be helpful when considering needs and has been used widely in needs assessment in education (Kruger & Casey, 2009).

Finally, in Phase 2c, professionals who regularly cared for people following TIA offered their insights into patients' needs, and how they are identified and met. This sub-study considered a range of material that had been obtained from Phases 2a and 2b. Professionals were asked about their views on needs following TIA, particularly regarding the unique needs previously identified.

Other approaches that were rejected included in-depth unstructured interviews with any or all three groups of participants. This would have given rich data, but the use of the SNM enabled easy comparison between groups, thus highlighting any mis-match between the perceptions of the various groups.

Phase 3

Throughout, but especially in this phase of the research, the axiology (ethics) was based on beneficence, respect and justice, with a focus on fairness, honesty and reflexivity. The aim within a constructivist axiology is to ensure the participant voices are heard, through transparency of analysis. The ontology

(Drummond, 2005) was relativist, demonstrating that the context is important and that individual mental constructs of reality exist. This means that multiple and potentially conflicting perceptions or truths may co-exist, this is because people construct meaning based on their experiences. Knowledge is constructed rather than objectively existing. The epistemology in this phase was based on the idea that the researcher and participant were co-creators of research findings. The methodology used was based on interactions between researcher and participants, where consensus was sought using a small focus group or participants using purposive sampling.

By aiming for maximum diversity within the group (patients, staff and a carer), the benefit of using a focus group method for the expert panel meeting was the interaction and discussions that provided richness to the data (Krueger & Casey, 2009), and helped to validate the proposed model.

Finally, it is necessary to consider the researcher's perspective, since that will inevitably impact on the way that findings are obtained and viewed (Walsh & Baker, 2004). The researcher is a nurse practitioner involved in the care of people following TIA and stroke. She works extensively with people who have been given a diagnosis of TIA, which is what sparked the interest in the research initially. It has proven challenging to switch from the role of practitioner to researcher and back again, since the roles are very different and require different skills and responses. This was perhaps one of the biggest challenges for the researcher and will be explored further, later in the thesis.

Other research

Since the research reported in this thesis started, work has been published from Canada, looking at 'actual' and 'ideal' services for carers in acute and rehabilitation stroke care (Rochette *et al.,* 2013). This research used a two-part design employing first interviews and then focus groups with patients, staff and carers. The focus groups were asked to discuss the findings from the interviews. Sampling throughout was purposive and data was analysed iteratively, and fed back into later interviews or focus groups for further consideration. The authors were explicit regarding theoretical stance, but did not identify a specific needs framework within the research.

That research bears similarities to this thesis. However, it only looked at part of the needs assessment process, which correspond to steps one and two of Lee's framework (identifying 'current status' and 'ideal state'). The research explored the needs of carers and relatives of people who had experienced stroke, whereas this thesis reports the needs of people following TIA themselves. Although there are similarities between the methods used in this thesis and the research undertaken by Rochette *et al.,* (2013), this thesis considers all five steps of the needs assessment framework in relation to needs experienced following TIA.

3.7 Summary

In this chapter, we have explored the theoretical underpinning of the research presented in this thesis. The rationale for choices made has been provided and clarity has been provided about the concept of needs, needs assessment and the reasons for the choice of needs assessment tool. This has set the theoretical scene for the following research. In chapter four, Phase 1 will describe the quantitative research into TIA service provision in 2011.

4. PHASE 1 – SETTING THE CONTEXT OF TIA SERVICE PROVISION AT THE START OF THE RESEARCH

4.1 Introduction

Chapters One and Two presented an overview of the context and literature that underpins the research presented in this thesis. Phase 1 presents the development of, and findings from, a survey of a range of TIA services provided by the NHS in mainland Britain in 2011. The aim of this survey was to develop an understanding of TIA services currently available in Britain in relation to organisational structure, service provision and alignment with best evidence based practice, with emphasis on the provision of follow-up care. This phase will create a context in which to later explore to what extent current services might identify and meet the needs of someone following a TIA.

4.2 Background to Phase 1

Previous research relating to TIA focussed mainly on diagnosis and treatment of the condition. Some audits of TIA service provision had been conducted, but these reported the process of TIA service provision rather than the content and quality of provision. Since there has not been a published comprehensive needs assessment following TIA, it is difficult to establish whether the services available meet the needs of people who have experienced a TIA. In this phase, the available audit results will be considered together with the national documents which have influenced TIA service development.

The British Association of Stroke Physicians (BASP) reported a benchmarking survey of stroke services, including TIA service provision, which was conducted from November 2000 to February 2001 (Rodgers *et al.,* 2003). This survey identified 54 neurovascular clinics from 91 responses, one of which was described as 'one-stop', where all assessments and investigations were completed on the same day. A further survey of TIA services was conducted in 2003 and published in 2007 (Beech *et al*., 2007). At the time of publication, the 'Gold Standard' model of TIA management was seen to be a 'one-stop' model where all investigations were completed and results reviewed on the same day, leading to a diagnosis and initiation of treatment, during a single consultation (Blight *et al.,* 2000). In 2003, when data for the Beech *et al*. study was collected, follow-up was not seen as an ideal model, and there was no requirement specified for follow-up. One reason for this might be that follow-up

was seen to offer an opportunity to delay investigations that were difficult to obtain quickly, thus delaying diagnosis and treatment. It was the launch of the NSS in December 2007 that formally suggested follow-up should occur:

> *"A follow-up one month after the event, either in primary or secondary care, means that medication and other risk factor modification can be assessed, and screening for cognitive or other subtle neurological impairments should be performed. Any neurological deterioration or recurrence should trigger further investigation."*
>
> National Stroke Strategy (DH, 2007) Page 26.

There were, however, no references cited in the NSS to support the recommendation, and little published data available at that time regarding cognitive or other sequelae of TIA.

There were massive changes in the provision of TIA services between 2006 and 2010. In 2006, 78% of sites offered a neurovascular clinic, with median delay of 12 days from referral to attendance (ISWP, 2006). The target at that time was for patients to be seen within seven days (ISWP, 2004). By 2010, 98% of sites had a neurovascular clinic, with a median delay of three days from referral to attendance (ISWP, 2010), although only 10% of services offered a seven-day service. The typical delay between referral and first attendance might, however, represent a much longer delay between onset and first attendance, due to potential delays in people reporting their experiences. Changes in TIA service provision were further expedited by a national requirement for reporting performance at an individual Trust level via Outcomes Framework with 'Vital Signs' monitoring (NHS England, 2012), and the introduction of a best practice tariff for TIA services (NHS England, 2011). The Vital Signs Monitoring Returns were focussed on the proportion of higher risk patients seen and treated within 24 hours of first contact with a health professional. Figures had to be submitted to Primary Care Trusts monthly. Payment by Results and the Best Practice Tariff (NHS England, 2008, 2011, 2013) also incentivised the provision of 4 week follow up in line with QM 6 of the NSS (2007), despite a lack of evidence upon which this recommendation was based.

The above surveys and audit reports provide a picture of improved provision of, and access to, TIA services in terms of the number of clinics available (per week or month), and shorter waiting times from referral to attendance in a secondary care environment. However, there was little detail in these reports about what clinic consultations included, and no information at all about TIA follow-up services. In 2003, the first benchmarking exercise undertaken by BASP was published (Rodgers *et al*., 2003). This identified the staff groups that were involved in TIA clinic provision. It also presented some information about the content of clinics, such as access to imaging. The Beech survey of BASP members conducted in 2003 and reported in 2007 highlighted the background of respondents (for example, Elderly care, Neurology, Vascular), the frequency of clinics, and the availability of, or delays in, accessing investigations (Beech *et al*., 2007). These surveys were building a picture of the processes of TIA service provision.

None of the above audit or survey methods could answer research questions relating to what typically happens at the initial and follow-up attendances at a TIA clinic. For this reason, a new survey tool was needed which would combine some of the same questions previously used together with others designed to obtain the new information required. It was also important to be able to evaluate each service description against the key features of 'best practice' in TIA management. A description of 'best practice' in TIA patient management was, however, not explicitly available, perhaps due to the discrepancies between the NSS, NICE and the national guidelines.

The NSS (DH, 2007) and the NICE Guideline 68 (NICE, 2008) were therefore reviewed in order to identify possible elements of best practice in TIA care.

Four key features were identified:

1) **Access to TIA clinics seven days per week service**. A seven-day service is necessary to meet the target of seeing people within 24 hours of onset of TIA symptoms (NICE, 2008) or within 24 hours of first contact with a healthcare professional (DH, 2007). Logistically this is the only way targets could be consistently met.

2) **Stroke Specialist clinical input**. This refers to registered medical practitioners with a recognised specialism in stroke, which would enable the provision of a specialist assessment which includes the exclusion of stroke mimics, identification of vascular territory and likely causes, appropriate investigation and treatment (NICE, 2008). There is also evidence that when specialist clinicians are assessing the patient, fewer unnecessary investigations are requested (Karunaratne, Norris & Syme, 1999), having a positive impact on both the individual patient and the health economy as a whole (DH, 2007). It is recognised that TIA is a difficult diagnosis to make (Brown, 2001; Johnston, 2002; Farhat *et al*., 2009). A specialist would be expected to be more likely to correctly diagnose both TIA and TIA mimics.

3) **Investigations and results (brain imaging, carotid artery imaging, blood tests and 12-lead ECG) available on the day of contact**. Access to not only investigations, but also the results on the day of first attendance in clinic enables the clinician to consider all relevant information in the formulation of a diagnosis, thus improving accuracy, ensuring appropriate treatment can start immediately and reducing diagnostic uncertainty as much as possible. This can be viewed as the 'one-stop' model where investigations, diagnosis and treatment all occur at a single attendance.

4) **All TIA patients receive follow-up**. The NSS was the first national document that suggested follow-up was an important activity after TIA (QM 6; DH, 2007). The recommendation was for follow-up at four weeks to review medication, reinforce risk factor management and assess for subtle neurological impairments. This also offers an opportunity to review the diagnosis and answer any patient questions. Potentially, unresolved needs of the patient could also be identified and addressed at this attendance.

In terms of service provision these four elements are all needed but are not necessarily sufficient to provide an optimum service. This is because if only the activities mandated by the national documents occurred, then the care might

not be patient centred and patient needs could remain unidentified and unresolved.

Phase 1 Aims

1. To identify the types of activity that occur in both initial TIA contact and TIA follow-up appointments.
2. To evaluate service provision in relation to 'best practice'.
3. To identify a range of service delivery models that might be investigated further in subsequent stages of the research project.

Phase 1 Objectives

1. To develop a survey tool to capture data about organisational structure and specific provision of TIA services.
2. To evaluate the provision of key features of best (evidence-based) practice.
3. To compare findings with previously published data (Rodgers *et al*., 2003; Beech *et al*., 2007).

4.3. Development of the survey

Rationale

The basis of this enquiry was quantitative in nature and one of the benefits of a survey method is the standardisation of questioning, which enables data to be readily grouped and compared (Moser & Kalton, 1971). Survey methods require significant planning to ensure the correct questions are asked and the optimum amount of information collected (Edwards *et al.,* 2009). The main drawback to survey methods is that poorly considered survey questions can be difficult to answer and deliver ambiguous data (Sahlqvist *et al*., 2011). There is also evidence that longer questionnaires have a lower rate of response (Edwards *et al.,* 2009). This survey could be considered a cross-sectional survey, as data was being collected from a single contemporaneous point in time (Moser & Kalton, 1971).

The questionnaire was developed to identify a range of service models by identifying which events occur at the initial secondary care contact. In the services where follow-up was offered, information was requested about which

clinicians were involved in the provision of follow-up care, and what activities typically occurred during these encounters.

Purpose and survey design

To ensure optimum response rates, it was necessary to design a survey tool that would be acceptable to busy clinicians. This required questions that could be answered in relation to a typical clinical encounter, rather than requiring data relating to specific patients. The data was requested to answer the research question 'what typically happens at the initial and follow-up contacts at TIA clinic?' It was the service provision, rather than the service outcomes that were of interest. The questions included in the survey were designed to give an insight into the patients' experiences rather than the internal organisation of the healthcare provider or their performance metrics.

Objectives of the survey

There were four main aspects of TIA service provision that were to be covered by the survey. These included:

1. **Organisation**. Information about frequency of clinics and durations of appointment slots**.**
2. **Personnel**. The background discipline and job role of staff involved in the provision of TIA services.
3. **Activity.** A clear understanding of which events occurred in initial attendance and follow-up clinics.
4. **Service models.** This was not explicitly asked in the survey, but derived from the replies received in response to organisation, personnel and activity. Evaluation of responses against the key features of a best practice service identified by the author with reference to the NSS (DH, 2007) and the NICE Guideline 68 (NICE, 2008).

Survey development

Questions were developed to obtain the information outlined in the survey objectives. All questions were designed as closed questions with a variety of forced options (either single or multi-response), but all questions also had a free text area in which additional information or clarification could be added.

Where possible, questions were developed that would allow comparison between data obtained from the planned survey and the data presented by the

previous surveys of BASP members regarding TIA services (Rodgers *et al.,* 2003; Beech *et al*., 2007).

Shorter questionnaires that are under 1000 words in length (Jepson *et al*., 2005), or that take less time to complete, (Fan *et al*., 2010), are more likely to be completed. For this reason, the questionnaire was limited to thirteen questions: six about initial contact, six about TIA follow-up, and a final question asking whether the participant would be willing to be contacted to discuss their responses in more detail.

Pre-testing (1)

Pre-testing of the initial questionnaire was conducted to establish whether the survey questions were easy to understand and would give rise to the desired type of responses. Pre-testing of the questionnaire is thought to be good practice in survey design (Bourque & Fielder, 1995; Jackson & Furnham, 2000), as it enables any lack of clarity to be identified prior to survey distribution and changes made accordingly (Fink, 2009).

The questionnaire was developed by initially collating the desired questions and listing a likely range of responses. The output from this was shared with the research team, who offered suggestions relating to clarity of the questions. In the pre-test survey, the specific content of responses was not recorded. Instead, feedback was given relating to ease of completion, clarity of questions, and time taken to complete, together with suggestions of how the survey might be improved. This was used to amend the initial version. Feedback was predominantly verbal and resulted in a number of changes over several iterations of the survey (Aldridge & Levine, 2001).

Clinical colleagues with an interest in research or stroke were asked to review the questionnaire and give feedback specifically on the issues outlined above. The questionnaire was sent by email and colleagues were asked to print and complete it on paper. They were asked to annotate the questionnaire as they completed it to capture their thoughts in real-time. A single sheet asking about the experience of completing the questionnaire, including the time taken to complete, was also included in the mailing to clarify the questions which the reviewers should consider in relation to the questionnaire. Feedback was

collected verbally, and where possible annotated questionnaire sheets were also collected.

The pre-test questionnaire reviewers comprised three stroke consultants, two stroke nurse specialists, a neurologist with a special interest in stroke and a stroke research nurse. Following the initial pre-test questionnaire feedback, some changes were implemented, including widening the list of personnel who might be involved in initial and follow-up clinic attendances. It was thought that for more common possibilities, such as vascular surgeons, it would be better to include them explicitly in the list of personnel, rather than rely on the catch-all 'if other, please specify'. The other changes to the initial contact questions were to offer the option of investigations being performed prior to clinic, and the addition of a question about when results were available for tests performed.

Pre-testing (2)

A second round of testing did not reveal any further suggestions for improvement of the questionnaire, but one final change to the survey cover letter was required to meet ethical standards. In the covering letter participants were asked to provide their contact details if they would be willing to discuss their responses in more detail, or would be willing to discuss the possibility of further TIA research. The final word count of the questionnaire was 505 words. The median time taken to complete the questionnaire during testing was approximately seven minutes (range five-nine minutes). An on-line version of the questionnaire was constructed using the survey tool SurveyMonkey™ (Appendix B1).

Several iterations of the questionnaire were created before the survey was finalised. There were a number of recommendations and suggestions offered by members of the pre-test questionnaire sample group that were not included in the final survey. These included questions relating to operational organisation of TIA services, such as requesting information about which directorate TIA clinics belong to; the use of telephone triage; and branded vs generic medications. The rationale for excluding these suggestions was the study's focus on the patient experience. Other suggestions included use of home blood pressure monitoring; frequency of blood pressure monitoring and changes to medication between initial and follow-up attendances. These were

more patient-centred questions, but it was felt that these issues were unlikely to be standard across the majority of patients in any one service, which would make them difficult to answer or appear vague or less meaningful to participants. It has been demonstrated that questions that are not well crafted tend to be left unanswered (Fink, 2009).

4.4 Survey method

Setting

The questionnaire was distributed via email correspondence from BASP to their members in mainland Britain. The survey was conducted in March and April 2011.

Subjects and sampling

All members of BASP were included in the distribution, including both full consultant members and associate members. Associate members comprised mainly specialist registrars, stroke trainees and specialist nurses.

BASP members were selected as the study population for a number of reasons. Firstly, it was the population studied in the two previous surveys of TIA services and as such would enable comparison between new data gathered and the previously published data. Secondly, physicians with an interest in stroke, or specialist training in stroke were likely to be members of BASP. Finally, with membership numbers running in excess of 600, and 213 acute NHS organisations providing TIA services, it was felt likely that the majority of NHS TIA services would employ at least one BASP member.

Ethics

There were no major ethical issues associated with the survey. Consent was implicit in the completion of the questionnaire**.** Healthcare professionals were the population being studied, so there was no requirement for NHS Research Ethics Committee (NRES) approval. Appropriate approvals from the University of Central Lancashire (UCLAN) Ethics Committee were granted (Faculty of Health and Social Care Ethics Committee [FHEC] 478, granted 25th January 2011).

Survey

BASP were contacted and agreed to circulate the survey to their members via email. For reasons of data protection and confidentiality, BASP could not share

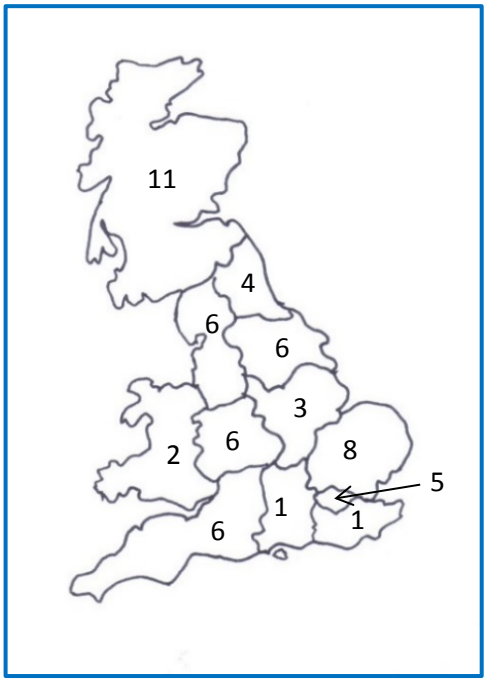
their membership list, but agreed to forward the covering letter and invitation, together with an embedded link to the questionnaire (Appendix B2). Embedded links have a better response rate to those links that need to be accessed manually (Bandilla, Couper & Kaczmirek, 2012). Each response was allocated a number for initial analysis purposes. Where two or more responses were received from a single site, responses were first sifted to identify the most complete, then, where there were still multiple responses to consider, the lowest level of service provision was selected to avoid over-reporting.

4.5 Results

Response rates and distribution of responses

BASP 645 members received an email inviting them to participate in the survey. 73 responses were received from 59 sites across mainland Britain. Responses were received from 59/213 (28%) of possible acute sites providing TIA services in mainland Britain, according to the Sentinel Audit results (ISWP, 2011), see Figure 6.

Figure 6 Geographical Distribution of Responses



Number of sites that responded by Strategic Health Authority Area.

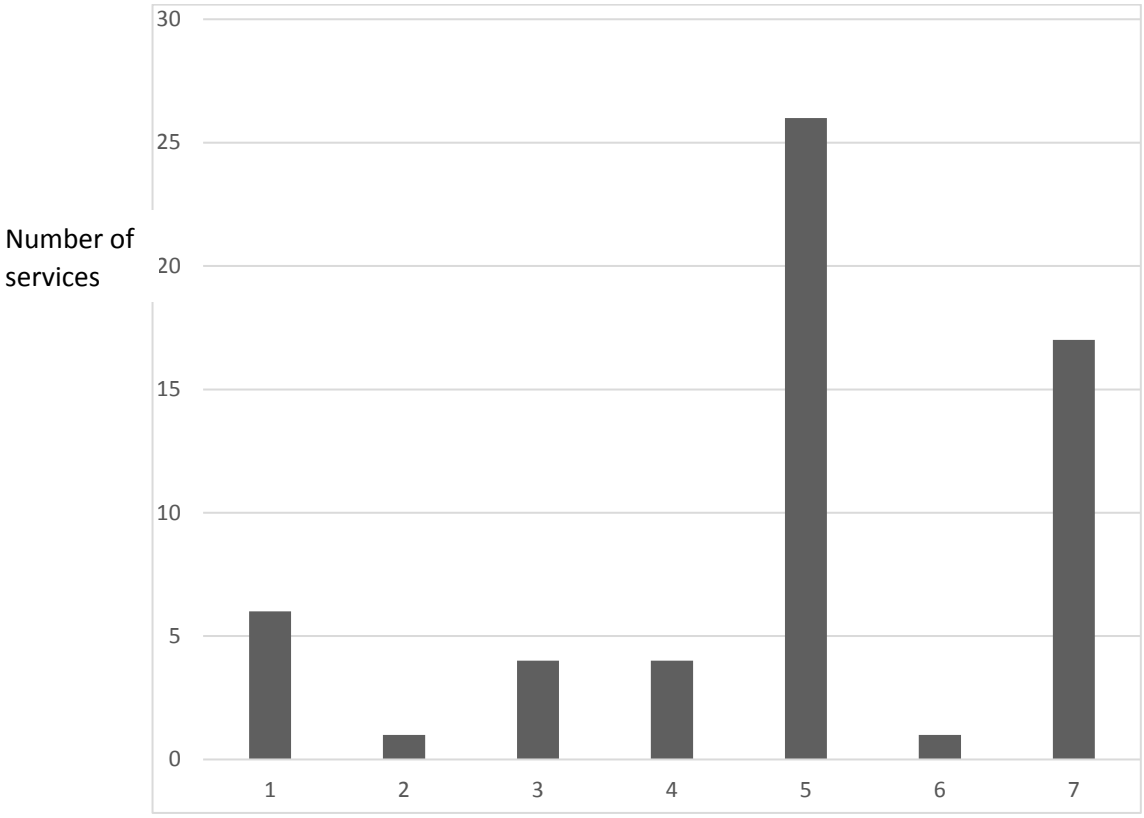
There was at least some representation from all Strategic Health Authority areas.

Organisation

Data have been reported in terms of the number of acute services described rather than the specific number of individual results obtained.

The range of service provision can be seen in Figure 7. Of the 59 services, only 17 offered daily TIA clinics seven days per week (29%). The majority of services 26/59 (44%) were able to offer a 'five days a week' service, with no provision at weekends. There were six services (10%) that only offered a TIA service once a week, and so would be unlikely to even achieve the median delay of three days reported in the 2010 Sentinel Audit (ISWP, 2010). A further nine services (15%) offered TIA clinics on between two and four days each week.

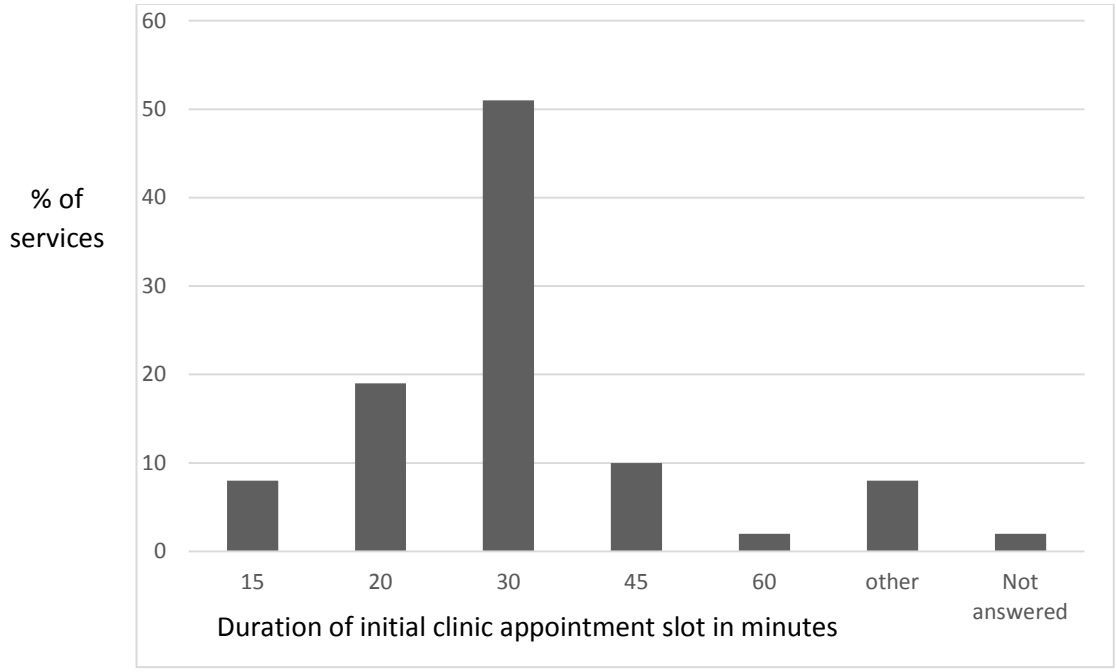
Figure 7 The range of TIA service provision



Duration of initial contact showed variation. The range and frequency of duration of initial clinic contacts can be seen in Figure 8. The most common duration of clinic appointment for initial contact was reported as 30 minutes. This was the case in 30/59 (51%) of services, followed by eleven (19%) services that offered 20-minute appointment slots. Six services (10%) allocated

45 minutes for the initial visit, whereas five services (8%) reported 15 minute appointments. The least common duration of clinic slot was 60 minutes and was reported in only one service (2%). Five services (8%) reported other models or durations for initial contact, and one service (2%) did not respond to this question. It is recognised that the duration of clinic 'slots' is only a proxy for actual appointment duration. Patients might in fact have a longer or shorter time with the clinician in practice.

Figure 8 The range and frequency of duration of initial clinic contacts

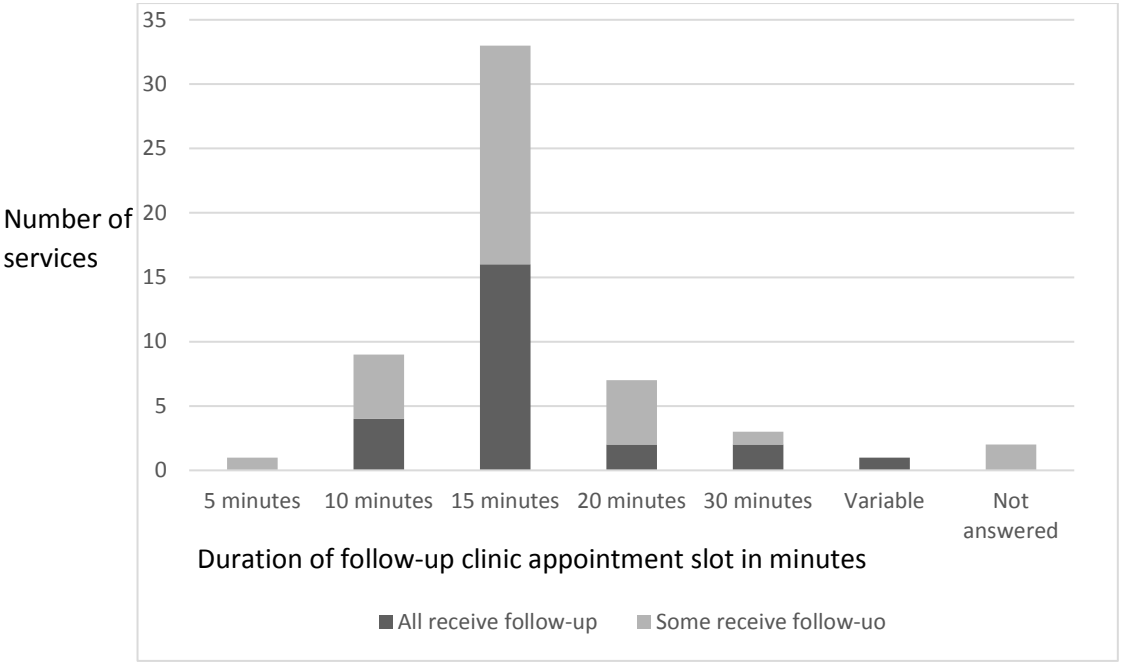


There were some free text responses relating to the duration of initial clinic contact. There were comments that the time slot might vary between clinicians e.g. The Specialist Registrar might have a 40-minute slot, but the consultant would have a 30-minute slot, in one case the patient was initially seen by an Advanced Nurse Practitioner for 40 minutes and later by a consultant for 30 minutes. Some services reported they would see the patient again later in the day with test results. A full list of free text responses can be found in Appendix B3. There were no free text responses that suggested the individual time allocation for clinic was too short or too long.

Duration of follow-up contact also varied between services. Figure 9 demonstrates the range and frequency of durations. There was little difference in the duration of follow-up slot between those services that always offer follow-up and those that only offer follow-up to some of their TIA patients. The most

common follow-up appointment slot was for 15 minutes and this was similar for the services that always offer follow-up 16/59 (27%) and the services that only offer some patients follow-up 17/59 (29%). One service (2%) offered five-minute slots, but didn't see all patients. Three services did not offer follow-up to any patients.

Figure 9 Duration of follow-up contact



There were some free text comments relating to duration of follow-up, which can be found in Appendix B4. Again, there were no free text responses that suggested the individual time allocation for follow-up was too short or too long.

Personnel

Most clinics were run more than once per week, so for that reason more than one individual was often involved in clinic provision. Across the 59 sites that responded, there were 194 professionals identified as participating in initial TIA clinics, and 122 personnel were involved in follow-up clinics. Only seven services appeared to be run by single consultants. Table 6 shows the staff groups and frequency of responses for initial and follow-up clinics. The participant completing the survey determined whether they classed themselves and their colleagues as generalists, had a 'special interest' or had received specialist training in stroke care. Special interest in the context of stroke care denotes a physician with stroke-specific skills, who is actively engaged in care

of stroke patients on a regular basis and is involved in stroke research or regularly attends at least annual stroke specific training or conferences.

The most common group of staff involved in initial visits were Elderly Care Consultants with specialist skills or a special interest (63%). Two other groups of staff commonly involved in both initial and follow-up clinics were specialist nurses (initial 56%, follow-up 41%) and stroke specialist registrars (initial 47%, follow-up 44%). Neurologists (39%) were also involved in initial TIA clinics, but few (19%) were involved in follow-up encounters. Follow-up clinics were staffed by a greater proportion of stroke specialist staff compared to initial visits. In one case (2%) the General Practitioner (GP) provided 4-week follow-up after TIA and in two services (3%) the patient was seen by a community stroke nurse.

There was a variety of free text responses relating to the staff involved in initial clinic provision. One comment was the lack of a stroke-specific consultant as an option, and this comment was received from four respondents. Three respondents wanted to identify vascular sonographers or technicians, and one reported that a clinical pharmacologist with an interest in stroke was involved in the initial contact. The full list of comments can be found in Appendix B5.

Table 6 The staff groups and frequency of responses within TIA services

	Initial clinic		Follow-up clinic
Number of responses	n = 59		n = 56
	General	**Specialist**	
Consultant – Elderly Care	12 (20%)	37 (63%)	43 (73%)
Consultant- General Physician	5 (8%)	7 (12%)	2 (3%)
Consultant – Neurology	6 (10%)	17 (29%)	11 (19%)
Consultant – Stroke	0	30 (51%)	7 (12%)
Consultant – Vascular Surgeon	2 (3%)	1 (2%)	0
Specialist Registrar – Stroke	0	28 (47%)	26 (44%)
Specialist Registrar - General	12 (20%)	0	0
Junior Doctor – Foundation Trainee	4 (7%)	0	3 (5%)
Stroke Nurse Specialist	3 (5%)	30 (51%)	24 (41%)
Clinic Nurse	0	0	3 (5%)
GP	0	0	1 (2%)
Community Stroke Nurse	0	0	2 (3%)

In many cases, more than one professional staff group were involved in initial and follow-up clinics, for this reason results are reported based on the 59 services, but the percentages for each group may add to more than 100%.

The clinical background of staff involved in TIA services appears to be similar between 2003 and 2011, with some variation reported in the survey published in 2007. The highest proportion of staff in each survey had their background in Elderly Care. There was approximately a 20% increase in input by Elderly Care Physicians in the results of the 2007 survey, compared with both 2003 and 2011. Both Stroke Specialist and Neurology Physicians are involved in TIA clinics. These two groups combined are greater than the proportion of Elderly Care Physicians in 2003 and 2011, but represented half the proportion of Elderly Care Physicians in 2007. Other consultants that contributed to TIA

services were General Medicine (approximately 10%), and Vascular Surgeons (less than 5%). This data is presented in Table 7.

Table 7 The background of consultant medical practitioners running TIA services

Consultant	Rodgers 2003	Beech 2007	Current findings 2011
	n = 93	n = 102	n = 117
Elderly Care	35 (38%)	64 (63%)	49 (42%)
Stroke	26 (28%)	22 (22%)	30 (26%)
Neurology	17 (18%)	9 (9%)	23 (20%)
General Medicine	10 (11%)	0	12 (10%)
Vascular Surgeon	4 (4%)	0	3 (3%)
Other	1 (1%)	6 (6%)	0

Activity

What was available at one-stop services?

Activity associated with initial clinic attendance was split into four main time-points for activity which can be seen in Table 8.

Table 8 Shows the reported activity at initial clinic attendance

Time points n = 59 **Activity**	**Prior to clinic**	**In clinic**	**Results available in clinic**	**Within 1 week of clinic**
Taking history	12 (20%)	55 (93%)	N/A	N/A
Physical examination	0	57 (97%)	N/A	N/A
Brain imaging	10 (17%)	30 (51%)	27 (46%)	16 (27%)
Carotid artery imaging	11 (19%)	39 (66%)	33 (56%)	10 (17%)
Blood Tests	0	41 (69%)	24 (41%)	11 (19%)
Blood pressure	14 (24%)	50 (85%)	50 (85%)	0
12-Lead ECG	10 (17%)	46 (78%)	46 (78%)	1 (2%)
Echocardiogram	2 (3%)	8 (14%)	3 (5%)	21 (36%)
24 Hour (+) Holter monitoring	1 (2%)	5 (8%)	N/A	26 (38%)
Give diagnosis	3 (5%)	52 (88%)	N/A	1 (2%)
Give prognosis	4 (7%)	53 (90%)	N/A	1 (2%)
Lifestyle advice	6 (10%)	53 (90%)	N/A	1 (2%)
Start antiplatelet	14 (24%)	50 (85%)	N/A	2 (3%)
Refer to Vascular Surgeon	3 (5%)	39 (66%)	N/A	17 (29%)
Consult with Vascular Team	1 (2%)	20 (34%)	N/A	26 (38%)

These are not mutually exclusive responses. Some sites have given more than one response which means that percentages are out of 59 services and therefore in some cases the percentages do not add up to 100%.

Services were mapped against current clinical guidelines (NICE, 2008). 27/59 (46%) sites offered brain imaging and results at first contact, 33/59 (56%) of sites could provide carotid artery imaging and results on the same day, and

31/59 (54%) of services performed and reported echocardiography within one week of first contact, as required by current clinical guidelines (NICE, 2008).

Less than half the sites had access to the results of blood tests whilst the patient was in clinic, which might impact on which medications were started in clinic. It would appear that not all services gave the patient a diagnosis or prognosis at the initial attendance. Free text responses gave some extra detail about what might occur at an initial consultation. Some services reported starting statins or anti-hypertensives. Also mentioned was giving advice about driving. Several responses reinforced the variability of presentation of TIA and the range of responses reflects this. A full list of the additional free text responses can be found in Appendix B6.

The planned comparison made between available data from the two previous surveys of BASP members relating to TIA service provision (Rodgers *et al.,* 2003; Beech *et al.,* 2007) and the data obtained in the current study (2011) can be seen in Table 9. Comparable data was not available for all parameters.

The proportion of patients who received their brain imaging in clinic or before increased at each audit, ranging from 24% (2003) to 68% (2011). The proportion of tests performed within a week increased in 2011 for brain imaging, carotid imaging and echocardiography, but this is likely to be due to patients needing to wait more than a week during previous audits, rather than access to imaging becoming worse.

Table 9 Comparison of TIA service provision between three surveys of BASP members

Investigation	Brain imaging			Carotid imaging			Echocardiography	
	Rodgers 2003	Beech 2007	Current findings 2011	Rodgers 2003	Beech 2007	Current findings 2011	Beech 2007	Current findings 2011
	n = 45	n = 78	n = 59	n = 44	n = 78	n = 59	n = 78	n = 59
Test performed in clinic or before	11 (24%)	26 (34%)	40 (68%)	18 (41%)	35 (45%)	50 (85%)	9 (12%)	10 (17%)
Results available in clinic			27 (45%)			33 (56%)		3 (5%)
Test performed within 1 week after clinic	7 (16%)	7 (9%)	16 (27%)	4 (9%)	5 (6%)	10 (17%)	1 (1%)	21 (36%)

Shaded boxes represent parameters where no data were available.

Follow-up characteristics

Less than half the services provided routine follow-up for all patients following TIA 24/59 (41%), but 30/59 (51%) reported they offered some patients a follow-up consultation. Where follow-up was offered, it was typically conducted in an out-patient clinic 48/59 (81%). However, 5/59 (8%) were seen in other locations e.g. the stroke ward, 4/59 (7%), their own homes and one patient each was seen in a community hospital day centre and a GP surgery, (2% each).

The content of the follow-up visits appeared similar where they were offered. See Table 10 for details of activities reported at follow-up contact.

Table 10 Activities occurring at follow-up contact

Activity	**Services offering follow-up to <u>all</u> patients with TIA**	**Services offering follow-up to <u>some</u> patients with TIA**
	n = 24	n = 30
Confirming diagnosis	21 (88%)	21 (70%)
Giving test results	22 (92%)	25 (83%)
Discussing prognosis	21 (88%)	21 (70%)
Modifying medication	23 (96%)	26 (87%)
Giving information	23 (96%)	24 (80%)
Lifestyle advice	23 (96%)	21 (70%)
Answering questions	24 (100%)	25 (83%)

Other activities identified included ordering any outstanding tests, referral to other teams e.g. vascular surgeons, neurology, haematology, cardiology and referral to a stroke group. See Appendix B7 for all free text responses.

Features of best practice

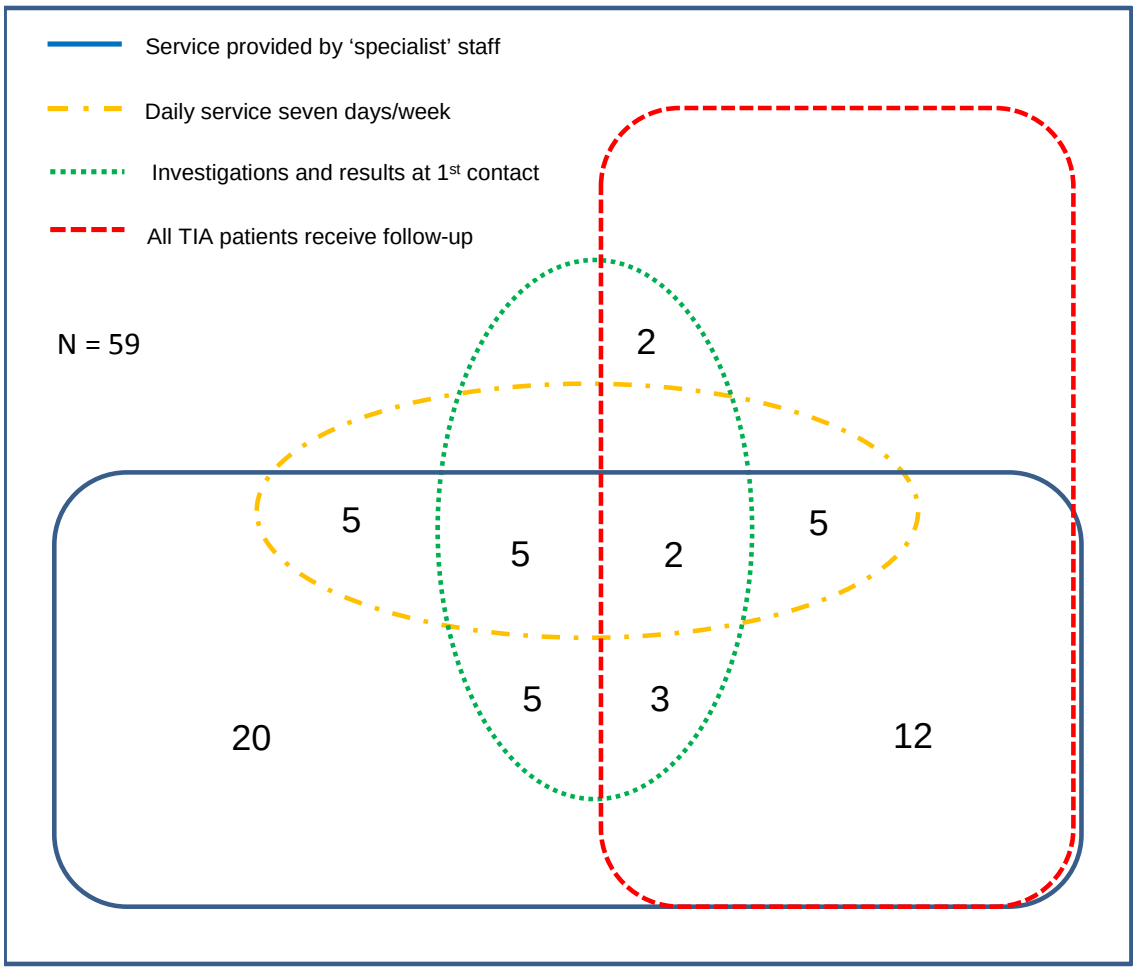
Table 11 shows the percentage of services that met each of the four key features of a best evidence-based practice service (page 52).

Table 11 The Four Key Features of Best Practice

Key Features of Best Practice	Sites That Have This Feature (%)
	n = 59
Seven days per week service	17 (29%)
Stroke Specialist clinical input	57 (97%)
Investigations and results available on the day of contact	17 (29%)
All TIA patients receive follow-up	24 (41%)

Figure 10 shows the distribution of key features of best practice. Only two services (3%) met all four key features of best practice. Two services did not have a consultant with a special interest, or specialist training in stroke or neurology, but both offered investigations and results at first clinical contact, although not seven days each week. Of the responses received, 13/59 (22%) offered three of the key features; 24/59 (41%) offered two of the key features, and 20/59 (34%) offered only one of the key features of a best practice service.

Figure 10 Venn diagram showing the numbers of services offering combinations of four key features of best (evidence-based) practice



Twenty of the services reported that they were run by stroke specialist staff, but did not meet any other feature of a 'best practice' service. Seventeen services were offering a seven-day service and a further 17 (not necessarily the same services) were able to obtain both investigations and results at first contact, thus enabling diagnosis and the initiation of treatment and referrals as appropriate. Twelve services offered follow-up for all TIA patients, and had specialist staff, but were unable to offer the other two elements of 'best practice', whereas only two services met all four key elements of best practice. The less common service configurations included those that met all four key features of a best practice service; Services where there was no secondary care (or formal primary care) follow-up; Services with a very brief (5 minute) medical follow-up; and Services with a long (30 minutes +) nurse-led follow-up.

4.6 Discussion

The main findings of the survey are that services have changed dramatically since the previous survey reported in 2007. Many more sites are now offering five or seven-day services, a greater proportion can access investigations and obtain the results of these on the same day, and only 5/59 (8%) services do not offer follow-up to any of their patients. Composition of the types of clinical staff providing services has remained similar across the three surveys.

Study limitations

The key limitation (for any survey) is that people's responses might not always match what happens in practice. This risk was minimised as far as possible in the study design by only asking for information that was expected to be readily available.

One of the major limitations of this survey was that whilst having BASP distribute the invitation to participate, thus providing a prestigious 'sponsor' (Murphy, 1993), BASP were unwilling to send any reminders to their membership, to protect members from multiple mailings and 'overloading members' inboxes' (personal communication). One of the evidence-based strategies for improving response rates is sending reminders (Asch, Jedriziewski & Grey, 1997; Edwards *et al.,* 2002; Edwards *et al.,* 2009; Sahlqvist *et al.,* 2011). Doctors are recognised as a hard-to-reach group, for surveys (Murphy, 1993; Asch *et al.,* 1997; Kellerman & Herold, 2001; Cook, *et al.,* 2009; Edwards *et al.,* 2009).

Due to the inability to review the BASP membership list, it was not possible to judge whether the group who participated was truly representative of the 213 acute NHS services offering TIA care. It was also impossible to determine whether there were in fact differences between responders and non-responders who received the invitation to participate. Another potential source of bias is the use of BASP to distribute the survey. It is possible that physicians who run stroke services and are not members of BASP may differ from those who are members. It is also possible that membership develops clusters, where a number of clinicians in a particular hospital or area are all members.

Within the questionnaire, clinicians were not specifically asked about whether patient needs were assessed, but a number of the elements included within follow-up activities could be seen as a marker for needs assessment, particularly answering questions, clarifying diagnosis, giving information and offering lifestyle advice.

It was essential that the questionnaire was easy to complete, with a view to optimising response rates. However, there can be many reasons for non-response: lack of time, lack of perceived relevance to participants, survey fatigue, and oversight (Aldridge & Levine, 2001). Strategies to improve response rates were considered. Pre-notification, reminders and follow-up were not permitted by BASP, which is unfortunate as they have been demonstrated to be effective in improving response rates (Bourque & Fielder, 1995; Bowling, 2002; Fink, 2009). No financial incentive was offered, although this has also been shown to have a positive effect (Aldridge & Levine, 2001; Fink, 2009).

Survey development

There was no pre-existing survey tool available for use, so it was necessary to develop a questionnaire that would address all the questions required, whilst being clear and concise (Bourque & Fielder, 1995; Fink, 2009).

During testing, there were some recommendations relating to the inclusion of questions relating to the timing of events such as time from onset to first contact; and timing of carotid endarterectomy. These questions raised interesting points, but the focus of the survey was on 'who, how and where' rather than on timings. Due to the need to keep the questionnaire short and focussed these questions were also not included. Finally, the annual number of patients seen was suggested but rejected as a survey question, due to a consensus that most clinicians are aware of annual stroke admission numbers but far fewer could give a reasonably accurate figure for TIA attendances.

Main survey subjects and sampling

The response to the survey was 73/645 (11.3%). However, not all of BASP members are stroke physicians, and it is possible that those who were not, were less likely to respond. In a study looking at clinician response rates in a similar survey of clinicians, up to a third of the distribution was to incorrect addresses

or ineligible subjects (Wiebe, Kaczorowski & MacKay, 2012). When looking at the proportion of responses in relation to acute hospital sites, the figure improves to 59/213 (28%) services, which is not dissimilar to other postal and email distributed surveys of physicians and other busy professionals (Scott *et al*., 2011). It is not clear whether there are BASP members working in every one of the 213 acute services identified in the Sentinel Stroke Audit report (ISWP, 2011). It could also be that where multiple members of a team received an invitation, in some teams, only one person responded, since the information should theoretically be the same for each team member reporting a single service.

The use of the internet for distribution and collection of survey data may reduce response rates by up to 11% (Manfreda *et al.,* 2008; Fan *et al.,* 2010). One possible mechanism for the lower response rate could be rapidly changing email addresses, referred to as 'churn' (Bandilla, *et al.,* 2012), and the risk that emails will be removed from the inbox by 'spam filters'. However, since the mailing was from BASP, a group to which recipients are paying members, these factors were thought less likely to have a detrimental impact on response rates.

Using BASP to distribute the questionnaire lent credibility and facilitated efficient targeted distribution to physicians who are recognised as having an interest in stroke. However, it was not possible to send a reminder, which may account for the lower level of response. There was some representation from all regions, and a relatively good response from Scotland. A lack of response was noted from South East England and Wales. A further difficulty arose due to multiple responses from individual sites (often reporting slight differences in service), which might have led to sites under-reporting progress towards best practice.

A further limitation could be that membership of BASP implies a keen interest in stroke. It is possible that the sites without a response were different to those from whom a response was received. Those sites where stroke is not seen as a priority, or the clinicians are less engaged with the professional stroke community generally, might be less progressive with service development. This suggests there is likely to be a degree of self-selection bias, and those clinicians

who believe that their service is high quality are more likely to respond than those who feel there are still major changes in service provision to be achieved.

Survey results

Organisational

When comparing the results of the current survey with those of the Sentinel Organisational Audits (ISWP, 2006; 2008; 2010), consideration should be given to the fact that Sentinel was specifically asking about speed of access and not necessarily the nature or quality of the contact. The Sentinel audits also report the proportion of patients being admitted to enable target requirements to be met, which the current study does not.

One feature that could be compared with Sentinel Audit results is access to carotid artery imaging. In the 2010 national audit only 20% of services could offer daily access to Duplex scanning or other carotid imaging, with results also available on the day of first attendance. Within this study cohort 21 sites (36%), reported that their patients can access clinics and carotid imaging every day of the week.

Daily TIA services were provided throughout the year to enable patients to access services within 24 hours in 17/59 (29%) sites. Weekday only services were provided by 26/59 (44%) of sites. There are still sites where TIA clinics continue to be provided on only one day per week 3/59 (5%). It is likely that those sites providing fewer TIA clinics per week are the ones where there is a single clinician providing the service. Unfortunately, this was not possible to confirm based on the data obtained.

Personnel

When data was analysed to look specifically at which groups of consultant clinicians are involved in TIA services, it could be seen that there has been little overall change during the past decade, see Table 7. One significant difference is the reduction in single-handed clinics, which appears to have fallen from 56% in 2003 (Rodgers *et al.,* 2003) to 12% in 2011. This is likely to be due to the requirement for very much more frequent clinics latterly, and an increase in the numbers of stroke physicians.

There are still generalist clinicians involved in TIA clinics. Although a minority, this is clearly not ideal. It is recognised that establishing a diagnosis of TIA is less than straight forward and requires a level of skill and experience, and even then, there are discrepancies in diagnosis (Kraaijeveld *et al.,* 1984; Koudstaal *et al.,* 1986; Koudstaal, Gerritsma & Van Gijn, 1989; Castle *et al*., 2010). Within the survey, respondents were asked which types of clinician were involved, but not how often each type ran clinics. It is likely that most TIA consultations are managed by stroke specialists, with support and cover from generalists, although this cannot be confirmed by the survey data. There were no initial clinics run solely by nurses. That is not to say that specialist nurses do not see patients at first attendance, but that they are part of a team including physicians or surgeons. It is unlikely that the sample population created a bias against reporting nurse-led initial consultations, since the BASP sample included associate members which also represents nurses.

Activity

The vast majority of services were able to give their patients a diagnosis on the initial visit 52/59 (88%), and 53/59 (90%) reported discussing prognosis. It is worrying to note that only 50/59 (85%) would start antiplatelet medication in clinic if it had not already been started by the clinician at first contact. This means that up to 15% of patients would not receive the treatment recommended in the NICE guidance 68 (DH, 2008). Lifestyle advice was also reported as an activity at initial contact in 50/59 sites (90%). Two thirds of clinics could refer patients to vascular surgeons during clinic in (39/59) of services, and one third (20/59) of clinics were reporting being able to have patients seen that same day.

Those services where TIA follow-ups were routinely provided demonstrated a more comprehensive approach to the activity. This included more consistently discussing results, diagnosis and prognosis, together with review and where necessary, modifying medication and promoting healthy lifestyle behaviours. Answering questions and giving information were more likely to occur when people were seen in services that routinely offer follow-up. Whilst all these activities were also carried out by those services that only followed up some of their patients after giving a TIA diagnosis, they were consistently less likely to

happen than at those site that always follow-up their patients. It might be suggested that the routine follow-up led to a more standardised and consistent approach and in those services where only selected patients received follow-up it was more individualised. However, there is insufficient evidence to support that argument. It seems unlikely that patients did not have their questions answered. However, the self-reported number of services that only follow-up some of their patients said that only 83% of patients would get their questions answered, as opposed to 100% in the services that always offer follow-up. This could be due to misinterpretation of the question, but is none the less surprising. There were no free text comments that explain this difference. Five sites offered no follow-up. So, in 30/54 (56%) of services patients may or may not get follow-up, and the quality of that follow-up in terms of the activities surveyed is likely to be less consistent than in services where all patients get follow-up.

This also suggests that patients may not get their needs assessed or met, since up to 20% may not be given information, up to 30% may not be given lifestyle advice and up to 17% might not have their questions answered. Whilst it is recognised that not all patients require all the elements outlined in the survey, it would be expected that they should be available if needed.

Key features of best practice

In the Beech *et al.,* survey (2007), the results showed that the majority of services were not meeting their targets of seeing patients within two weeks of symptom onset. It also showed that 70% of services had at least a one week delay for CT brain imaging and in 7% of services the delay could be as much as eight weeks. Carotid artery imaging was also subject to delay with 41% of services waiting more than 7 days for access. Only 13% of services could offer echocardiogram within 7 days of clinic attendance.

There is an improvement in TIA service provision between 2003 and 2011, reflecting the keen focus on TIA over the intervening 8 years, particularly since the publication of the National Audit Office Report (NAO, 2005) and the NSS (DH, 2007). Only 2/59 (3%) of services in the current study were offering a ‘best practice’ service, especially since there was a self-selected group of responses, from clinicians sufficiently interested in stroke to take up membership of BASP. It could be argued that non-responders’ services are

likely to be worse. It is probable that a true seven-day service culture within the NHS will be needed to meet best practice. This will enable the generally available comprehensive five-day service to expand to offer equitable access across all days of the week. However, seven-day service is currently a highly controversial topic, with hospitals being asked to provide a seven-day service within existing resources (DH, 2015). Detractors argue that the most likely outcome will be a dilution of weekday services if additional staff are not employed. In that case, staff working at the weekends will need time off during the week, thus reducing week day capacity (British Medical Association [BMA], 2013).

Identification of distinct service models

One of the aims of this study was to identify a range of distinct service delivery models. In this respect, the survey has fulfilled its purpose and a variety of models have been described.

The most common service was offered 5 days per week, with 30-minute new patient slots. Some (but not all) results of investigations were available on the same day, only some TIA patients were offered a 15-minute follow-up slot. The lead clinician was most likely to be an Elderly Care Consultant with a Special Interest in stroke, the personnel involved in follow-up was varied and included consultant physicians, junior doctors and specialist nursing staff. Some services were provided by non-stroke-specialists. It would be interesting to investigate in greater detail whether the content or approach was different between specialist and non-specialist services. The other distinctions of interest were related to follow-up. Five services offered no follow-up at all after TIA diagnosis. One service offered some TIA patients a five-minute follow-up with the consultant physician during which medication might be modified, questions answered and lifestyle advice provided. At the other end of the follow-up spectrum were services that offered 30-minute follow-up slots with a specialist nurse to all patients with a diagnosis of TIA. These encounters were reported to cover all elements of follow-up suggested in the survey and referral to other teams and stroke groups.

Services were, however, evolving rapidly at the time, and sampling at any of the distinctive 'atypical' services did not prove feasible as there had been further service developments since the survey was completed.

4.7 Conclusion

Implications for practice

TIA services have become more readily and speedily available over the last decade. However, there is still wide variation in the experience patients can expect to receive in terms of access to investigations whilst in clinic and both the provision and content of follow-up services. Standardisation of services and genuine 7-day operation are desirable goals but the progress towards this demonstrates the difficulties of achieving consistent services.

Implications for this research

It had been hoped that this study would lead on to an exploration of the variety of service models in subsequent studies, but the landscape within TIA service provision was very fluid at that time (2011), and when approaching services to sample their service models, a number of them had developed their services to the point that the elements of difference and interest were no longer characteristics of the service.

4.8 Summary

Phase 1 has comprised a national survey of TIA service configuration at the start of the programme of research. The survey was conducted with a view to identifying models for further investigation and developing an understanding of what occurs at initial and follow-up clinic attendances. It has shown that just under 90% of patients receive a diagnosis at their initial visit, with 97% of eligible patients receiving antiplatelet medication and 90% being given lifestyle advice. Most services offer at least some patients a follow-up appointment 54/56 (96%). Three sites did not respond to this question. Although only 24/56 (43%) offer all patients with a TIA diagnosis a follow-up visit.

The ongoing changes in service provision at the time of the survey and subsequently, prevented the original plan of sampling a variety of service delivery models. The plan was to investigate the impacts of various service

provision on patients' experiences and needs. This was modified to enable a greater focus on TIA follow-up experiences and after-care.

The survey of TIA service provision has addressed the first step, "*ascertaining current status*", in Lee's model of needs assessment (Lee *et al.,* 2007b). Steps two three and four of the model involve looking in more detail at what might constitute the '*ideal state*', '*quantifying gaps between ideal and actual*' and identifying '*causes of discrepancy*'. These steps form Phase 2 of the research.

One of the key features of 'best practice' explored in the survey was the provision of follow-up, which has not received much attention until now. The variation in the provision and quality of follow-up suggests that in some cases patients' needs are being partially addressed in relation to information and support to reduce their risks of further cerebrovascular events, but there were no explicit reports of assessing needs. Nurses are often given the task of managing many aspects of patient counselling and support, e.g. lifestyle interventions, and for that reason it was felt that asking nurses and allied health professionals regarding their experiences of people's needs following TIA might help to understand those needs.

A structured approach was needed to help standardise the early investigations in Phase 2 of the research. A comprehensive stroke survivor needs survey information mapping exercise (French *et al*., 2008) previously commissioned by the Stroke Association, has been used as the initial structure to assess needs following TIA. This structure has been used with nurses' and allied healthcare professionals', patients and carers using a mixed methods approach. This forms Phase 2 of the research.

5. PHASE 2: STAFF, PATIENTS' AND CARERS' VIEWS ABOUT NEEDS FOLLOWING TIA BASED ON NEEDS IDENTIFIED FOLLOWING STROKE

5.1 Background

Phase 1 explored the type of intervention available to patients following TIA in Britain. It demonstrated the variability of both follow-up provision and content. Services designed by staff who assume that needs following TIA will only be based on secondary prevention and medication may not recognise and address the true needs of patients, due to a paucity of evidence relating to needs in this patient group. Those services identified in Phase 1 as offering routine follow-up after TIA appeared to offer a more comprehensive intervention. Chapter Five presents Phase 2 of the research programme and is an exploration of people's perspectives of need following TIA. The groups include staff, patients and carers, and will identify mis-matches between these groups in terms of perceived need. Finally, in Phase 2, a draft model of needs following TIA will be developed.

Aims of Phase 2

Phase 2 comprises a series of inter-linked sub-studies. The overall aim was:

- To develop an evidence-based draft model of needs following TIA, by exploring the perceptions of patients, staff and carers.

Objectives of the study

- To determine which of the needs previously identified in stroke patients in the Stroke Needs Mapping (SNM) (French *et al*., 2008), were also thought by staff and researchers to be relevant or important to patients following TIA, and to elicit any other potential needs unique to TIA. (2a).
- To ask patients and carers who have experience of TIA to determine which of the stroke needs if any, were felt to be relevant to them and to explore whether there were other needs that they had experienced that were not to be found in the SNM. (2b).
- To explore the differences (mis-match) between the perceived needs identified by patients who have experienced a TIA, and those of the staff who care for or support them. (2c).

- To consider how needs following TIA might be presented as a model by synthesis of the findings of Phase 2.

Phase 2 study conduct overview

Within Phase 2 there are three sub-studies, which were conducted sequentially. Phase 2 is a mixed methods phase. Table 12 shows the methods used in each sub-phase.

Table 12 Flow diagram showing the components of Phase Two

Phase 2 →		
2a	**2b**	**2c**
Survey of nurses and other healthcare staff	Interviews and Focus groups with patients	Interviews with professionals regularly involved with TIA
	Questionnaire with carers	

This phase of the research is based on the premise that stroke and TIA are both on a continuum of cerebrovascular disease. On that basis, it is not unreasonable to expect that there might be needs in common between the two conditions. Phase 2 links to steps two, three and four of Lee's framework of needs analysis.

5.2 Methods

Phase 2a Survey of nurses and other healthcare staff

A survey method was selected for Phase 2a to enable the collection of a range of responses from staff over a wide geographical area, in a relatively short time and at minimum cost (Jackson & Furnham, 2000; Fink, 2009). One disadvantage of using the SNM was that the needs identified within the document were based on the views of stroke survivors, who often have continuing physical, cognitive or communication difficulties. According to the definition of TIA as a transitory event these should not be ongoing physical or cognitive issues for people following TIA. Having made the decision to use the SNM as the basis for this enquiry, it did not seem reasonable to make *a priori*

judgements as to which elements should remain and which should be excluded. Since it was not possible to predict the stroke needs that staff might feel were relevant after TIA, they were all included. In addition, it was expected that staff might also identify some potentially unique needs in relation to TIA.

There was no pre-existing survey that could be used to collect the required data, so a new survey tool was created. The survey used a predominantly quantitative approach. A questionnaire used a range of questions with a multiple-choice structure. There was a free text section to record any other views participants wished to share. It was felt that the comprehensive nature of the list of stroke needs was likely to cover many of the needs experienced following TIA. However, staff were also asked to identify any needs they felt might be experienced that had not been covered in the SNM. These needs would potentially be unique to TIA.

The questionnaire was anonymous with no information about name or specific place of work requested. Participants were asked to provide minimal biographical detail relating to their professional role and frequency of contact with patients following TIA. This was done to encourage completion and honesty of responses (Moser & Kalton, 1979; Fink, 2009).

Each element of the SNM was listed as it appeared in the original report (French *et al.,* 2008, page 21). For each individual element, the participant was asked to judge whether the need was 'definitely relevant', 'may be relevant' or was 'not relevant' to people following TIA. A three-part ordinal scale design was selected to encourage completion (Fink, 2009), reducing the time taken to complete the questionnaire (Aldridge & Levine, 2001). Another benefit of multiple choice questions is that it makes the data easier to both answer and analyse (Jackson & Furnham, 2000). The end of the questionnaire incorporated a free text box which allowed participants to add any further information they might choose to add. It was anticipated that any needs identified as TIA only would be found within the free text section.

The survey was conducted predominantly using on-line data collection via SurveyMonkey™ although some participants were contacted by post. A copy of

the final questionnaire and supporting documentation can be found in Appendix C1.

Pre-testing of the proposed questionnaire was conducted to ensure the tool would be fit for purpose. Pre-testing fell into two parts. Part one investigated the content of the questionnaire and part two investigated the acceptability of the electronic format. The pre-test panel comprised four stroke nurses, a therapist and a research nurse.

Main survey

When considering how to access staff who were likely to have contact with people following TIA, it was felt that since the focus was on post-TIA needs rather than medical management, nursing staff might be better placed to respond. Based on the results of the national survey reported in Chapter 4, follow-up was more frequently provided in services with specialist nursing input. For that reason, it was decided to access staff via stroke nursing conferences and stroke nursing fora. It was recognised that recruiting at conferences would potentially give rise to participants other than nurses, but their attendance at a nursing conference was thought to indicate interest in stroke and participation would suggest that they wished to share their views. For this reason, the participants are referred to as healthcare staff (with an interest in stroke), reflecting the anticipated range of participants. However, due to the methods of recruitment, the expectation was that the majority of participants would be nurses.

Setting

The survey was conducted at a stroke nursing conference held in a hospital in the Northwest of England on 29th September 2011 (76 delegates) and was also available at a regional stroke conference in the South of England on 18th November 2011 (60 delegates). On both occasions, all delegates at the conference were invited to participate. Following the conferences, the link to the questionnaire was more widely distributed by the National Stroke Nursing Forum (NSNF) to their members (190 members). The Scottish Stroke Nurses Forum (SSNF) provided their membership list for the researcher to contact

members directly (180 members). The members of the stroke fora were contacted during March and April 2012.

Sampling

As part of the introduction and 'housekeeping' instruction at both conferences, it was announced that there was an opportunity to participate in the research whilst attending the conference. Delegates were encouraged to visit the stand set up in the area where refreshments were provided. On the stand were copies of the participant information sheet and three computer terminals, linked to the on-line questionnaire via the internet.

A second sampling method was to send the questionnaire via email or post to members of NSNF and SSNF. The NSNF was contacted and agreed to send their members a copy of the questionnaire, while the SSNF provided their membership list to enable direct mailing. Not all members of the SSNF had an email address available, in which case, those members received a mailed paper copy of the questionnaire, together with a pre-paid return envelope. Between 1st and 31st March 2012, the NSNF contacted 190 of their members by email inviting them to participate. At the same time 98 members of the SSNF were also contacted by email. A further 24 members of the SSNF were contacted by post, enclosing the questionnaire and a stamped addressed envelope (SAE). A single email reminder was sent two weeks after the initial mailing for those members who provided an email address. No reminder was sent to those SSNF members who received the questionnaire by post, for logistical reasons.

Completion of the questionnaire was mainly via a web-based tool. This had the benefit of combining response with data entry. Those responses which were paper-based were added to the web-based tool by the researcher. The quality of data entry was checked by review of 10% of data with no errors.

Ethical issues

Approval for Phase 2a was obtained from the University of Central Lancashire (UCLAN) Ethics Committee (FHEC 523, granted 22nd August 2011). The questionnaire was not distributed via NHS work places, so neither NHS Research Ethics Committee (NRES) nor NHS Research and Development approval were required. The participants were all adults and healthcare

professionals, who could be presumed to have capacity to participate. People could decide for themselves whether they chose to contribute. If they decided to participate their response was taken as tacit consent, so no formal consent process was required.

Phase 2b – Patients' and carers' views

This phase was designed to determine which of the stroke needs if any, were felt to be relevant to patients and carers and to explore whether there were other needs that they had experienced that were not to be found in the SNM.

Setting

Participants were drawn from two pools of patients, from both the Northwest (site one) and Southwest of England (site two), which was the work-place of the researcher. Patients from the Northwest did not receive follow-up, whereas patients in the Southwest were all offered a follow-up appointment at four weeks after their TIA.

Participants / sampling

For this study, patients were included if they had been told they had experienced a TIA, and if the diagnosis was documented in their medical records. For pragmatic reasons, the definition of TIA used was the older WHO clinical definition based on duration of focal neurological symptoms (WHO, 1975), rather than the newer tissue-based definitions (Ay *et al*., 2009; Easton *et al*., 2009).

It was necessary, to ensure that only suitable participants were contacted. Therefore, a set of screening criteria were developed:

- Did the patient have a documented diagnosis of TIA? (yes).
- Is the patient still alive (retrospective invites only)? (yes).

If the response to the first two questions was yes, then further data was collected:

- Is there evidence of a pre-existing therapeutic relationship with the researcher? (no).
- Is there evidence the patient has not had a completed stroke since TIA diagnosis? (no).

- Is there evidence the patient has not had a formal diagnosis of dementia or terminal illness? (no).
- Is there evidence the patient does not have a documented communication problem? (e.g. severe deafness, language problems), (no).

If the answer to all the questions was no, then the patient was considered eligible to be invited to participate. Patients were either given information, including an invitation to participate in the research prospectively, whilst in clinic as a new patient with a diagnosis of TIA, or received the information and invitation by post retrospectively. Recruitment started in January 2012 and continued intermittently until April 2014. Participants were either invited to attend a focus group or individual semi-structured interview.

Ethical issues

Patients were initially recruited via a hospital in the Northwest of England. It was necessary to obtain NHS NRES approval. An ethics submission was approved on 5th January 2012, Research Ethics Committee (REC) No. 11/NW/0820. The original ethics application was for focus groups only. An amendment to the ethics application was submitted, to enable further contact with those patients who had already been invited to participate in a focus group, offering the opportunity to participate in individual interviews. This was approved on 14th March 2012. Due to slow recruitment, subsequently a second research site was opened in the Southwest of England to improve recruitment. This required local NHS Research and Development approval.

Study conduct

The researcher assisted with participant eligibility screening for those patients approached retrospectively by post. Screening was in collaboration with the Stroke Nurse Practitioner, under the supervision of the local investigator (Consultant Physician) and adhering to the appropriate checks and permissions (letter or access and research passport etc.). Initial identification of potential participants contacted by post was via the TIA database held at the hospital situated in the Southwest of England. Medical records were screened using the screening criteria. This was done by the local investigator with the assistance of the researcher. Those patients who met the study criteria received a written

invitation to participate. Stationery and mailing costs were covered by the researcher. If potential participants had any questions, they were encouraged to contact the researcher by telephone, who would then call them back, to minimise the cost of the telephone call.

The researcher is part of the clinical team at the Hospital in the Southwest. It was considered preferable that the researcher did not develop a therapeutic relationship with patients who were subsequently invited to participate in the research. Patients did not attend a healthcare consultation with the researcher either prior to, or following their invitation to participate in the research. However, their invitation to participate would not have prevented them from receiving emergency care from the researcher, should this have been necessary. If this occurred after recruitment, but before the research occurred, the participant would have been offered the opportunity to withdraw from the study. If data had already been collected from the patient during a focus group, it would not be possible to isolate and remove an individual's contribution.

Ground rules of confidentiality and respect were discussed at the start of each focus group, although due to the nature of focus groups, complete anonymity could not be guaranteed. The focus groups were audio-recorded and specific consent was sought for this. The recordings were kept in a locked cupboard until they could be transcribed, at the earliest possible opportunity. Once transcription was checked against the recordings, and identified as being correct, the audio recordings on tape were destroyed; the electronic recording was retained for initial analysis and destroyed as soon as possible.

Transcription of audio recordings and any other electronic data were stored on the S:/ Drive of the Hospital mainframe computer, in accordance with local Research and Development Department requirements and on UCLAN mainframe computer. Data files were password protected and available only to the research team, via UCLAN computer system. All written records were scanned and stored electronically. The original documents were then securely shredded.

Written consent was required from all participants prior to involvement in the research. Consent was taken at the start of the interview or focus group by the

researcher following the principles of Good Clinical Practice (GCP). There were always at least two facilitators (one being the researcher) in each focus group, to provide additional support for any participant who needed it or wished to withdraw from the group (temporarily or altogether), although this did not occur.

An ethics submission was completed for focus groups via Integrated Research Application System (IRAS) and was reviewed and approved on 13th January 2014, NRES No. 13/SC/0951. Local Research and Development and University approvals were also obtained.

Interviews

Interviews were conducted between October 2012 and July 2013. Potential participants contacted the researcher by post, telephone or email, to express interest in participating in the research. A mutually convenient appointment was made for a meeting, either in the participant's home or at their local hospital. Prior to commencing the interviews, the research was discussed, and any outstanding questions answered. Each interview was expected to last no more than 90 minutes, and was audio-recorded to enable verbatim transcription as soon as possible following the interview.

Initially the interviews were quite structured, including an initial section where patients were asked to perform a card sort using cards with the various elements of the SNM identified and determining whether the needs were relevant, might be relevant or were not relevant to their experience of TIA. As the interviews progressed, it was felt that the focus was too heavily aimed at the stroke needs, so in later interviews the process was modified. Following a discussion about the experience of TIA and perceived needs, the researcher then identified the SNM cards that appeared relevant to the individual. Understanding was checked with the participant, before offering the full set of 'stroke need' cards in a random order to the participant to see whether there were any other issues or elements they felt should be included. This made the interviews flow better as a dialogue, but ensured that all elements of the SNM were still considered. It also had the added advantages of demonstrating active listening, which is an important skill in interviewing (Lang, Floyd & Beine, 2000; Fassaert *et al.,* 2007; Rubin & Rubin, 2012), and providing initial respondent

validation of the researcher's interpretation. Interview guides can be found in Appendix C2.

Focus groups

Focus groups were conducted on 24th March 2012 and 21st May 2014. On arrival, the researcher gave all participants an opportunity to ask any further questions and answer any queries. Participants were reminded that the groups would be audio-recorded. If they were satisfied with the information they were given and still willing to participate, they were informally assessed for capacity to give consent and asked to sign a consent form prior to participating in the focus group.

Informal assessment of capacity to give consent was conducted over the phone by the researcher, whilst discussing the research. If the patient appeared to understand what would happen at the focus group and could relay the information back to the researcher, it was assumed that they had sufficient capacity to give consent to participate. Whilst it is recognised that this is an assumption, it was a pragmatic way of reducing the likelihood of a potential participant arriving at the focus group with significant cognitive impairment. Participants were informed that they could withdraw at any time without needing to give a reason.

Each group started with a welcome and a brief overview of the programme of research. Then participants were introduced to the group. Ground rules were established, such as confidentiality, respect for other people's views, the need to have only one conversation within the group, and the aim of getting the group talking to each other, rather than answering questions. A list of ground rules were developed by the researcher, who read them out at the start of the group and invited discussion or any other suggestions from the participants.

Each member was asked to introduce another participant at the beginning to ensure everyone spoke early in the session (Krueger & Casey, 2009). Focus group participants were given material to start the discussion. Two facilitators (one of whom was the researcher) were present to ensure everyone was able to express their opinions within the group and that the discussion flowed.

The first focus group had two participants and the aim of this group was based on the needs identified in the SNM. Participants were asked to rank needs collectively, thus prompting discussion about the stroke needs identified as being relevant following TIA. Focus group template can be found in Appendix C3.

Two further focus groups, comprising of four members and lasting two hours each, were conducted and analysed sequentially (Krueger & Casey, 2009). Groups were held at the local hospital in the Southwest of England.

The main part of the focus group sessions conducted in May 2014, were based on needs previously identified within the SNM and by people who had experienced TIA. Each need was discussed, looking for agreement and outlying views and opinions (Krueger & Casey, 2009). Participants were also asked to comment on the importance of each need and how it could be met. At the end of the discussion the information gathered was summarised, to ensure clarity and probe for misunderstanding, consensus and outlying views. This also helped to ensure the researcher's interpretation was correct, and enabled clarification where necessary (Krueger & Casey, 2009). Finally, the group was invited to add any other needs they experienced following their TIA, which they did not feel had been identified by the more structured discussion.

A question template was used for the two focus groups conducted in May 2014, to ensure consistency in how the groups were run, and to facilitate data synthesis. The template included questions to ensure everyone spoke early in the group, since this has previously been found to improve inclusion within the group (Krueger & Casey, 2009). The key questions were asking whether the needs previously identified following stroke and TIA seemed reasonable, and whether there were any additional needs that could be included. The groups were asked to identify their "top five" needs from any of those presented in the material, and to make suggestions about how the needs might be met. Finally, the participants were asked for any thoughts or views that had not been covered elsewhere.

Where the focus group had caused a participant to have further questions or concerns about their own health or treatment they were asked to consult their

own GP. A list of local and national resources for stroke and TIA survivors was available for all participants at the end of the focus group. Following each group, the researchers discussed and reflected on the focus group and facilitation process. This reflection was audio-recorded, transcribed and included in the analysis of each group.

Carers

In addition to asking staff and patients their views about needs following TIA, a small number of carers were also invited to give their opinions. A modified version of the questionnaire used with nurses and other staff was given to the carers to standardise the approach. This enabled comparison between the views of carers and staff.

Setting & sampling

Carers were recruited via potential participants who had attended a TIA clinic in the Southwest of England. Typically, patients received follow-up contact from the stroke services following TIA. Recruitment was conducted via the person who had experienced a TIA. This decision was made in recognition that the formal next of kin may not be the person who offered the support. For that reason, the individual who had experienced a TIA was best placed to identify the most appropriate person to be approached for the research.

Patients who were invited to participate in a focus group or interview, were also asked if they could identify someone who had helped them physically, emotionally or practically. If such a person existed, the patient was asked to forward an invitation for the 'carers' to participate in a separate study looking at 'carer' views of need following TIA.

Study conduct

Initial biographical questions were altered to collect age range, gender, relationship to the person who had experienced a TIA, and a self-rated report of general health. The body of the questionnaire remained the same as previously, with minor changes to some elements to make them more understandable for lay people. This was done in line with the changes made for the card sort exercise. After the core questions relating to the seven domains, further questions were included to elicit views about what could have been done

differently in relation to the hospital / clinic experience, and primary care experience. Participants were also asked whether anyone or anything made things easier following diagnosis. Finally, participants were asked whether there were any comments they had which had not been covered elsewhere. A copy of the 'carers' questionnaire can be found in Appendix C4.

This study ran from February 2012 to May 2014. People who accompanied participants to a focus group and were willing to participate in the 'carers' questionnaire, were given this in a separate room from the focus group or interview. Copies of the questionnaire were available at each interview, for the carer to complete and either hand back or mail back to the researcher. There was no personally identifiable data collected within the survey, only age range and relationship to the patient.

Since carers were approached via participants contacted via an NHS organisation, NRES and local Research and Development approvals were required prior to commencing this research. This was in addition to the University Ethics Committee approval which was the sole requirement for the previous surveys.

Phase 2c – Professional interviews

The focus of Phase 2c was to explore the differences (mis-match) between the perceived needs identified by patients who have experienced a TIA, and those of the staff who care for or support them. The method used to gain an in-depth understanding of professional views was semi-structured interviews. This allowed exploration of specific areas of experience (Barriball & White, 1994; Carruthers, 1990). The structuring of the interview enabled common threads to be identified across interviews, which facilitated the analysis of the data in real-time, as data were collected, thus informing later interviews.

Setting

Professionals were drawn from those who had expressed an interest in participating at a regional stroke conference, or who had been recommended to the researcher during the course of the study. Most professionals were from the South Coast or Southwest of England. One participant was from the Home

Counties, and had attended the conference, where she had expressed an interest in participating in the study.

Participants / sampling

This study was designed specifically to interview professionals who have regular contact with people who have experienced TIA.

Inclusion criteria

- Aged 18 or above.
- Willing to participate.
- Offer support or services to people following TIA in a professional capacity.
- Offer support or services to people following TIA as part of a charitable or community organisation.

Exclusion criteria

- Supported a friend or family member following TIA, outside their role of professional or member of a recognised local support group.

Initial participants were a hospital consultant who regularly sees patients immediately following TIA, a specialist nurse in secondary care who regularly sees patients at follow-up and a community practitioner, who supports people with stroke and TIA in the community, all based in the Southwest. Further interview participants were determined by their recommendations. A modified snowball sampling technique was used to identify and contact potential participants. This was done to reduce researcher bias in determining which professionals were approached. It also enabled a wider range of personnel to be contacted. Potential participants were purposively selected to give a rich range of views and experiences. Snowball sampling is usually used in hard to reach groups (Faugier & Sargeant, 1997; Atkinson & Flint, 2001; Sadler *et al.,* 2010). In this case, it was used to make best use of the expertise of the participants, and to ensure that groups, or roles unknown to the researcher, where possible, were not missed. Interviews were conducted between June and September 2014.

Certain professional groups had been highlighted as being potential targets for interviews following earlier research. These included an optician, a GP and a paramedic. Potential participants were contacted by either letter or email. If no response was received after two weeks a second contact was made via email or letter, since the potential participants were all busy professionals who might have overlooked the first contact. No further attempt to contact an individual was made if there was no response to the reminder.

Study conduct

Professionals were asked to consider the needs identified by the previous sub-studies. An initial interview schedule was produced. Core questions included a description of the professional's involvement with people following TIA; their views on the needs identified by the focus group, based on the SNM (French *et al*., 2008). As the interviews progressed the interview schedule was modified (Appendix C5). This is in keeping with qualitative interview methods, where data are reviewed during the data collection process and influence subsequent data collection (Charmaz, 2006; King & Horrocks, 2010).

All professionals interviewed were provided with the most recent summary Venn diagram and table, representing the combined views obtained in earlier studies within the program of research (Table 26, page 139; Figure 14, page 140). Permission for interviews with staff was obtained via UCLAN Ethics Committee.

Interviews were conducted either in person, or via telephone. Face to face interviews took place at the local hospital, the place of work or home of the participant, whichever was most convenient to the participant. Local Trust lone-working processes were followed by the researcher in all cases.

The researcher gave all participants an opportunity to ask any further questions and answer any queries prior to the interview commencing. Written consent was required from all participants prior to involvement in research. Consent was taken prior to the interview by the researcher following the principles of GCP. If the interview was not face to face, participants were asked to sign a consent form prior to participating and send it back to the researcher. A scanned electronic copy of signed consent was considered sufficient to enable the interview to commence, but an original signed copy was required for the

local site file. Participants were told they may withdraw at any time without needing to give a reason.

Audio-recordings were stored in a double locked brief case in transit, and in a locked drawer in a locked room until transcription was completed at the earliest possible opportunity. Audio-recordings were written up and original tape recordings destroyed. All data was stored with no personal identifiers (just a participant number) in secure electronic storage at UCLAN and at the local Hospital NHS Trust. Any paper based information generated during the group was scanned and saved electronically. Electronic data is password protected and stored on the University's mainframe computer. Access to any data is restricted to the research team only and no information that could identify the participant was made public.

5.3 Analysis

Data collected in Phase 2a was entered onto a web-based survey tool and downloaded into Excel where it was analysed using simple descriptive statistics. No formal statistical analysis was performed. When reviewing the responses to each domain of the SNM it could be considered that a 'yes' response and a 'no' response indicated certainty in the view of the respondent, whereas a 'maybe' response would indicate uncertainty regarding the relevance of an element of the SNM to someone following TIA. The findings were collated electronically and used to develop a comprehensive list of potential needs following TIA.

Quantitative data were summarised in a Venn diagram. In creating the Venn diagram, responses were placed in the 'definitely relevant' sector if the majority response was 'yes'. The 'might be relevant' intersection was used if the majority of responses was 'maybe', and the 'not relevant' sector if the majority response was 'no'. Where responses were split equally between 'relevant' and 'not relevant', the element was placed in the 'maybe' intersection. Where there were only two types of response, the majority determined the position in the Venn diagram. However, when two responses were equally represented then the item was positioned in the more 'positive response' (e.g. if the response was split 50/50 between 'yes' and 'maybe', the item would be placed in the 'relevant' sector, rather than the 'might be relevant' intersection). Free text responses

were also examined looking for any trends or themes. Because one of the objectives of the study was to develop a comprehensive list of needs, when reporting findings for the various domains, both 'relevant' and 'might be relevant' responses were considered as positive needs.

Data collected in Phase 2b & c. Audio-recordings of interviews from both patients and professionals were transcribed verbatim. To provide some standardisation the interviews were semi-structured in nature, allowing the exploration of similarities and differences between the reported needs identified by professionals and patients. Each participant was assigned a unique identifier to anonymise the transcribed data. The transcripts were entered into Atlas.ti™ software to facilitate qualitative analysis. Atlas.ti™ enabled easy manipulation of data, codes and themes (Friese, 2012). Atlas.ti™ is a computer system that supports data analysis. Coding was done manually and the program assists with organising, retrieving raw data and combining codes and themes from a range of data sources (Friese, 2012). The software allowed easy cross referencing between transcripts which helped to identify and clarify concepts within the data.

Coding and theme identification was performed by the researcher, who immersed herself in the data, by means of repeated listening to the recordings whilst reading the transcripts. Using an iterative approach to analysis, concepts and themes were identified. Verbatim transcripts of interviews were coded on a line by line basis, to identify the meaning of the discussion (Friese, 2012). Transcripts and initial open coding decisions were repeatedly reviewed by the researcher. A sample was also reviewed by one of the supervisory team to ensure consistency and to minimise bias.

The SNM cards were presented to the participants in a random order, although as the interview guide changed, the items thought to be relevant were presented first to participants, followed by all other cards in a random order. The SNM was also used as a framework for data extraction. Card sort data was collected from the transcripts manually using tally charts based on the SNM headings.

Focus group audio-recordings were transcribed in full. Transcriptions were reviewed for errors and to understand the dynamics of the group, (e.g. laughter, pauses, tone of voice). Theme identification was performed by the researcher, in a similar manner to that used with interviews. Using a key concepts framework classic approach to analysis, units of meaning and themes were identified (Sim, 1998; Krueger & Casey, 2009). This was reviewed by a senior academic with experience in analysing focus group data.

Following the detailed open coding of interview transcripts all the interview and focus group data were pooled and Key Themes were identified (Kruegar & Casey, 2009). Axial coding enabled large amounts of data to be reconstructed into coherent themes (Charmaz, 2006; Saldana, 2009). Interview and focus group data were reviewed by a senior academic with experience in analysing qualitative focus group and interview data. Where differences in interpretation occurred, these were discussed with the research team and agreement reached.

Data from carers were analysed using the same process outlined for the staff questionnaire above. Only basic descriptive statistical analysis was performed. Due to low response rate data is reported in frequency tables rather than as percentages. Finally, a draft model of TIA needs was created, based on the perspectives of those who contributed to the research.

5.4 Findings

Phase 2a

Response rates

A total of 96 responses were received from all sources, 34 were responses from the two conferences. The total attendance at the conferences was 136 people, therefore the response rate at conferences were 25%. A response of 62/312 (20%) was received from email or postal requests sent to the members of the NSNF and the SSNF, which is slightly better with published rates of clinician responses 12-14% (Scott *et al.,* 2011; Wiebe *et al.,* 2012).

50% of responses were from stroke specialist nurses, 20% were from stroke unit nurses, 5% were general ward nurses and 25% classed themselves as ‘other’. Where ‘other’ was selected, there was an option to clarify the response,

see Table 13. There were a variety of roles that could be re-classified into wider groups. Table 13 shows the range of 'other' responses as they appear on the database.

Table 13 The range of 'other' roles as identified by those who completed the survey

	Other (please specify) n = 24
Stroke specialist	Stroke Liaison Nurse
	Stroke Co-ordinator Community
	Stroke Nurse at Stroke Prevention and Neurovascular Clinics
	Consultant Nurse in Stroke Care
	Community neuro rehab nurse
	Stroke Coordinator
	Community Stroke Specialist
	Trainee Advanced Practitioner in Stroke
	Consultant Stroke Nurse
Management	Matron in charge of stroke patients
	Administrator
	Manager
Research & Education	Academic Post-graduate Research Student (Nursing)
	Stroke Research
	Researcher
	Research Nurse
	Post graduate Research Student (Stroke Nursing)
	Education and training
	Nurse Lecturer (stroke nurse background)
Therapy	Speech and Language Therapist (x2)
General	Social Worker
	Nurse Consultant (speciality not specified)
	Health Care Assistant

Stroke specialist nurses formed the largest group of participants 45/96 (47%), increasing to 56% when including the stroke specialists above. Stroke unit nurses comprised 19/96 (20%) of the participants, and 'others' were 26/96 (27%) of participants. General ward nurses accounted for four responses (4%), and two respondents (2%) did not disclose their professional role, but did not appear to have regular contact with people following TIA. A further 8

participants with roles in research, management, therapy or education, reported little or no contact with people following TIA. The majority of participants 68/96 (71%) reported they saw TIA patients on at least a weekly basis.

Seven domains of stroke needs

Physical Needs

Table 14 shows that staff identified ‘secondary prevention’, ‘health status’ and ‘health behaviour’ as being highly relevant to patients following TIA. ‘Fatigue’ also scored highly with 90% of respondents reporting they thought this was likely to be an issue. There was less certainty expressed by respondents regarding some needs such as ‘falls / accidents’, ‘vision / hearing’ issues, and ‘sleep’, whereas there appeared to be greater certainty (more ‘no’s) regarding the lack of importance of elements such as ‘swallow’, ‘spasticity’ or ‘fracture / bone loss’.

Table 14 Nurses and healthcare staff assessment of the relevance of physical needs following TIA

	Response %		
Needs / problems	**Yes**	**Maybe**	**No**
Secondary Prevention	99	1	0
Health status	96	4	0
Health Behaviour	88	12	0
Fatigue	62	28	10
Altered sensation	40	40	20
Swallow	30	26	44
Falls / accidents	30	38	32
Vision/hearing	29	39	32
Sleep	27	39	34
Pain	26	43	32
Nausea / vertigo	19	42	39
Spasticity	15	31	54
Spasms	14	35	51
Dental/oral health	13	36	51
Epilepsy	9	46	45
Fracture/bone loss	2	22	76

Psychological / Emotional Needs

All participants identified fear as a problem for people following TIA, and 99% identified anxiety. All items in this category were scored 'definitely yes' or 'maybe relevant' by over two thirds; and all were scored 'definitely yes' by over one third of respondents.

All the items identified in the SNM in relation to psychological and emotional needs rated highly in terms of perceived needs following TIA. Only body image

and personality change were thought not be relevant by more than 20% of participants. There was least agreement about personality change, with 26% of respondents reporting that they did not feel this was likely to be relevant for people following TIA. See Table 15 below.

Table 15 Nurses and healthcare staff assessment of the relevance of psychological / emotional needs following TIA

	Response %		
Needs / problems	**Yes**	**Maybe**	**No**
Fear	84	16	0
Anxiety	89	10	1
Motivation/focus/ confidence	73	23	4
Depression	67	30	3
Independence	54	31	15
Quality of life	53	37	10
Mood disorders	51	41	8
Anger/frustration	51	43	6
Coping/adaptation	50	35	15
Emotional lability	46	38	16
Dealing with others' reactions	46	42	12
Body image	41	37	22
Carer strain/well-being	41	44	15
Personality change	36	39	25

Communication needs

Memory was the item in this domain considered most likely to be a problem following TIA, with 85% of respondents judging it definitely or possibly an issue. At least 68% of respondents reported each element of communication and cognition as being 'relevant' or might be relevant' to people following TIA. See Table 16 below.

Table 16 Nurses and healthcare staff assessment of the relevance of communication needs following TIA

	Response %		
Needs / problems	**Yes**	**Maybe**	**No**
Memory	50	35	15
Understanding	50	25	25
Expressive speech	45	23	32
Cognitive impairment	38	37	25
Reading/writing/number	36	32	32

Everyday living needs

Table 17 shows that managing medicines was the element in this domain thought most likely to be important to people following TIA, with 90% of respondents feeling this was, or could be, relevant. A range of physical issues rated highly; all scoring more than 65% for combined 'yes' and 'maybe' scores. The proportion of responses indicating uncertainty (maybe) appeared high in this domain ranging between 24 – 43%, with greatest uncertainty in needs relating to cooking and shopping.

Table 17 Nurses and healthcare staff assessment of the relevance of everyday living needs following TIA

	Response %		
Needs / problems	**Yes**	**Maybe**	**No**
Managing medicines	65	25	10
Dietary adaptations	60	27	13
Walking	54	24	22
Arm movement	46	28	26
Balance/standing	46	34	20
Hand/fine control	43	32	25
Eating	41	29	30
Washing & Dressing	36	36	28
Continence	35	30	35
Cooking	26	43	31
Shopping	27	43	30

Re-enablement needs

Table 18 shows that re-enablement needs were also rated highly in the survey, with 65% of respondents reporting that they feel aids and adaptations could potentially be relevant or important following TIA, although only 25% felt it would definitely be relevant. Elements such as Advocacy, IT and Web access and aids and adaptations showed low levels of certainty regarding relevance.

Table 18 Nurses and healthcare staff assessment of the relevance of re-enablement needs following TIA

	Response %		
Needs / problems	**Yes**	**Maybe**	**No**
Information/advice	95	5	0
Self-management	88	10	2
Empowerment	82	17	1
Access to services	80	16	4
Training/support	77	21	2
Health & Safety	48	34	18
Advocacy	36	54	10
Information technology (IT) / Web access	27	63	10
Aids and adaptations	23	42	35

Social needs

All participants felt that driving and transport was a definite or potential issue for people following TIA, and all but one (99%) felt that work would potentially be affected by having experienced a TIA. The lowest rated element of this domain was religious observance, with only 22% of respondents rating this as definitely relevant. Religious observance also showed the highest proportion of uncertainty within the domain. See Table 19 below.

Table 19 Nurses and healthcare staff assessment of the relevance of social needs following TIA

	Response %		
Needs / problems	**Yes**	**Maybe**	**No**
Driving/transport	88	12	0
Work	87	12	1
Relationships/sexuality	70	25	5
Social activity/contact	56	30	14
Leisure/holidays	55	35	10
Participation/engagement	46	38	16
Role change	44	43	13
Religious observance	22	50	28

Financial / legal needs

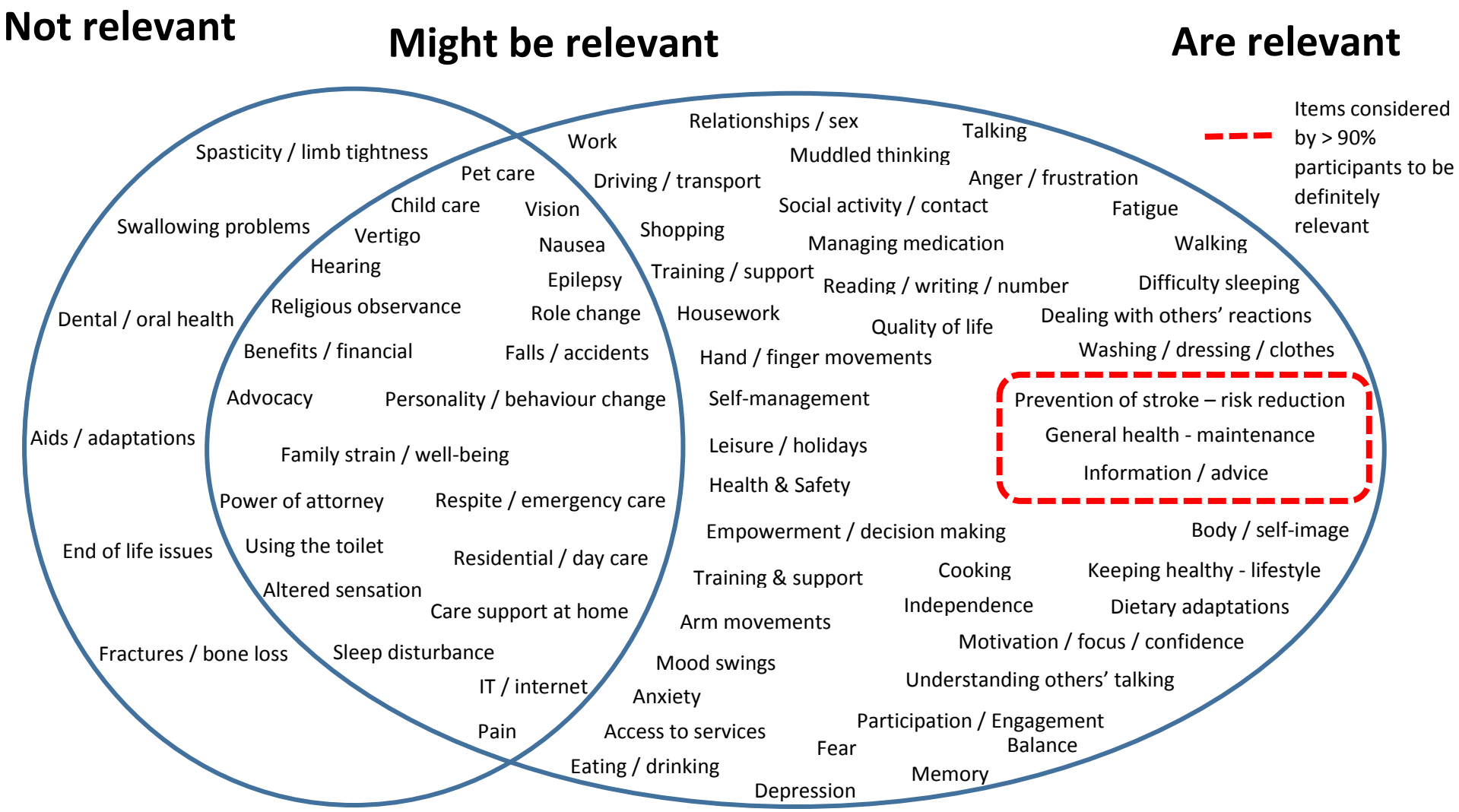
This was the lowest rating domain overall, with less than 10% of participants definitely expecting people following TIAs to have needs associated with pet care, respite care, residential care or palliative care. This domain shows over 40% 'maybe' responses in all elements except palliative care, where there is a higher level of certainty (fewer 'maybe' responses). This indicates that respondents are undecided about the relevance of these needs following TIA, with the exception of palliative care. See Table 20 below.

Table 20 Nurses and healthcare staff assessment of the relevance of financial / legal needs following TIA

	Response %		
Needs / problems	**Yes**	**Maybe**	**No**
Benefits/financial support	41	47	12
Child care	24	59	17
Power of attorney/Next of Kin (NOK)	19	59	22
Care support/packages	16	47	37
Pet care	9	56	35
Respite/emergency care	8	52	40
Residential/day care	7	51	42
Palliative care	4	26	70

A Venn diagram is shown in Figure 11, summarising the responses above. This demonstrates that very few needs identified in the SNM are thought to be not relevant following TIA. All other needs are considered at least possibly relevant. The top three needs identified as relevant were prevention of stroke, general health and information / advice. All stroke needs in the Psychological / Emotional domain also rated very highly.

Figure 11 Venn diagram summarising staff views on the relevance of stroke needs to people following TIA



Free text comments

There were 29 free text comments. These covered a range of themes including general comments about the questionnaire; clarification of TIA diagnosis; repetition of elements within the SNM, and TIA specific comments. General comments about the questionnaire (n=5) explained participants' approach to the survey, clarifying the assumptions they had made when answering the survey. Participant 78 wrote:

> *"I have answered the survey thinking that the patients have already resolved but may still have worries about certain aspects."*

Eight free text responses were about clarifying the definition of TIA and showed that some delegates found the questionnaire difficult to complete, because their perception was that following TIA, none of the needs should apply. An example response from participant 8:

> *"Following TIA, all of these symptoms should have resolved in a 24-hr period. If the symptoms have not then all of the above will affect the individual differently depending on what they themselves place most value on.*"

This also demonstrates an awareness that need is also influenced by the individuals' beliefs and possibly their coping strategies. There were nine free text responses which were a reiteration of questionnaire items, clarifying participants' views. The majority of these responses related to secondary prevention, or emotional support in some way, participant 68 said:

"In my experience after a TIA people need lots of information and help/encouragement to change lifestyle as required."

TIA specific comments (n=7) included clarification for the patient about what to expect after the diagnosis, who should provide follow-up, and travel information, specifically travel insurance.

A full list of free text comments can be found in Appendix C6.

Phase 2b

Patient participation comprised individual interviews (n=11) and three focus groups (n=10).

Recruitment & summary of participants –

Semi-structured interviews

From Site One, two potential participants agreed to be interviewed, both in their own homes out of a possible 55, see Appendix C7.

At Site Two, 59 patients were retrospectively identified as potentially eligible to participate in the study, from a possible 126 people screened. Appendix C7 shows the breakdown of eligibility screening. A further 33 patients were prospectively given the information and invitation in clinic by the clinician who made their TIA diagnosis. Of the 92 potential participants approached from Site Two, a further ten agreed to participate (six retrospectively approached and four prospectively approached). A total of twelve semi-structured interviews were conducted within this study. Subsequently following discussion with the supervisory team, the data from one interview was excluded. This was because despite meeting the screening criteria, it transpired that the participant had experienced a completed stroke whilst staying with her daughter, and had been admitted to another hospital. This had not become apparent until during the interview, so to avoid causing offence the interview was completed but the data not included in any analysis.

Quantitative data from interviews and initial focus group were combined for analysis. Of the thirteen participants (two from the focus group and eleven

interviewees), the mean age was 74.1 years old, (range 36 – 88 years), gender distribution was eight females (F) and five male (M), the mean time elapsed from TIA to contact with researcher was 20 weeks (range 6 – 40 weeks). Four participants were recruited from Site One, the rest were recruited from Site Two. Table 21 shows a summary of participant characteristics.

Table 21 Summary of participant characteristics

Participant	Age	Gender	Time from onset (weeks)	Main symptoms
1	79	F	40	Confusion and speech disturbance
2	36	F	28	Co-ordination and speech disturbance
3	72	M	8	Facial weakness and speech disturbance
4	59	M	16	Cognitive problems
5	70	F	6	Face and arm weakness
6	88	M	12	Leg weakness
7	82	F	24	Altered sensation face and arm, speech disturbance
8	87	F	8	Leg weakness and speech disturbance
9	83	M	20	Speech disturbance
10	86	M	16	Facial weakness and speech disturbance
11	80	F	16	Arm and leg weakness

The remaining two participants are included in the descriptions of focus group participants (A & B). Thumbnail pen sketches of participants can be found in Appendix C8.

Recruitment & summary of participants

Focus group 1

In total, 150 potential participants were identified and their medical records assessed against screening criteria. Of those considered, 62 met the screening criteria. GPs would not provide information relating to mortality status of patients since diagnosis for six patients, and therefore, those patients were not approached. One patient had died since her last hospital attendance. See

Appendix C7 for breakdown. Of the 55 patients who were sent invitations to participate in focus groups, there were five positive responses. One subsequently declined due to ill health, one declined due to spousal illness and one failed to reply to subsequent contact. Thus, the first focus group consisted of two participants.

Focus groups 2 & 3

A total of thirteen people expressed an interest in participating in focus groups, of which three were unable to attend on the date that the meetings were planned. An initial pilot focus group was conducted at the start of this phase with two participants (A & B). Two further focus groups were conducted, each with four participants. There were two male and six female participants, mean age was 73.4 years (range 58 – 91 years), and mean time elapsed since TIA was 12.5 weeks (range 7 – 20 weeks). A summary of participant characteristics can be seen in Table 22. Thumbnail pen sketches of participants can be found in Appendix C9.

Table 22 Summary of participant characteristics for focus groups

Participant	Age (years)	Gender	Time since TIA (weeks)	Main symptoms
A	65	F	11	Arm, leg, face weakness and speech disturbance
B	76	F	7	Facial weakness and altered sensation
C	69	F	12	Hemianopia
D	83	M	7	Monocular blindness
E	63	F	10	Amaurosis Fugax
F	91	F	8	Dysphasia and arm weakness
G	72	F	20	Dysphasia and arm weakness
H	58	M	16	Dysarthria, arm weakness, unsteady
I	87	F	9	Hemiparesis
J	64	F	18	Aphasia

Card sort data from the initial focus group (Participants A & B)

The initial focus group, conducted in March 2012, tested the screening and recruitment processes, in addition to seeking views relating to needs following TIA. Appropriate individuals were selected, demonstrating that the processes. Table 23 shows the findings of the initial focus group card sort data, where the group prioritised the issues or needs identified.

Table 23 Results of the focus group card sorting exercise, showing group 'relevant' and 'might be relevant' issues

Card sort at Focus Group with patients following TIA			
Relevant		**Might be relevant**	
1	Prevention of stroke	1	Self-management
2	Anxiety	2	Motivation/confidence
3	Information & advice	3	Independence
4	Sleep disturbance	4	Dealing with others' reactions
5	Keeping healthy	5	Training & support
6	General Health	6	Body image/self-image
7	Dietary adaptation	7	Falls/accidents
8	Eating & drinking	8	Housework
9	Driving/Transport	9	Leisure & holidays
10	Fatigue/tiredness		

Limited inferences can be made from the card sort exercise, but the two participants (A & B) agreed a core of ten items which they felt were relevant to them both (Table 23). There was a list of another nine items which they jointly felt might be relevant. The vast majority of stroke related needs were not considered relevant to the two participants, based on their own experiences, although they did acknowledge that other people's experiences and needs might differ.

A further eight patients participated in two focus groups in May 2014. The data previously generated within Phase 2 from the initial focus group and interviews formed the content of material which the focus groups considered and discussed (Figure 13, page 131).

Card sort data from interviews

Table 24 shows those stroke needs thought to be definitely relevant or possibly relevant, following TIA. Participant 7 did not complete the card sort. Items not thought to be of relevance can be seen in the Stroke only segment of the Venn diagram, Figure 13 (Page 131).

Key themes in the data

The focus of this sub-study was to investigate the experience of TIA and patients' perceived needs following TIA. Content analysis of the focus group and interviews were combined. The SNM provided a framework of stroke needs that informed data collection. Following an iterative process of coding and review of transcripts, six potential needs following TIA were identified (see Figure 12).

Figure 12 Key themes identified

The need to:

1. Access early recognition & action
2. Have access to knowledgeable staff
3. Take steps to avoid a stroke
4. Manage fear & anxiety
5. Deal with restrictions and regain independence
6. Develop confidence in self and future

There was an additional theme about the role of family and friends, which will be explored further in the carers' questionnaire.

Table 24 Summary of elements of Stroke Needs Mapping (SNM) for which a positive response was given

SNM Needs	Definitely or might be relevant
Prevention of stroke (risk reduction)	9
Keeping healthy (lifestyle)	8
Fatigue (tiredness)	7
Talking	7
General health (maintenance)	5
Balance / standing	5
Quality of life	5
Anxiety	5
Managing medication	4
Dietary adaptations	4
Vertigo (dizziness)	4
Dealing with others' reactions	4
Fear	4
Muddled thinking	4
Memory	4
Family strain/well-being	4
Depression	3
Motivation / focus / confidence	3
Body image / self-image	3
Reading/writing/numbers	3
Driving / transport	3
Information / advice	3
Eating and drinking	2
Independence	2
House work	2
Arm movement	2
Mood swings	2
Personality / behaviour change	2
Role change	2
Social activity / contact with others	2
Dental / oral health	1
Altered sensation (e.g. numbness)	1
Nausea	1
Walking	1
Falls / accidents	1
Hand and finger movement	1
Sleep disturbance	1
Difficulty sleeping	1
Anger / frustration	1
Work	1
Relationships / sex life	1
Leisure / holidays	1
Training / support	1
IT / internet access	1

n=10.

Key themes. The need to:

1. **Access early recognition & action**

This was not part of the SNM, but could be broken into a variety of components. There were a number of references relating to the shock of having a TIA. Denial was also mentioned in terms of feeling that the symptoms were not serious enough to worry about. Participant 1 said:

> *"I said I'm Ok, don't need to go anywhere. I thought I was wasting their time."*

Denial could also be seen where patients felt that the diagnosis must be wrong. Participant 4 said:

> *"There are still parts of me in denial. You don't have any evidence, you can't find anything wrong."*

Also in this theme were a variety of identified delays, caused by the participant, and linked to denial and the need for encouragement to act on the event. Participant 8 explained how her daughter was the driving force for her to seek medical help:

> *"(she said) 'You've got to go mother', so I did. I went to the doctor, and she referred me to the clinic."*

Other participants talk about frustration caused by delays within the health system itself. Participant 4 speaks of his perception of delay in seeing a stroke specialist:

"I wish we'd gone straight to A&E because I think I would have been seen straight away, not gone through the doctor, it all took too long."

2. Have access to knowledgeable staff

Knowledgeable staff was identified in relation to doctors and nurses who offered support, reassurance and information. When speaking about his encounter with a doctor in TIA clinic participant 9 said:

"He's very good at giving you self-confidence and [has] what I call a responsible bedside manner, not soothing you over, but very practical, and I think that's ideal."

The need for information was highlighted both from the stroke needs and the interviews, with some accounts of poor or inadequate information provision, as in the case of participant 3:

"It seems like a grey area of what you can do and what you can't do and what you should do and what you shouldn't do."

It was also felt that knowledgeable staff helped patients and carers to develop confidence post TIA. Participant 4, when talking about his encounter with a specialist nurse, said:

"I just felt it was a good example of the support people need in that situation…I came out feeling a lot better about the situation."

One participant (3) specifically mentioned the need for psychological support:

> *"This is a time when people need, not just physical support, but psychological support…if you've got positive people around you, always helpful."*

3. Take steps to avoid a stroke

This theme was about stroke risk reduction. From the stroke needs, those highlighted were General Health, Keeping Healthy and Prevention of Stroke. A number of participants mentioned 'taking it easy', diet changes and medication. A huge reliance was placed on taking the medication as a protection. One participant (9) felt that taking medication was the most important thing that can be done to reduce the risk of stroke. He said, when asked what information should be given to people following TIA:

> *"Really to reassure them that they haven't got much to do except perhaps take a tablet."*

There were accounts both good and bad relating to experiences with medication. Participant 4 had a bad experience with lack of information about potential side effects of medication:

> *"Doctor prescribes it, no warning whatsoever of any side effects and I've since found some…but telling somebody that the drug might affect your love life, I would have said OK, and I could have been ready for it."*

Whereas his initial attitude to medication had been much more positive:

"It's a bit of a wake-up call and then you find your blood pressure is up and your cholesterol is up and you think, alarm bells, let's do something with it."

Information was also identified in relation to secondary prevention. It appeared that taking steps to avoid strokes help to form a 'positive attitude' which, in turn, helps to develop confidence. Participant 3, when talking about confidence in the future said:

"The sooner you start doing something about it and being positive, the more you seem to develop confidence in yourself."

4. Manage fear & anxiety

Learning to manage fear and anxiety in relation to the future appeared to be a significant need post TIA. This was covered by the SNM and it is recognised that both anxiety and fear are problems following TIA. This includes more recent reports of post-traumatic stress disorder being experienced by some people (Kronish *et al.,* 2012; Kiphuth *et al*., 2014). Fear of having a stroke was the biggest issue, with the impact that fear has on quality of life. Participant 5 explained how she feels her TIA has changed her life:

"The fact that I feel scared, then my quality of life has changed, but everything else is the same, no it's only the 'sacredness' I've got that's different. It impairs on my quality of life a bit, because I do worry."

Anxiety and general worry was also a very common theme. Depression was not as common and there was only one participant who was anxious about job

security following her episodes. It was felt that developing confidence helps with the fear and anxiety. Participant 9, when asked about anxiety said:

> *"You're obviously pleased it's not more serious, but I know it could lead on to a full stroke which is the one thing you are afraid of obviously."*

5. Deal with restrictions and regain independence

Driving scored highly in this category, participant 3 described the driving restrictions as feeling almost like a disability in itself. He said:

> *"Which is a problem, at first, because it feels like you've had your legs cut off."*

Fatigue was also highly identified from both the stroke needs and in direct relation to people's experiences. Participant 11 when asked about fatigue reported that, initially this had been a big problem for her, but had improved over time:

> ***"****It's gradually, it's gradually changed, at first it was quite sort of … I was tired full stop you know, and then gradually I started to come out of it and do more, now … I'm all right, I don't think about it now."*

There were several mentions of family or friends 'watching' or monitoring those people who had experienced a TIA. There were also reports of family and friends being over-protective and reducing independence. Participant 10 talked of the frustration of being told what to do, but accepted that it was due to concern from his family:

"And I have to do what's told, I'm not asked whether I'm going to do it, I'm told that's what I've got to do, so once again it's done with the best of intent and so I take it in that manner, and I'll take it in that spirit, do you know what I mean?"

One participant (2) was concerned regarding the impact of TIA on personal relationships, she said:

"in terms of actually a relationship, coz I think, I don't want them to know that I've had it, coz I think that it puts people off."

6. Develop confidence in self and future.

Confidence is difficult to define, but most participants mentioned it at some point in their discussions. It appeared to be linked to positive attitude and acceptance of the situation. It was identified that confidence in healthcare professionals helped to develop self-confidence post TIA and in being able to identify what is 'safe'. Participant 9 when talking about the encounter with a stroke nurse said:

"It's helpful if you have been told what goes on, and why it's happening and whether it's likely to lead to a stroke and that. Yes, without that information I would feel very much lost, so I think that giving the patient information is vital."

The groups recommended changes to the classification of a number of elements of the SNM. Typically, elements were moved from the stroke only classification to the 'stroke and TIA' intersection. There appeared to be three new emergent needs in the TIA only classification. One emergent need was

‘sustaining change’, where changes made initially following the TIA became increasingly difficult to maintain over time. Another emergent need was related to the feeling of being ‘a fraud’ and ‘making a fuss about nothing’, the need is about how to cope with these feelings. The third emergent need was about support and information specifically for carers and family members of people following TIA.

Prioritisation of needs was completed as a group exercise and suggestions were sought about how the groups might like needs to be addressed.

Most important needs

Each focus group was asked to agree a ‘top five needs’ to discuss in more detail and possibly establish ways to address the identified needs.

The needs identified by group one were: Help seeking; Information; Vision; Avoiding delay and Motivation. Group two selected: Driving; Risk reduction; Help seeking; Information and Finances.

When asked to identify the top five needs, the groups between them identified eight, with two needs appearing in both groups. The two needs identified by both groups were Encouragement to seek help and Information / advice. A summary of top five needs for both groups can be seen in Table 25.

Table 25 Showing a summary of top rated needs

	Needs identified as most important.
Shared	Encouragement to seek help Information / advice
Group 1	Vision Avoiding delay Motivation
Group 2	Driving Risk reduction Finances

Encouragement to seek help. The common theme was that people after a TIA needed encouragement to take it seriously, because the temptation was to ignore it, since the problem had 'gone away'. This suggests that encouragement to seek help overlaps with denial, and validation of experience, but is distinct, in that it prompts action in the form of help seeking behaviours. The group recommendations for meeting this need were that there should be a wider awareness of TIA and its symptoms. They also felt it is important to recognise that no symptom is too minor to mention, participant E said:

> *"Well I think that is more important, that we should realise that yes you do need to seek help whenever odd things happen to you. Because we do tend to say, 'Oh no, I'm fine and don't bother,' but no, it's wrong."*

Information / advice. The discussions in both groups focussed on TIA awareness, rather than the information required following a TIA. It was felt that the public tends to be unaware of the condition, unless they have had personal experience of it in the form of family or friends who have also had a TIA. The participants talked about the Face, Arm, Speech, Telephone (FAST) campaign and felt that it does not go far enough in terms of describing stroke and TIA events. The group identified that between them they had experienced face, arm and speech difficulties, but also had visual disturbance, loss of balance and generally 'feeling funny'. This led to discussion of the Stroke Association campaign 'Not just a funny turn' (Stroke Association, 2014). The groups' recommendations for how to address this need included an advertising campaign similar to the FAST campaign, to clarify that even if the symptoms resolve, medical help is required. They also suggested including a character in one of the soap operas who could have a TIA. Finally, they felt that there should be more leaflets and posters in doctors' surgeries and opticians prompting people to report strange, unexplained symptoms, which might represent a TIA. There was a consensus that both doctors and opticians should ask the question, '*has anything strange or funny happened to you since I last saw you?*' Participant C said:

"But you know, that has never been mentioned to me, by opticians or by doctors. And I feel it should have been, some questions should have been asked, you know, possibly more by my optician since it was eyes affected. Have you ever had any funny things?"

Vision. A number of the participants in the focus groups had experienced visual disturbance as part of their TIA. Both amaurosis fugax and homonymous hemianopia were symptoms experienced by group members. This led to discussions about visual problems as a feature of TIA. Concern was raised that vision does not feature in the FAST campaign. The optician was the first healthcare contact following their TIA for two of the participants. In one case, the optician recommended an urgent GP appointment, in the other, the recommendation was to attend the local eye infirmary. Visual disturbance leading to less common pathways into health care with associated delays were first reported in 2014 (McSharry *et al*., 2014; Wilson *et al*., 2014). It is recognised that isolated visual symptoms are less likely to result in rapid access to TIA services, since they tend to have a low stroke risk score (Lavallee *et al*., 2013).

There was a general feeling that TIA is not well known and understood by the public, and visual problems, as a manifestation of TIA, were not really recognised. It was felt that if ten seconds of loss of vision in one eye could result in major vascular surgery within a week of the episode, then no visual symptoms should be ignored. Until this meeting 'vision' had been in the stroke only section of the TIA needs Venn diagram. Participants not only felt it needed to be moved into the TIA and stroke classification, but also, formed one of their top five needs, because of the perceived lack of recognition of vision as a potential symptom during TIA. The group recommendations for addressing vision as a need. In relation to educating opticians to ask about any strange visual episodes at each consultation, and to encourage people to report any minor events, participant D said:

"Information for the public about TIA, opticians should ask more questions and also GPs, they don't routinely ask, and it's something, that you felt was too trivial to mention…"

This fits with research that was published at the same time this element of the research was conducted in May 2014 (McSharry *et al*., 2014; Wilson *et al*., 2014).

Avoidance of delay. The group stressed the importance of taking immediate action following a TIA. Not all group members did initially, but were surprised at the swiftness of response once they contacted a healthcare professional. One participant mentioned her event when she attended a routine blood pressure check at her surgery. She was seen at a TIA clinic the same day. She said it made her feel like a 'damn fool' for ignoring it at the time. All the group said they would have no hesitation in seeking immediate medical attention if they had any unexplained symptoms in the future. When asked how this need might be addressed, the group felt this need also tied in with the need for encouragement to seek help and the need for information and advice. The overwhelming message was that public education about TIA needs to be improved, participant D commented:

"I've been told, it seems, that speed is of the essence."

Motivation / focus / confidence. It was felt by the group that the first thing people need is the motivation to try and do what is necessary to recover. The changes made to reduce the risk of further TIAs or strokes helps to build confidence in the future. Then as confidence grows, a positive attitude forms and one can accept the event, learn from it and move on. When asked how the need could be addressed, the view of participant E was that if professionals give clear, non-contradictory advice, this builds trust and helps to develop the motivation to start the recovery process:

"I think it should be motivation, you need to be motivated before you accept… Well not to give up and accept it, but to continue with any form of physio or any therapies that help."

Participant F:

"So, would that go along with confidence, in the need description you have motivation, focus and confidence as a single group? Yes, it would, wouldn't it?"

Driving / transport. It was recognised by the group that those people who normally drive are significantly affected by the 28-day driving ban. It was also accepted that this is a legal requirement of the Driver and Vehicle Licensing Agency (DVLA, 2016), and not the decision of the clinician who makes the diagnosis. However, there are times, either due to delay in presentation, or due to clinician error, when people are not informed of the driving restriction. There was discussion about whether driving restrictions apply to bicycles, golf buggies and mobility scooters. The group consensus was that it probably should, but doesn't appear to apply. There was also discussion that because of the age of the participants, the majority have bus passes, which should help people to maintain mobility in the absence of the ability to drive. The main difficulty expressed was the loss of independence and freedom. There was also the discussion that with the cost of petrol, maybe a month without driving might pay for occasional taxis for essential journeys. Participant J said:

"Not being able to drive for a month was pretty awful."

"That was the only thing I found difficult about the whole thing."

It was also felt that people should not be put at risk by not being informed of DVLA restrictions, and that it is imperative that everyone is told about driving restrictions at the earliest opportunity.

Prevention of stroke – risk reduction. There appears to be great dependence on the medication prescribed to protect against stroke. Although there were some participants who were reluctant to take medication this was described by participant H:

> *"Then all of a sudden I've got 4 pills to take on a daily basis."*

The majority saw medication as a positive step towards reducing the risk of stroke. Three main reasons for taking medication emerged. Some people took medication to reduce the risk of stroke. Participant D talked about his view of risk reduction:

> *"A lot of the things we mentioned about reducing the risk is very important and is about not having the stroke and that's the aim of the game, in terms of preventing strokes."*

Some people took the medication to reduce worry and anxiety, participant E explained:

> ***"****Some people could get in quite a state, ooh I've had a TIA I've got to be careful, I've gotta do this or not do that."*

Some took medication because the doctor said so, participant G:

"Well I said, if we continue with our healthy diet, very low fat, do I need to keep on the statins and he said yes."

Lifestyle issues such as stopping smoking, reducing alcohol intake, changing diet and taking more exercise, were also discussed and the discussion moved on to how to maintain lifestyle changes. One participant who had her TIA several months ago stated that fear was the main motivator, which helped her to continue with the changes that were implemented following her TIA. Other participants talked about starting out with good intentions, but finding it difficult not to let 'old bad habits creep in'. The group felt there needed to be sufficient information to help people help themselves initially following TIA, but, there should also be some longer-term services to help maintain the changes participant H said:

"As someone who appears to have had a very minor event, I certainly feel that I, after the initial period, when I saw a doctor, I didn't take it very seriously, but he made lots of effort and brought my blood pressure down, so on and so forth, but because I feel well within myself, I feel the old bad habits creeping in, you know like chocolate cake and things."

Benefits / financial. There were two main themes to this need. The main one was about the impact of having a TIA diagnosis on travel and car insurance. Discussion identified the risk that people may have invalid travel insurance, and not realise it. One participant reported that the financial impact of her TIA was that it cost her £200 in additional travel insurance premiums. It was felt that healthcare professionals should ensure that people who receive a TIA diagnosis, should also be advised to contact their car and travel insurance providers. In the case of car insurance this is to ensure the policy is not declared null and void. In the case of travel insurance, this often results in a raise in premiums or even exclusion of cover. Either way, it was felt that it is better to know the situation before needing to make a claim (H):

"Difficulties of making sure these things are valid really, particularly around travel insurance. They ask so many questions, what's important and what's not. And that potentially the insurance links to finances, coz it's a consideration when you are going on holiday."

The other financial issue was raised in relation to power of attorney, which costs quite a lot to set up, but in the event of a stroke would save money overall. One participant (I), who had experienced her TIA quite recently, had a sister who had survived a severe stroke. She believed an event, such as a TIA, should prompt people to plan for their future. She felt that people need to consider all eventualities and a TIA could be seen as a 'wake-up call'. She recommended that people should consider organising power of attorney, will and funeral arrangements following a TIA:

"Power of attorney could be very important, couldn't it? If you do it after the TIA, if you have a stroke it's done. Well you just don't know what the future holds. So, a TIA, because it's a little warning shot, I suppose, isn't it?"

Other group members felt that this might be a response to her sister's situation, and that the type of future planning suggested would not be suitable for everyone. The group as a whole agreed that a sudden illness of any kind might prompt considerations of future planning, and this was not specific to TIA.

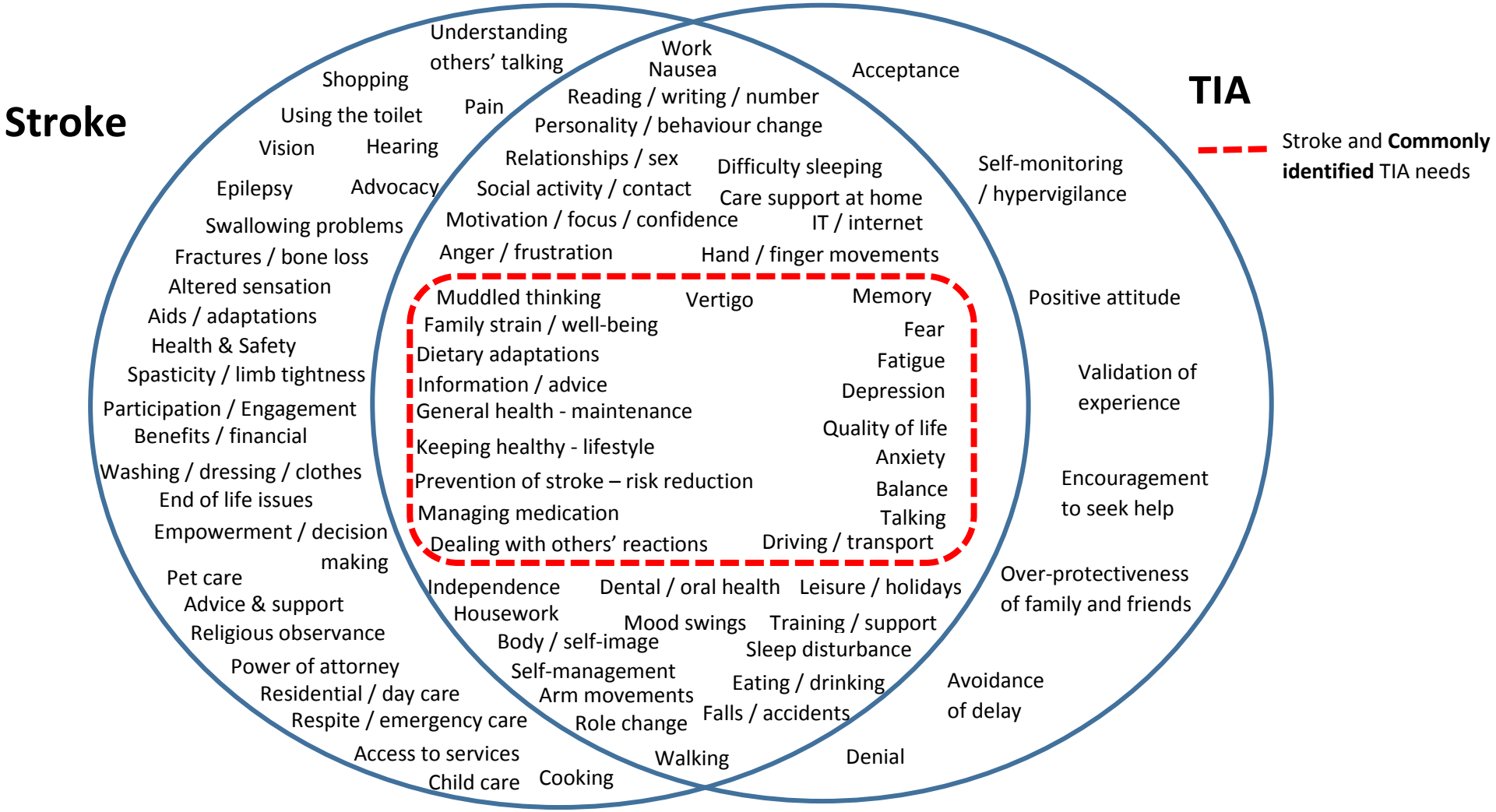
Self-management. One of the groups talked about taking control of their health and monitoring their own blood pressure, and how they have been helped by their GP to keep an eye on their own health. There is a precedent for this, and home blood pressure (BP) monitoring is an established mode of treatment (Schmid *et al.*, 2009). It was acknowledged by the group that not everyone wants or would be able, to do this. However, it was felt that where an

individual is motivated to do this themselves they should be supported in doing so, participant H:

> *"Having purchased one from a pharmacist's it cost me £20, the lady in the GP office checked it was giving an appropriate reading I thought that whoever pays for that, and I'm very happy to pay for it myself, if it saves you two trips to here, or several days with an inappropriate machine at the GPs then it's actually a very good investment, so I would strongly recommend that."*

There is evidence in stroke patients who were given BP monitors and asked to continue monitoring their BP that half the study group continued weekly checks at 6 and 18 months post event (Ovaisi *et al.,* 2013), suggesting that this could be a useful strategy in those people who want to 'take control'.

Figure 13 Venn diagram showing the relationship between stroke and TIA needs as determined by patients following TIA during interviews



TIA specific needs

TIA specific needs emerged from the qualitative data analysis and represent novel themes that do not directly relate to the elements of the SNM. A wider range of quotes relating to TIA specific needs can be found in Appendix C10.

There were a number of issues or needs expressed by people following TIA that did not quite fit within the SNM. Some of the needs are similar to those found in the SNM but are discussed in a different context to that following stroke, where longer lasting physical or mental impairments occur.

Acceptance. This is in the context of accepting that something had happened, taking reasonable precautions, and not letting it dominate the future and cause ongoing concern. Due to the brevity of symptoms and the full physical recovery, some people appear to find it difficult to accept that the event carries a significance beyond the duration of symptoms. Acceptance is not explicitly found in the SNM, although it could be seen to be categorised under the heading of 'coping and adaptation' which is part of the SNM. Participant 11 said:

> "*It's no good worrying, you've just got to get on with it, you know*…"

Self-monitoring / hypervigilance. A number of participants explained that they were more aware of their bodies after a TIA and, as a result, if they noticed anything out of the ordinary they would test themselves to see whether it was happening again. There is no obvious category of the SNM which includes this need. Participant 5 stated that if she felt in anyway unwell she would 'check' herself:

> "*I sometimes think 'are my arms alright, are my legs alright', so I check them and then I rub my neck and head."*

Hypervigilance is not a recognised feature of either stroke or TIA. In fact, with stroke, since there is a persisting disability if a patient were to be checking their function, it would be likely to be with the hope that the symptom has improved or resolved, whereas following TIA, due to the heightened awareness, minor unusual or unexpected sensations would prompt 'self-testing' behaviour, with the patients checking for possible new TIA / stroke. It is likely that this behaviour is further fuelled by the lack of warning before the TIA. Patients appear to feel vulnerable and hypervigilance is likely to be a coping strategy to manage their anxiety. There might be a link between hypervigilance and hypochondriasis, as described in the literature (Taylor, 2004).

Positive attitude. This was thought to be important, linked with acceptance, to enable people to get on with their lives following a TIA. Whilst confidence can be found in the SNM, it would appear to be referring to confidence and ability in terms of recovery and ability, rather than confidence in the future and their future health. Participant 3, when talking about the need to be positive said:

> "*It's important to try to get back to normal as soon as possible, with a view that everything was positive, and I think if you've got positive people around you, that's always helpful.*"

Validation of the experience. This has no parallel in the SNM, in as much as a number of participants recounted how they were not aware of symptoms, or had dismissed them, only to be convinced of the need to seek help by another person. This phenomenon has since been reported in stroke survivors (Jones *et al.* 2007), where it was demonstrated that the majority of calls to the emergency services were made by people other than the person having the stroke, although that could be due, in part, to diminished ability to operate a telephone. In the case of TIA, it would appear that people may trivialise their symptoms and fail to act on them (Gibson & Watkins, 2012), requiring others to 'validate' that something really did happen and requires help. In the case of

participant 1, her daughter and neighbour both agreed that something had 'not been right' so they arranged for her to see her doctor the following day:

> *"They tried to see me move my arms and I seemed to be alright then…I wondered what came over me*."

Encouragement to seek help. People following TIA have less physical incentive to seek help, once the symptoms have passed. Sometimes people do not tell friends or family about the event for several hours or even days. It does not appear uncommon for people following TIA to delay seeking help for days or even weeks after the event. Delays in help seeking are reported widely in the stroke literature (Sprigg *et al*., 2009), where the impact of delay can determine the difference between whether or not a person can be considered for acute treatments such as thrombolysis, so perhaps it is not surprising that those people who are no longer experiencing symptoms might be reluctant to seek help. Participant 8, when talking about how he came in contact with healthcare after her TIA said:

> "*Well my daughter, my eldest daughter wanted to take me straight to the hospital and I said no, I don't want to go, so she got on to the doctor, my doctor, and got me an appointment into the clinic."*

Over-protectiveness. There is concern expressed by people following TIA about how others worry, and that whilst the concern is appreciated, it can be troublesome. They report feeling 'watched'. A number of family members or friends present during some interviews also expressed their anxieties. Managing the levels of anxiety in family and friends to ensure that the person recovering from a TIA does not feel over-protected, is an important need

following TIA. This could equate to 'independence' following stroke in the SNM. The husband of participant 5 explained:

> "*I used to phone or text her and we were texting all the time, coz I was worried about leaving her on her own, because of what happened in the first place.*"

Avoidance of delay. The SNM does not cover the acute pre-hospital episode since it was based on needs following discharge after a stroke. For this reason, early help seeking behaviour is not recognised in the SNM framework, and therefore is included as a TIA specific need. One might argue it is equally relevant following the onset of stroke symptoms, and indeed, until symptoms have resolved, it may be unclear whether the focal neurological deficit represents TIA or stroke. Ideally, everyone who has experienced a TIA should be seen in a specialist clinic within a maximum of seven days. This still does not always happen as recounted by participant 4:

> "*The number one concern really was the passage of time having seen the doctor before being seen at the hospital…I can remember the final diagnosis meeting I had with (names doctor) in the hospital and she said I couldn't drive within a month. I said, 'A month is up tomorrow."*

There were, however, also good examples of delay avoidance as described by participant 9 when talking about his partner:

> "*Fortunately, he knows, he's seen it before, and well, he immediately calls an ambulance, and we make our way up to the hospital, which only takes five or ten minutes."*

Denial. Denial is also not a feature of the SNM, since it was conducted based on patients' post-discharge following stroke. Denial appears to be a mixture of minimising the potential severity of the episode and disbelief that such short-lived symptoms could represent stroke disease. Participants talked about 'feeling a fraud' and not wanting to waste peoples' time, as described by participants 1 and 3 respectively:

> *"I feel a bit of a fraud really, why have I got you out?" (to paramedics).*

> "*Oh yes, coz I didn't want to go the next day. I said, 'I'm OK, I don't need to go anywhere'. I thought I was wasting their time, you know."*

Participant 4 explains why he is still not convinced he has had a TIA:

> "*There's been no physical evidence that I've had a TIA, which is great, I was thinking, coz you do wonder what the hell is going on, but there's been no physical evidence other than the behaviour on the day.*"

The diagnosis of TIA is based on the history of the event and, in terms of investigations, it is a diagnosis of exclusion, thus making it more difficult for people to come to terms with, since there is no positive test result that shows a conclusive diagnosis.

Summary Venn diagrams (Figure 13 & 14) illustrate the views of the pooled sample from both the interviews and the focus groups in relation to the relevance of stroke needs for people following TIA. The needs within the central rectangle represent those needs most commonly identified within the card sort or during discussions. The sector to the far right which represents 'TIA only' needs, is based on the findings from the qualitative elements of this

enquiry. TIA only concepts include: Acceptance; self-monitoring / hypervigilance; positive attitude; validation of the experience; encouragement to seek help; over protectiveness; avoidance of delay and denial.

The TIA only needs, presented from the interviews previously conducted (Figure 13), were discussed by both focus groups. There seemed to be a consensus that the TIA only needs seemed reasonable and participants could identify with them. There were, however, three new needs that became apparent when the groups were talking together (Figure14). One need related to '**feeling a fraud**' and 'making a fuss about nothing'. This, it was agreed, was due to the brevity of symptoms and the fact that they apparently recovered completely. This impacted on the participants' desire to seek help. There was concern that they might have imagined their symptoms, or concern that they would not be believed. This fits in with denial and avoiding delay, but seemed distinct from those needs participant E:

> ***"****I just felt a fraud, I felt I was making a fuss about nothing because I felt so well, I mean after this I was playing badminton. It was just so quick."*

The second emergent need relates to **sustaining changes** made acutely following a TIA. One participant spoke of 'slipping back' into his old ways and behaviours. This need links closely to stroke prevention and risk reduction, but again is subtly different in terms of context. It is well recognised that lifestyle changes often do not always translate into long-term behaviour changes (Leistner *et al.,* 2012). But sustaining changes was felt to be a need following TIA and was included on that basis participant H:

> *"That's when you were saying, you initially took it very seriously, but the longer it goes on the less it feels you're more in the safe zone."*

The final emergent need from the focus group data was **TIA specific information for carers and family**. This is distinct from information in relation to stroke. The group discussed the reactions of friends and family and that they would like specific information to be made available for them to pass on to the appropriate people. This links with over-protectiveness, but also helps to validate the event with carers, to ensure patients feel they are able to ask for help or support participant H:

> ***"****Communication with relatives, so you know, how to tackle that really and potentially, we talked about how something like the TIA leaflet might be useful there suggesting what sorts of things you should [be] expressing to relatives."*

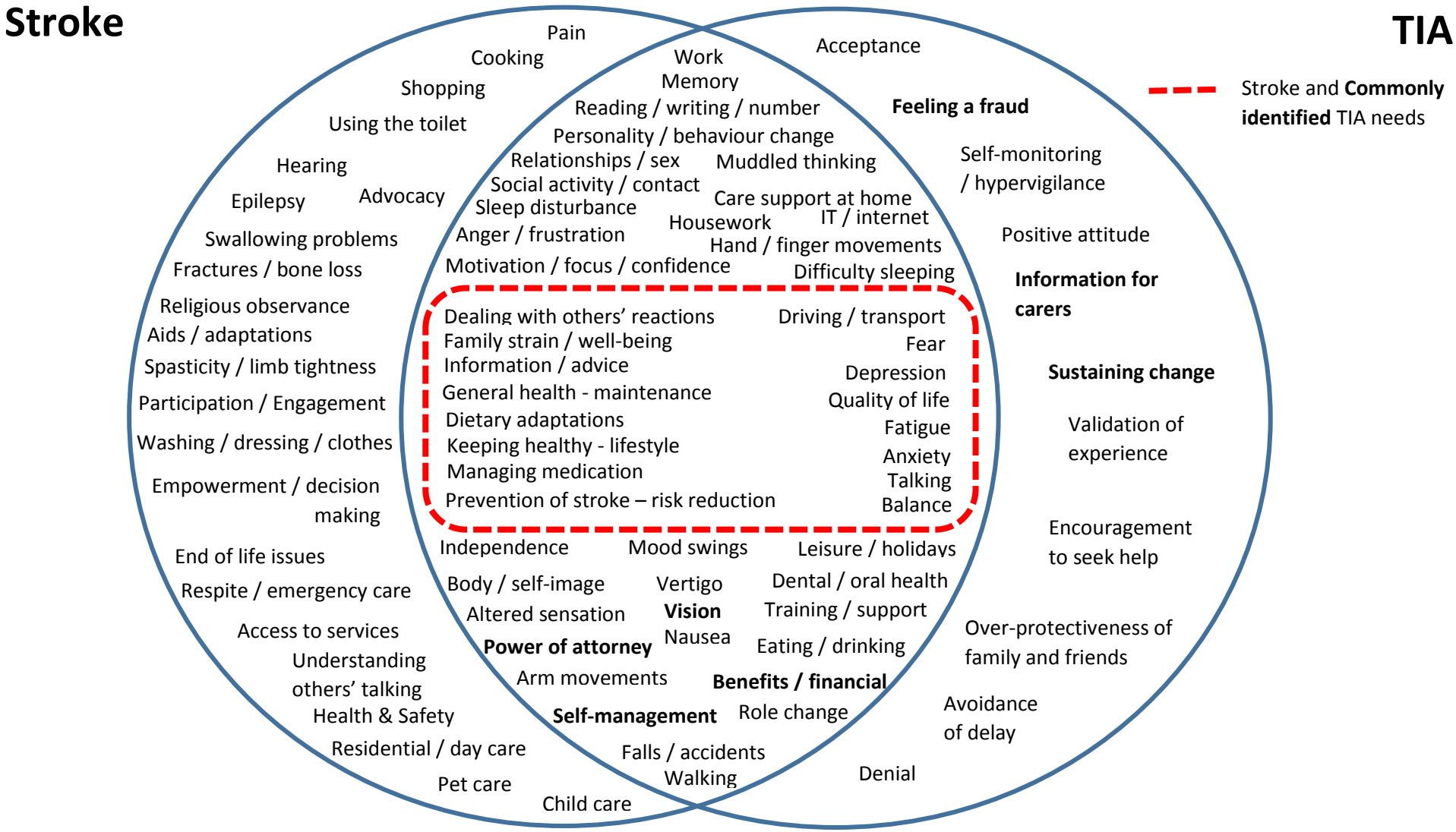
Table 26 shows in bold those needs that changed categories following the focus group discussions and those needs that were added as new TIA only needs.

Table 26 Showing stroke and TIA needs

Stroke only	TIA and stroke less common	TIA and stroke common	TIA only
Using the toilet Washing/dressing/ clothes Cooking Shopping Pain Hearing Fractures / bone loss Epilepsy Spasticity / limb tightness Swallowing problems Understanding others' talking Religious observance Participation / engagement Empowerment / decision making Access to services Advocacy Aids / adaptations Health & Safety Child care Training & support Residential / day care Respite / emergency care Pet care End of life issues	Dental / oral health Eating and drinking Independence Housework Altered sensation Nausea Vertigo Walking Falls / accidents Arm movements Hand / finger movements Sleep disturbance Difficulty sleeping Mood swings Anger / frustration Personality / behaviour change Motivation / focus / confidence Body / self-image Reading/writing/ numbers Muddled thinking Memory Work Relationships / sex Role change Social activity / contact Leisure / holidays Training / support IT / internet Care support at home **Benefits / financial** **Vision** **Power of attorney** **Self-management**	General Health maintenance Keeping healthy lifestyle Prevention of stroke risk reduction Managing medication Dietary adaptations Balance Fatigue Quality of life Anxiety Dealing with others' reactions Talking Driving / transport Information / advice Family strain / well being Depression Fear	Self-monitoring / hypervigilance Over-protective family & friends Positive attitude Acceptance Validation of experience Encouragement to seek help Denial Avoid delay **Sustaining change** **Feeling a fraud** **Information for carer**

Bold needs are those that moved from 'Stroke only' to 'Stroke and TIA', or new 'TIA only' needs.

Figure 14 Venn diagram summarising Focus Group views on the relevancy of stroke needs to people following TIA



The accrual rate for this research was very low at only six participants, suggesting that carers of people who have had a TIA are potentially a hard to reach group. Minimal biographical information was collected relating to the carers. This has been summarised in Table 27 below. The data helps give context to the responses, but due to the paucity of recruitment, no wider analysis was possible. Participants came from both the Northwest and Southwest of England.

Table 27 Demographic details of the carers

Participant Number	Gender	Age Range	General Health	Lives with patient?	Relationship
I	F	76+	Good	Yes	Spouse
II	M	61-75	Very good	Yes	Spouse
III	M	61-75	Very good	Yes	Spouse
IV	F	46-60	Good	No	Daughter
V	M	46-60	Good	No	Son
VI	F	46-60	Good	Yes	Spouse

A large number of elements of the SNM were identified by both carers and professionals in the survey conducted in Phase 2a. Only five elements identified in the SNM were considered not relevant to people who have experienced a TIA, 27 elements were considered possibly relevant following TIA. The majority of elements (40) were considered to be relevant to people following TIA. Within the group of 40 elements eight were considered by all carers to be important. These were ‘anxiety’; ‘quality of life’; ‘dietary adaptations’; ‘independence’; ‘washing, dressing and clothes’; ‘general health – maintenance’; ‘keeping healthy – lifestyle’; and ‘prevention of stroke – risk reduction’.

Stroke needs - Physical needs

Table 28 shows the needs that rated most highly in the physical category were balance / standing, walking and fatigue, although if considering yes and maybe responses, then falls & accidents and vertigo also rate relatively highly. There was one additional free text comment received for this category, which was from participant (I):

> "*Following diagnosis, it is strange how one notices things that have really been happening for a while but one realises how more observant we should be.*"

This comment links in well with findings from chapter five where 'self-monitoring' and 'hyper-vigilance' are discussed as TIA specific issues. There are few elements where 'no' is the dominant response, these are swallowing problems, spasticity & limb tightness and epilepsy. No element was discounted by all respondents.

Table 28 Carers' assessment of the relevance of physical needs following TIA

	Yes	Maybe	No
Fatigue (tiredness)	5	1	0
Walking	5	0	1
Balance/standing	5	0	1
Falls / accidents	4	1	1
Altered sensation	3	1	2
Arm movement	3	0	3
Hand & finger movement	3	0	3
Vertigo (dizziness)	2	3	1
Vision	2	2	2
Sleep disturbance	2	2	2
Swallowing problems	2	0	4
Nausea	1	3	2
Fracture/bone loss	1	3	2
Epilepsy	1	2	3
Hearing	0	4	2
Pain	0	3	3
Spasticity & limb tightness	0	2	4

Mental / emotional needs

Quality of life was thought to be important by all the participants. Both quality of life and anxiety were identified by all participants, with fear and motivation / focus / confidence having five positive responses each. All elements of this category were considered to be relevant by at least two participants. Only two elements resulted in a split result with equal numbers of responses in each possible option. These needs were Personality / behaviour change and Mood swings. Both needs were classified as 'might be relevant' in the summary Venn diagram (Figure 15, page 152). There was one free text comment from participant (IV), which said:

> "*Again, the emotional side can be tricky – especially if there are mood-swings/anxiety/other changes*".

This suggests that the person this participant supported had some needs associated with mood or emotions. The implication of the comment is that those needs were unmet. See Table 29 below.

Table 29 Carers' assessment of the relevance of mental / emotional needs following TIA

	Yes	Maybe	No
Quality of life	6	0	0
Anxiety	6	0	0
Motivation / focus / confidence	5	0	1
Fear	5	0	1
Dealing with others' reactions	4	1	1
Anger / frustration	4	1	1
Difficulty sleeping	3	2	1
Depression	3	2	1
Body image / self image	3	2	1
Personality / behaviour change	2	2	2
Mood swings	2	2	2

Communication needs

It is interesting to see that all of the communication needs rated highly with all needs identified by at least 4/6 participants. Only one participant did not feel that muddled thinking was potentially one of the difficulties facing someone following a TIA. It is somewhat difficult to determine whether this category rated high due to the initial symptoms or due to on-going problems / needs. There was one comment provided in the free text response box from participant (V), which read:

> "*From my mother's experience, but I am aware that other people are affected differently – more severely*".

It can be seen from the recent literature that cognitive problems are becoming more widely recognised as an issue following TIA. The findings in the literature are supported by the small sample in this study. Most participants have identified memory and muddled thinking among the communication needs identified. See Table 30 below.

Table 30 Carers' assessment of the relevance of communication needs following TIA

	Yes	Maybe	No
Talking	5	1	0
Reading / writing / numbers	5	1	0
Memory	5	1	0
Muddled thinking	4	1	1
Understanding others' talking	4	1	1

Everyday living needs

Table 31 shows six needs identified in the SNM that were thought by all carers to be relevant. These were Independence, Dietary adaptations, Washing & dressing, General health (maintenance), Keeping healthy (lifestyle), and Prevention of stroke. Only one participant felt that 'dental and oral health' was certainly relevant following TIA, however, another four felt it might be relevant. There was an even split in responses for domestic chores, suggesting there might be some needs associated with them as well. There were two free text comments provided for this category from participants (III) and (VI) respectively:

> "*Most of these are very important to ensure the everyday function of any person.*"
>
> "*Quality of life and the persons value as an altered person*."

The two free text responses from different respondents could be considered as relating to independence and possibly the second comment could also relate to the need for a positive attitude. However, yet again it appears that despite a TIA diagnosis, the carer / participant seems to regard the individual as an 'altered person'.

Table 31 Carers' assessment of the relevance of everyday living needs following TIA

	Yes	Maybe	No
Prevention of stroke	6	0	0
Keeping healthy (lifestyle)	6	0	0
General health (maintainence)	6	0	0
Washing & dressing	6	0	0
Dietary adaptations	6	0	0
Independence	6	0	0
Eating & drinking	5	0	1
Managing medicines	5	1	0
Using the toilet	3	2	1
Cooking	2	2	2
Shopping	2	2	2
Housework	2	2	2

Re-enablement needs

Information and advice was thought to be the most important element of re-enablement. Both health and safety issues and aids & adaptations were thought to be 'not relevant' by the majority of respondents. This would be expected based on TIA definition. When considering responses for both 'relevant' and 'might be relevant' more than half the respondents felt IT / web access, advocacy, access to services and empowerment / decision making, together with self-management, should all potentially be considered needs. These can all link to regaining confidence, which scored highly in the mental and emotional needs category. There were no free text responses for this category. See Table 32 below.

Table 32 Carers' assessment of the relevance of re-enablement needs following TIA

	Yes	Maybe	No
Information/advice	4	0	2
Empowerment / decision making	3	1	2
Access to services	3	1	2
Advocacy	3	1	2
Training/support	3	0	3
IT / Web access	2	2	2
Self-management	2	2	2
Aids and adaptations	2	1	3
Health & Safety	1	2	3

Social needs

Table 33 shows the highest rated element of social needs relates to driving and transport, closely followed by participation / engagement and work. These needs are easily seen by others and therefore easily recognised. Religious observance scored lowest. There was one free text comment provided by participant (IV) for this category:

> "*All of these relate to being a whole person – they are all important to confidence and being who we want to be".*

This maps to mood / motivation / confidence and independence elements of the SNM and demonstrates an appreciation of the impact of role change, which interestingly, was reported as belonging to the 'might be relevant' group in the summary Venn diagram (Figure15, page 152). It could be argued that those people who have an identified carer following TIA are less likely to have unmet social needs, compared with those without support within the community.

Table 33 Carers' assessment of the relevance of social needs following TIA

	Yes	**Maybe**	**No**
Driving/transport	5	0	1
Participation/engagement	4	1	1
Work	4	0	2
Social activity/contact	3	2	1
Relationships/sexuality	3	1	1
Leisure/holidays	2	2	2
Role change	2	2	2
Religious observance	1	3	2

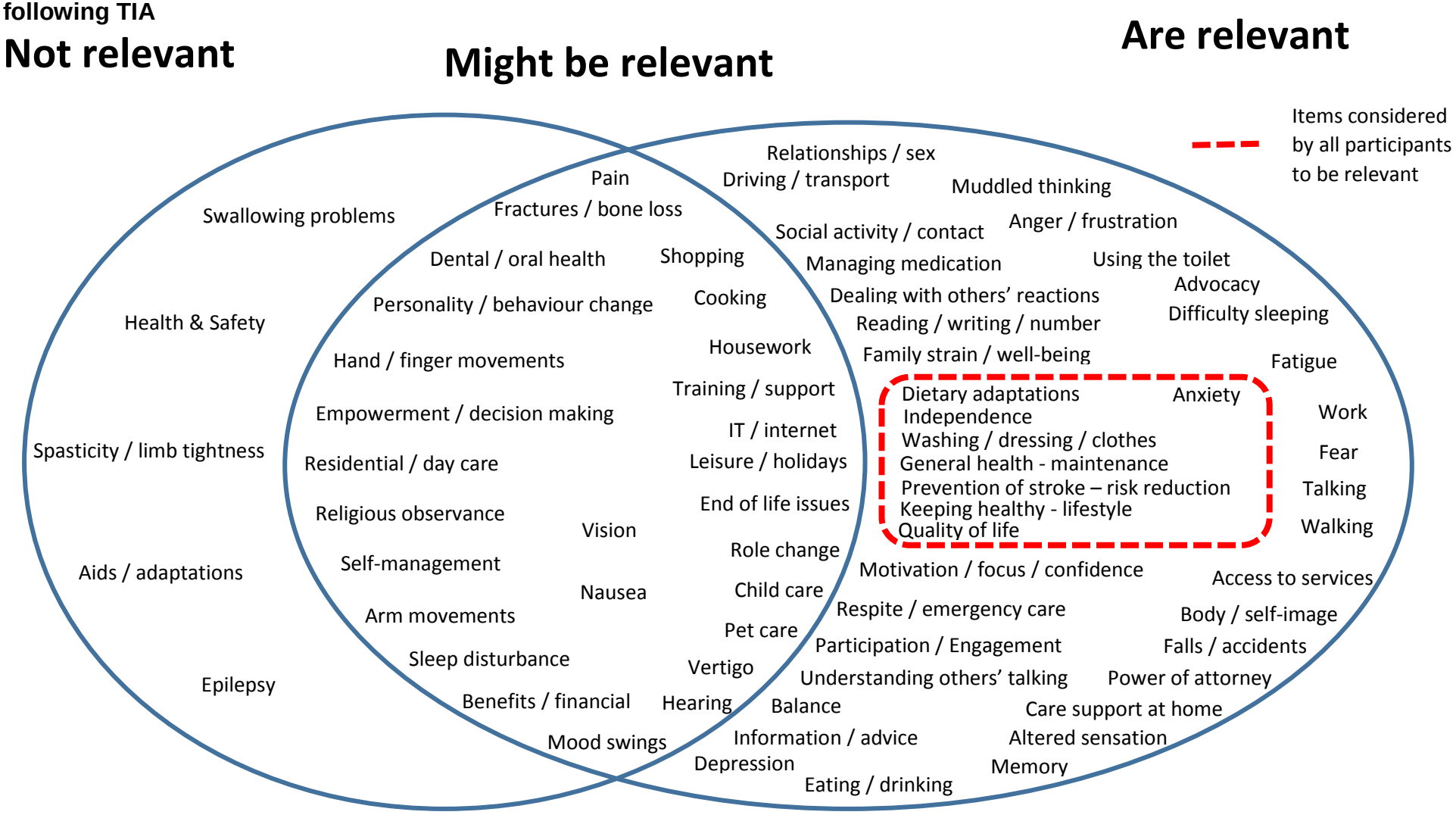
Financial / legal needs

In this category, there were two elements which none of the participants felt was 'definitely relevant' to people following a TIA (Table 34). These were 'end of life' issues and 'pet care'. The highest rated element was care support at home. There were no free text comments relating to this category of needs. It is possible to foresee circumstances in which pet care could become a worry or a need for someone living alone, who might worry about the consequences to a pet companion if they were to be taken ill. However, it is more difficult to rationalise end of life care in relation to TIA, which, by definition, is not of itself, a fatal condition. The assumption could be that a TIA may make someone consider their own mortality and prompt them to feel the need to plan for all eventualities.

Table 34 Carers' assessment of the relevance of Financial / Legal needs following TIA

	Yes	Maybe	No
Care support at home	4	1	1
Power of attorney/NOK	3	2	1
Respite/emergency care	3	2	1
Family well-being	3	2	1
Residential/day care	2	3	1
Benefits/financial support	2	2	
Child care	1	3	2
Pet care	0	4	2
End of life issues	0	3	3

Figure 15 Venn diagram summarising carers views on the relevancy of stroke needs to people following TIA



Other free text responses

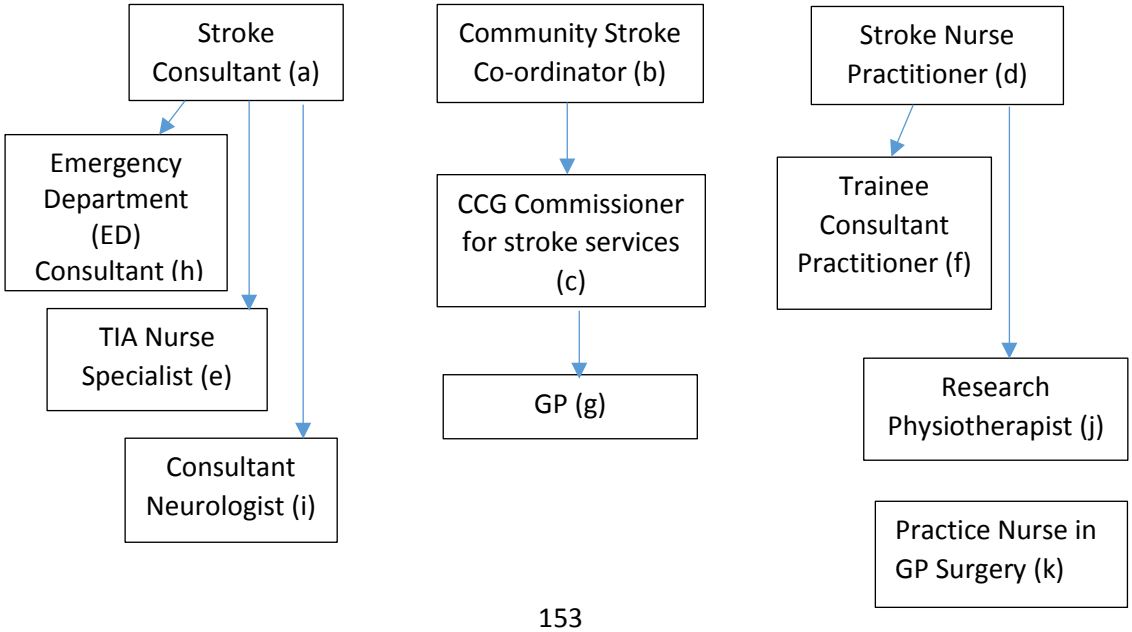
A full list of free text responses to the other questions in the questionnaire can be seen in Appendix C11. Free text responses were invited with four questions. The first question was whether the hospital could have done anything differently that might have improved the experience? The second question was about whether the GP or primary care could do anything to improve the experience? The third question was whether a specific individual made a particular positive impact on their experience? The final question was whether there was anything not covered elsewhere in the questionnaire?

Phase 2c Staff interviews

Recruitment & summary of participants

The first three participants were selected specifically by the researcher as being professionals who would be able to contribute to the understanding of professional views of TIA needs, how they are identified and subsequently addressed. A further eight interviews were conducted with people who were either recommended to the researcher, or who had expressed an interest in participating previously at a regional conference (Figure 16). There were some professional groups which the researcher attempted to access, based on previous research output, but were not easy to recruit. These included opticians and paramedics. Participants were asked if they could recommend contacts in these groups, but unfortunately, interviews could not be secured.

Figure 16 Shows the snowball recruitment process for professional interviews



Thumbnail pen sketches of participants can be found in Appendix C12.

Professional themes identified

There were four distinct themes or needs that emerged from the data collected from professionals. In most cases, they mirror or fit with previously identified needs from a patient perspective. The only one which does not appear to have a counterpart from a service user perspective is 'TIA as part of wider vascular disease.

Diagnostic uncertainty. It is recognised that the diagnosis of TIA is a difficult one to make (Wasserman *et al*., 2010), with considerable scope for individual judgement (Castle *et al*., 2010). It is not always possible to make a definitive diagnosis following a brief episode of focal neurology or other 'funny experiences'. The clinician takes a detailed history of the event, considers past medical history and risk factors, but if the presentation is atypical, there may be some diagnostic uncertainty. When explaining this to a person in clinic, the message they might take is that there is no evidence that something went wrong, or that there is no need to worry because all the tests have produced normal results. This fits with issues around denial and adopting secondary prevention strategies and lifestyle changes, reported in Phase 2b. Participant (a) talked about the difficulties of a diagnosis of exclusion, where ruling out other potential causes of the symptoms experienced, left TIA as the diagnosis. It is recognised that this is unsatisfactory for both clinician and patient:

> "*There are certain patients that we think "well it's highly probable you have had a TIA but we can't completely exclude that it's, you know, epilepsy or demyelination" and we will get an MRI scan, then obviously in the time that they are having, waiting for that MRI scan, they are in a bit of limbo*."

The patient perspective of diagnostic uncertainty was discussed by participant (i), who said:

"I just wondered whether there was something around uncertainty, uncertainty about the diagnosis and uncertainty about what is going to happen in the future."

Another difficulty for patients can be that some appear to be given a diagnosis of TIA when they have some persisting symptoms, which should give rise to a diagnosis of (minor) stroke. Participant (j) was speculating on the impact for patients in this situation and said:

"*Is there benefit from a patients' perspective if they have got issues that are worrying them, in being told actually it was a stroke, it might almost be "oh I wasn't just imagining it" it was real...*"

TIA as part of wider vascular disease. Initially raised by the Clinical Commissioning Group (CCG) Commissioner of Services, this was about how services are not currently 'joined up'. There are a variety of services in the community that could be of benefit to a wider range of people, but they are provided in 'silos'. For example, cardiac rehabilitation, provided for people following a myocardial infarct, might be equally suitable for someone who has experienced a TIA. There are a range of lifestyle interventions in the community for healthy eating, weight management and exercise promotion, but not all are currently accessible to people following TIA. The view was that services need to be provided for vascular disease rather than for cardiac or diabetes, or neurovascular conditions. Participant (a) said:

"There should be a lot going on, around vascular protection and some patients will have TIA's, some patients you know will have a heart attack or whatever, but what is the support network? and meeting the patients' needs are actually quite similar whichever one of the diagnoses it is."

There is evidence that some people after TIA do appreciate and engage with a cardiac rehabilitation model of support (Hillsdon *et al.,* 2013). That model of care would meet a number of the needs that people have previously identified, although there is conflicting evidence that cardiac rehabilitation has a demonstrable impact on risk factors and outcomes (Prior *et al*., 2011; Kirk *et al*., 2014; Wilson *et al*., 2014). Cardiac rehabilitation for people following TIA was a common theme, and was thought by the participants to offer a model of care which would normalise the patient's situation and also offer empowerment, thus promoting sustainable change. Participant (d) said:

"It's normalised, it's not a healthcare professional telling you its other people who have had that experience who are sharing their story."

Participant (i) agreed, saying:

"You can reduce their future risk by putting in place a programme which includes not only their physical fitness, but working on their mind and their thinking about themselves…. linking it in with a more formal sort of cardiac-rehab type of thing, where the whole approach becomes one more of enablement and rehabilitation and bringing the locus of control back within the person themselves again."

There is evidence that cardiac rehabilitation programmes may also reduce self-reported depression (Lennon *et al*., 2008; Lennon & Blake, 2009).

Returning to 'normal'. This links to a number of previously identified needs following TIA. Regaining confidence in self and future, developing a positive attitude, and avoiding over-protection from family and friends, could be some of the equivalent needs from the perspective of someone who has experienced a TIA. People after a TIA seem uncertain about what activities they can safely engage in. They typically require specific advice about returning to normal activity as far as possible, taking potential fatigue into consideration. Participant (d) said:

> *"Sometimes, they just need our reassurance and acknowledgement that yes, they can go back doing the gardening, they can go back doing the housework and those sorts of things."*

The main activity that is affected by TIA is driving, which impacts on independence. It is a short-lived restriction (28 days), unless there are multiple episodes of TIA, which might require a three-month period free of events before returning to driving (DVLA, 2016). Participant (f) said:

> *"Advice about returning to everyday life really, within that I am thinking things like, yes they need driving advice, they need advice about letting their insurance companies know, they need that, but also, you know, you need to chat with them about well what have you thought about returning to work, and have you got back to your hobbies, and is there a reason why you are not going swimming any more, or what have you."*

There is however evidence that staff and professionals do not have good knowledge about the DVLA requirements following TIA and that communication and documentation relating to this important area is poor (Goodyear & Roseveare, 2003).

Willingness to change. One of the features of post TIA care is the delivery of information and advice about risk reduction, lifestyle changes and in the importance of taking any prescribed medication. However, information on its own is not perceived as useful for everyone. Professionals recognise that willingness to change has a significant impact on short and longer term secondary prevention measures. Some professionals recommend formal motivational interviewing, when people seem stuck in a position of reluctance to change. Motivational interviewing is also linked to motivational stages of change (Markland *et al*., 2005). The motivational stages of change were described by Prochaska and Velicer (1997), and pass from pre-contemplation, through contemplation, preparation, action and finally to maintenance. However, this is rarely a linear journey. It would appear that the professionals recognise the difficulties associated with behaviour change and the need to assess each person's willingness to change at each contact, Participant (i).said:

> *"Addressing people's fears, giving fairly formal motivational interviews with patients who are in a bit of a stuck position and aren't very easily going to be helped to change their lifestyle, and they will need that sort of motivational challenge to get them out of that circle."*

Participant (d) observed:

> *"Certainly, when they are in clinic at that particular time, that is, how can we stop this from happening again, they are very receptive at that time, whether that is continued, some of them when they come back in to follow up clinic then yes, they are still very frightened by the whole event, they are wanting to do everything and anything they can, whereas others, the enormity of what has happened has sort of dropped off."*

There was also recognition by Participant (e), that badly managed interventions relating to lifestyle and behaviour change can cause additional anxiety, and therefore cause the patient additional problems:

> *'Patients need to have responsibility for their own health, so it's a good thing, but you need to make sure that you're not feeding anxiety.'*

Top three needs in the opinion of professionals

At each interview participants were asked to identify the top three needs in terms of priority to address. A number of participants clustered pre-existing needs, others identified needs not previously within the needs lists. Two participants felt they really must have a top four, a full attributed list can be found in Appendix C13. In Table 35 the identified needs are clustered into loose themes.

Table 35 Professional views on high priority needs

Theme	High priority needs	Frequency
Avoiding Stroke	Secondary prevention	7
	Lifestyle advice	6
	Medication	4
	Risk reduction	2
	Keeping healthy	2
Emotional / psychological	Psychological support	6
	Advice and support	2
	Reassurance	1
	Confidence	1
	Validation	
	Help seeking	1
	Empowerment	1
	Family strain	1
	Self-image	1
Getting back to normal	Restoring physical fitness	1
	Returning to everyday life	1
Professional processes	Seeing the bigger picture	1
	Sustaining change	1
	Willingness to change	1

Draft model of professionals' view of needs following TIA

The views of professionals were summarised in a flow diagram which outlines the various areas of conversation relating to TIA needs (Figure 17, page 162). A number of needs were identified relating to current service provision, including the roles of primary and secondary care in relation to TIA. The interface between primary and secondary care and transfer of care were also identified as areas that can create needs when not well managed. Difficulties with diagnosis and promoting early presentation were discussed, and the role and situation for formal follow-up was also discussed. The area labelled 'professional perceptions of patient problems fell into four categories. Responses, which relate to the reactions of others, including carer anxiety and the risk of over-protective behaviours towards the person who had a TIA. Reactions, which relate to the individual's emotional responses to experiencing a TIA. Issues which are the more tangible effects of TIA, such as driving restrictions, fatigue, sleep disturbance, the impact on sexual activity or the ability to work. Financial issues such as the increased cost of travel insurance,

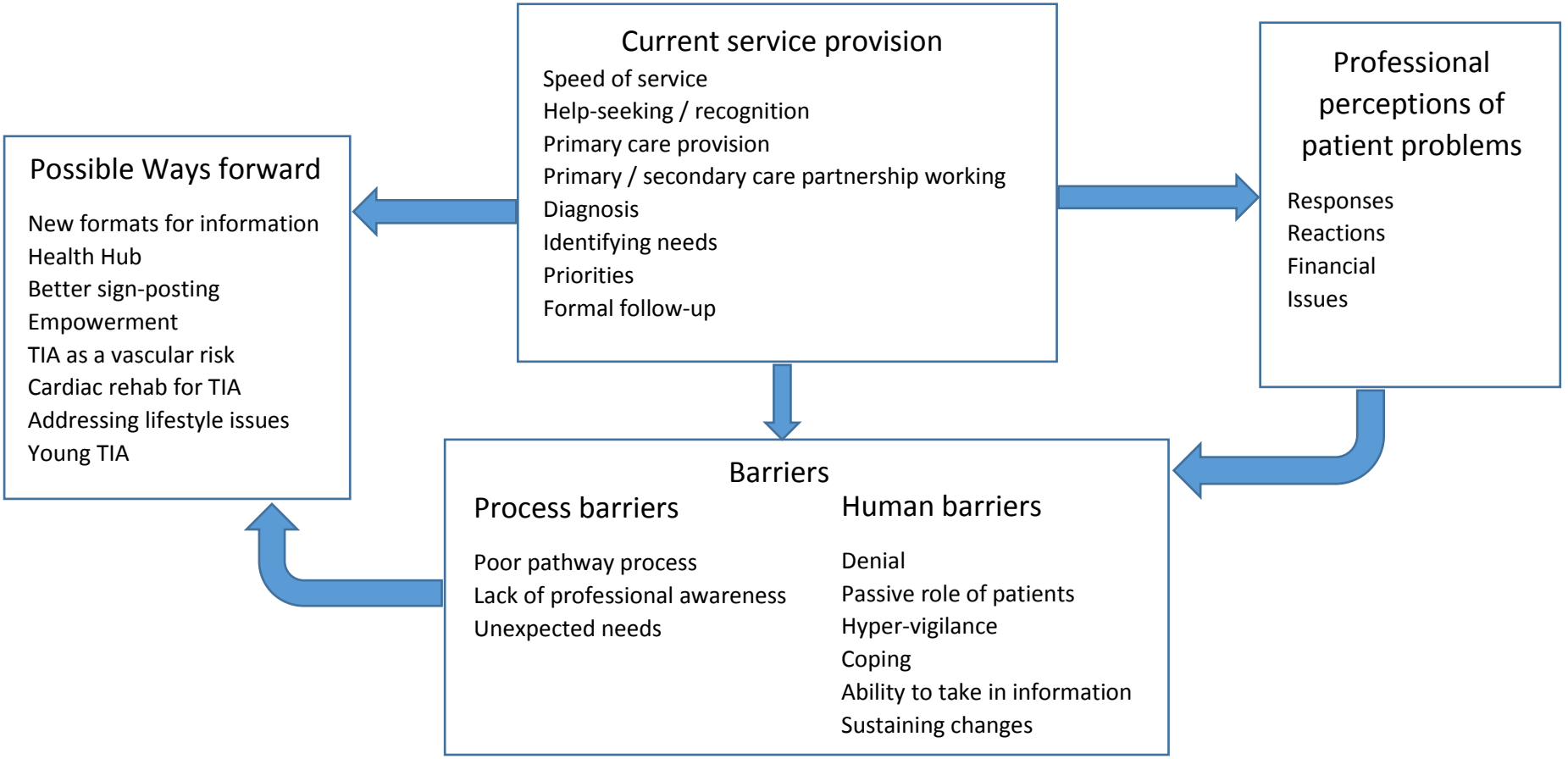
the potential impact on obtaining life insurance or mortgage cover as well as the more obvious short-term costs of not being able to drive.

Professionals identified a number of barriers to recovery following TIA, these were divided into the process barriers, where the health service systems can impede diagnosis, timely assessment or the availability of ongoing support. Human barriers tended to be intrinsic to the person who had the TIA, these included a number of behaviours and possible coping strategies, which were likely to delay or derail secondary prevention measures or increase anxiety.

Possible ways forward were the suggestions made by professionals about how services might be adapted to better meet the needs of those that use them. This included offering formal groups for exercise and education based on the model of cardiac rehabilitation. Providing peer support via groups, offering existing information in new and more interesting formats, for example consider the use of apps to engage the IT literate. There has been talk in the Southwest for some time about the development of a ‘health hub’ where all services can be accessed from a single point, thus making sign-posting more effective.

The model is predominantly a digest of the interviews, but forms a narrative, which makes the data easier to follow.

Figure 17 A draft model summarising the themes that came from the professional interviews about people's needs following TIA



5.5 Discussion

Summary of findings

The survey showed that staff recognise the potential for problems to be experienced and therefore, needs to arise following TIA. There was a commonly held belief that needs would be specific to the individual and their circumstances, although there were a number of needs that were thought to be highly relevant, such as 'secondary prevention', 'information and advice' and 'maintaining health status'. The survey gave rise to some interesting responses, when considering that TIA, by definition, requires all symptoms to have resolved within 24 hours. However, it highlights the willingness of staff to consider potential needs or problems following TIA.

Patients identified several issues that were either not found in the SNM, or were related to a specific context found within the TIA experience. Many needs were found to be shared between stroke survivors and people following TIA. There was a core of commonly identified needs from the SNM that most participants identified with. Then there were a wider range of less commonly experienced needs, which appeared to be more specific to the individual concerned.

Participants of the focus groups recommended some changes to the placement of elements within the Venn diagram. This resulted in a few elements, which had previously been considered needs only in stroke survivors, being moved into the 'stroke and TIA' intersection. Three new TIA specific needs were also identified. Two of these were the need to sustain changes over time and the need to not feel a fraud. The other new TIA specific need was related to carer informational needs.

The groups were asked to identify their top five needs. There was some overlap between groups, with eight individual needs identified, two of which were identified by both groups. It is surprising perhaps, that risk reduction was not found in the top five needs of both groups.

Finally, the focus groups were asked to consider how the identified needs might be addressed. Suggestions were made relating to 'information giving', 'raising awareness of TIA', and looking at how some of the 'financial difficulties might be addressed'.

The carers questionnaire requires much larger numbers of responses to enable rigorous analysis. However, it was interesting to note the similarities between carer and professional responses to a similar research tool. TIA 'carers' have not previously been systematically asked for their views in relation to needs following TIA. Due to the very small number of participants it is not possible to draw any firm conclusions but this line of enquiry has offered some intriguing insights into life after TIA.

Interviews with professionals involved in the care of people following TIA demonstrated the range of approaches used. Some of the medics were very clear that their remit was primarily focused on diagnosis and medical management. The nurses reported an approach that looked at people holistically, considering physical, emotional and social issues. There was general agreement that the materials presented from initial interviews and focus group appeared reasonable. There were four new needs identified from a professional perspective. They were 'diagnostic uncertainty; 'TIA as part of wider vascular disease'; 'returning to "normal" '; and 'willingness to change'.

Recruitment / response rate

2a – staff survey

The email and postal requests were sent together with a reminder, two weeks after initial contact. The response rate of 20% was lower than would be desired, despite the use of a single reminder, it is in keeping with the response rates of other remote surveys (Nulty, 2008; Scott *et al.,* 2011). There are likely to be several factors influencing the response rate, such as available time. Many of the members provided work email addresses rather than their personal email addresses to the fora (personal communication), which may have influenced their ability to complete the survey at work. There had been comments regarding difficulty understanding the relevance of the questions to the subject matter during development. This had been addressed as far as possible, by trying to clarify the intent of the survey in the participant information sheet and invitation. However, it is recognised that nurses are less likely to complete a survey if it does not appear relevant (Van Geest & Johnson, 2011), and the free text comments also suggest that perceived relevance may have been an issue.

The response rate was within acceptable limits, although on the low side. Most respondents were stroke specialists (56%), a further 20% were nurses working on a stroke unit. Therefore 76% of the respondents work regularly with stroke and 71% saw TIA patients at least once a week.

2b – patient and carers views

The initial focus group demonstrated that the participant selection and screening processes worked. The actual accrual of participants was low Northwest. There was approximately a 10% positive response rate (5/55) for the focus group, which is in keeping with the reported experiences of other researchers (Reynolds, 2011). The focus group aimed to recruit people who had experienced a TIA over the previous 13 months. The positive responses were all from people within seven months of their event. This means there could be differences in peoples' perceptions of the relevance of research for them as time passes. The TIA service from which the potential participants for the focus group were recruited was one where follow-up was rarely offered; outstanding results were forwarded to the patient and GP when they became available.

Recruitment for interviews was also approximately 10% in the Southwest (10/92). Most patients who participated in semi-structured interviews had received care in a service where investigations and results were typically available on the first day of attendance, and follow-up was routinely offered to all patients with a diagnosis of TIA.

TIA patients can be difficult to recruit into research due to a range of possible reasons, including; a desire to forget the event and 'put it behind them'; lack of belief in the diagnosis; low importance attached to the event; and a need to play the event down and minimise importance of the TIA (Gibson & Watkins, 2012). Carers can be even more difficult to identify, reach and recruit. Also, carers may not recognise the contributions that they have made following a loved-one or friend's TIA. The role may be viewed as normal behaviour in the face of illness on the part of a significant other. Finally, it is not possible to predict what number or proportion of the invitations were actually passed to a potential carer for consideration. Therefore, it is not possible to know whether the low

recruitment was due to the lack of recognition of the carer role by the person experiencing TIA, or a lack of interest in participating on the part of the carer themselves.

In view of the very slow recruitment into the carers' questionnaire, an alternative approach was considered, which would allow carers to potentially be recruited at clinic attendances directly. This change was drafted as a protocol amendment and submitted to NRES as a substantial amendment. This was considered to be too far from the original protocol and approval was not granted. It was suggested that drafting the proposed recruitment method as a separate protocol was more likely to be successful; however, this was not pursued due to time constraints of the research project.

2c – Staff interviews

Recruitment used a modified snowball method. This method of recruitment is usually used with hard to reach groups where personal contact is likely to improve the chances of participation (Atkinson & Flint, 2001). Although the author had a short-list of professional groups deemed to be desirable to interview, the recruitment was led by the recommendations of previous participants. The benefit of using this sampling strategy was that professionals that were unknown to the researcher or may not have been considered by the researcher as potential participants would be considered and contacted. The starting point for recruitment was a Stroke Consultant physician, a Community Stroke Co-ordinator and a Stroke Nurse Practitioner. These professionals had expressed an interest in participating in TIA research at a previous stroke conference held in the Southwest of England. Each of the index participants made recommendations for further potential participants. Some of whom were subsequently interviewed, whilst some were not. The GP Practice Nurse was a professional of particular interest in the research, since it appeared that Practice Nurses provide the majority of the support and advice available in primary care. The recommendations locally did not deliver a potential participant. One Practice Nurse had expressed an interest in participating in research at the stroke conference. She works in the Home Counties and it is possible that service delivery is different in that area to the services provided in the South of England.

Findings in relation to SNM

It was interesting that the staff survey showed high levels of positive responses to physical needs and problems, particularly since participants were asked to consider TIA in isolation of any other conditions. This could represent staff acknowledging that sometimes patients are given a diagnosis of TIA, when they clearly still have on-going focal neurology, or could be due to the interpretation of the question and might relate to the symptoms at onset of TIA. Participants were asked to disregard other pre-existing problems. However, that does not explain 15% of respondents reporting that spasticity or spasm were relevant or important. Fractures and bone loss are also quite difficult to understand in this context. The 30% response that falls / accidents were definitely relevant, might be in relation to leg weakness at the time of onset, leading to a fear of falling (if another TIA or stroke were to occur). Another possibility might be that respondents were considering the needs of the patients they typically see in TIA clinics where up to 50% of those seen may not have a TIA diagnosis (Dennis *et al*., 1990; Kelly *et al*., 2001). When considering the 'yes' and 'maybe' responses together, there appeared to be a real appreciation of the potential mental / emotional impact of TIA. It is interesting to note that only 78% of respondents felt that body image would be related to any needs following TIA. There is a growing body of research to support the views of respondents regarding elements in the mental / emotional domain. In particular, 'anxiety', 'fear' and 'depression' (Moran *et al*., 2013), all of which have rated very highly in the survey. Added to that is 'anger and frustration' which rated highly in the survey but is not so prominent in the literature. 'Motivation, focus and confidence' is also highly rated in the survey and there are some previous reports of difficulties with those issues (Arts *et al*., 2008).

Since this research started, there has been a publication looking at memory loss following TIA (Pendlebury *et al*., 2011). In practice, there was a recognition and awareness of memory being a concern following TIA. It can be argued that on-going cognitive impairment represents stroke rather than TIA, and could demonstrate misdiagnosis of the patient. Speech and understanding problems and needs identified may possibly relate to the symptoms at initial onset of TIA. On-going problems, by definition, would indicate stroke rather than TIA.

In terms of TIA as a condition, taken in isolation, many of the everyday living needs would not be expected to feature highly following TIA. Particularly the needs relating to functional issues such as ‘walking’, ‘limb movement’, ‘balance’, ‘hygiene’ and ‘continence’. These relatively high responses (>30% definitely, or possibly relevant) could be due to misinterpretation of the question, symptoms experienced at onset or again, may be due to misdiagnosis of a minor stroke.

When considering the responses from the domain of re-enablement, it was difficult to understand why such a high proportion of respondents felt that ‘aids or adaptations’ might, or would, be needed following TIA. However, all the re-enablement needs rated highly, and this was perhaps due to the nursing and therapy ethos of health promotion working towards the recovery of independence and autonomy.

Within the domain of social needs, ‘driving and transport’ was recognised as a key feature following TIA. This is perhaps not surprising since TIA is a short-lived phenomenon which, in the UK carries a DVLA requirement to cease driving for 28 days, despite the early resolution of symptoms (DVLA, 2016). Patients need to be informed of these regulations and understand the rationale and consequences of non-compliance. Another element that rated highly was ‘work’. This may demonstrate an appreciation of the psychological impacts of TIA or the fatigue that some patients report. Obviously, support in relation to work will not be needed by all patients, for example, those who have retired, but it is none the less high on the agenda of the healthcare professionals who participated.

Finally, financial / legal needs responses were considered. It was somewhat surprising to see that 5% of respondents felt there was a definite need for ‘palliative care’ following a TIA. Although TIA would not typically be considered a terminal event, it is well recognised that it can be a warning of an imminent major stroke (Rothwell *et al.,* 2004). It might be, that those staff who responded positively to ‘palliative care’, were in fact referring to discussions about advanced planning in the event of a stroke, although it would also seem likely that the TIA had not been considered in isolation. A few of the responses in this domain suggest that the questionnaire may not have been completed as

intended, therefore, caution may be required when interpreting the data obtained.

In looking at the frequency with which each need was identified by patients, there is a risk that less common, thus potentially more hidden needs could be overlooked. For example, one of the participants who identified oral health as a need, had been diagnosed with sub-acute bacterial endocarditis, which is likely to have influenced his perceptions due to the links between oral health and hygiene and his cardiac disease. Dental and oral health would not be a need or issue for most people, and could potentially be overlooked without specific insight into this participant's history, but for him, it was a significant concern. Another example is that only one person identified needs relating to relationships and sex life. However, for this individual it was his greatest concern following his TIA, and had caused him significant anxiety and upset.

Physical needs. Considering the definition of TIA as focal neurological symptoms that had completely resolved (WHO, 1975), it is interesting to note the high levels of fatigue reported within the group. It might suggest that fatigue is centrally mediated or due to unrecognised cerebral infarct (Winward *et al.,* 2009; Barbour & Mead, 2012; Fens *et al.*, 2012). The other two frequently reported issues (more than three participants) were needs relating to 'vertigo' and 'balance'. It is difficult to know whether these concerns are related to central neurology, because there is the possibility that in addressing risk factors, in particular hypertension, there could be an element of drug induced postural hypotension (Kamaruzzaman, *et al.,* 2010; Milazzo *et al.,* 2012), that could cause, or contribute, to these difficulties. There are also reports of patients being given a diagnosis who have persisting neurological deficits (Moreau, Jeerakathil & Coutts, 2012).

Mental / emotional needs. 'Quality of life' was identified as a need in over half the participants, demonstrating that although, by definition, the medical view would be that these people are 'back to normal', the experience has had a detrimental impact on their perception of quality of life. Relatively high levels of 'anxiety', 'fear' and 'depression' were also identified. These are recognised after effects of stroke, but their presence following TIA has only been reported

more recently (Arts *et al*., 2008; Luijendijk *et al.,* 2011; Spurgeon *et al.,* 2012). Dealing with others' reactions was also highlighted. TIA does not generally carry a stigma. On probing, this related to feeling a loss of autonomy or feeling 'watched' caused by the behaviour of friends and family.

Communication needs. 'Talking' scored highest in the communication category. This was usually due to communication difficulties during the TIA itself, rather than following the episode. Participants were keen to discuss this element of their symptoms and it was clearly very disturbing for them at the time. Needs relating to both 'muddled thinking' and 'memory' were also identified by four participants in each case. These problems were ongoing, following the initial TIA, although one participant reported her memory was initially poor, but improved over the following weeks. These deficits have been reported in the literature (Pendlebury *et al.,* 2011).

Everyday living needs. These included 'prevention of stroke', which scored highest with ten out of the twelve participants identifying it as important. This was closely followed by 'keeping healthy' being identified by nine participants. Seven participants identified 'general health' (maintenance). These are commonly identified needs which fit in well with TIA service provision, so they are more likely to be met than some of the less obvious needs. Other slightly lower scoring needs were 'managing medication' and 'dietary adaptations'. Both are likely to have slightly different meanings for people following stroke or TIA. Those with TIA appear to be referring to ensuring they are taking the appropriate medication and altering their diet in line with healthy eating recommendations, rather than the physical dexterity and swallowing skills to manage their medications and food.

Re-enablement needs. The only re-enablement need to be identified by five participants was the need for 'information and advice'. It was unexpected that this was not highlighted by more participants considering the body of evidence relating to information provision following stroke reported in a recent Cochrane review (Forster *et al.,* 2012). It could be that the participants felt they had received the information they required, and therefore it was not perceived as a need.

Social needs. ‘Driving and transport’ was the only need in this category to be identified by five participants. This initially appeared a low response rate for an issue that is likely to be a significant restriction for people following TIA, however only seven of the twelve participants were drivers prior to their event, which is in keeping with research findings (McCarron, Loftus & McCarron, 2008).

Financial / legal / care needs. The main concern relating to care needs, was regarding ‘family strain / wellbeing’. This research included a small non-probability sample. For this reason, it is possible that any need identified in the SNM might apply to an individual at some time following their TIA. It is also the case that the more commonly identified needs tend to be more readily recognised by professionals, as can be seen in Phase 2a. However, the less common needs may well represent a larger problem for the person who experiences them, because those needs are less likely to be recognised and addressed in clinical practice.

There were several issues or needs expressed by people following TIA that did not quite fit within the SNM. Some of the needs are similar to those found in the SNM but are discussed in a different context to that following stroke, where longer lasting physical or mental impairments occur.

The findings from the patient interviews were presented to patients as part of the focus groups. This showed that the following needs were originally in the stroke only classification within the Venn diagram, but the group participants felt they needed to be moved to the Stroke and TIA intersection. ‘Benefits / financial’ related to potential increased costs associated with the diagnosis, such as travel costs caused by not being able to drive, but also including higher premiums for travel insurance, or not being able to access some financial products following diagnosis. ‘Vision’ was included because the composition of the focus group participants had a high number of patients who had experienced visual disturbance as part of their TIA. This added a new perspective to the research of TIA, not only, by including vision as part of the TIA / stroke intersection of the Venn diagram but also, by demonstrating a variety of pathways into healthcare that had previously not been considered.

Patients within the focus group who experienced visual problems at onset, typically appeared to consult their optician as their first contact with healthcare. The response of the optician was varied, with one patient advised to attend the local eye hospital as a matter of urgency and the other advised to see their GP. In each case this led to delay in attending TIA services, and potentially offering an opportunity for improving access pathways to promote rapid recognition and referral and appropriate treatment.

Power of attorney was also highlighted as important following TIA. The participant who felt strongly about this had a personal experience with her sister having a TIA followed by a major stroke, after which she (sister) lacked capacity to make her own decisions. The participant had experienced difficulties dealing with her sister's affairs on her behalf and felt people should be encouraged to put a power of attorney in place following TIA, to reduce the burden on family and friends, although this may not be as generalizable as some of the other findings. Finally, 'self-management' was identified as desirable following TIA, with people being encouraged to take responsibility for their own health.

There were similarities between the responses obtained from the staff survey and carers questionnaire. Out of 48 elements identified as relevant to carers, 31 elements were shared by the 'nursing and other staff' who had identified 42 elements in total. During the focus groups one of the TIA only needs related to information for carers / significant others about TIA. This has also been highlighted by the carers themselves.

Findings in relation to needs not found in SNM

Some of the comments received in the free text section of the staff survey had in fact been covered within the main body of the questionnaire, for example the responses relating to secondary prevention and lifestyle issues. There were also a few people who felt the need to clarify their interpretation of what constitutes a TIA. This was probably due to the bias towards on-going symptoms in the elements identified given that the SNM was developed with stroke survivors. Some responses indicated that needs would be based on an individual's coping strategies; perception of events; and their support network; and should be based on what the patients themselves place most value on.

Only a single research paper was published before this research was conducted illustrating the fear and anxiety people may experience following TIA (Arts *et al*., 2008). The most obvious example of the loss of independence for many people is the suspension of driving privileges for 28 days following the event. Within the small number of participants interviewed, all but one driver had been told about the DVLA regulations. It is well documented that driving advice is not always well managed by staff, probably due to their lack of awareness of DVLA regulations following TIA (Batool *et al*., 2014). A repeated theme during discussions was about the need to rebuild damaged confidence. Because the TIA occurred with no warning, there was concern about their abilities to continue with their normal activities, for example, cycling, and in some cases a reluctance to plan for the future. These themes offer a target for clinical intervention, possibly at the follow-up consultation.

The previously identified TIA only needs were discussed by both focus groups. There seemed to be a consensus that the TIA only needs initially identified, seemed reasonable and participants could identify with them. There were, however, two new needs that became apparent when the groups were talking together. One need related to '*feeling a fraud*' and '*making a fuss about nothing'*. This, it was agreed, was due to the brevity of symptoms and the fact that they apparently recovered completely. This impacted on the participants' desire to seek help. There was concern that they might have imagined their symptoms, or concern that they would not be believed. This fits in with denial and avoiding delay, but seemed distinct from those needs.

The other emergent need related to the ability to 'sustain changes' made acutely following a TIA. One participant spoke of 'slipping back' into his old ways and behaviours. This need links closely to stroke prevention and risk reduction, but again is subtly different in terms of context. It is well recognised that lifestyle changes often do not always translate into long-term behaviour changes (Leistner *et al*., 2012). However, sustaining changes was felt to be a need following TIA and was included on that basis.

Strengths

2a – Staff survey

It would have been useful to know where individuals who completed the survey worked, to evaluate the geographical scope of the survey. However, in many hospitals there are only a few specialist stroke staff, which would have potentially made some of the participants identifiable. For this reason, work locations were not requested. By distributing the questionnaire through the NSNF and SSNF there was the potential to capture views from across the UK, thus representing a range of service provision models as well as a range of professional roles. This can be considered a strength of the research.

2b – Patients and cares views

Previously within the programme of research, the approach had been predominantly quantitative, with the use of survey tools. The initial patient focus group, and interviews were the first elements of the research, designed to seek a greater understanding of responses by using a mixture of both quantitative and qualitative methods. This was achieved by combining a card sort exercise and review of the SNM with qualitative data collection using a focus group and semi-structured interviews. The methodology used in this sub-study was broadly iterative, using a realist approach, trying to be impartial, but employing active listening skills and reflection. It could not be considered Grounded Theory since a pre-existing framework (SNM) was used to guide the focus group and interviews. The analysis was conducted using systematic coding of concepts. The data analysis led the discovery of trends and patterns within interviews and between participants (Corbin & Strauss, 2015), and influenced the evolution of the data collection methods during the study, based on an iterative process (Charmaz, 2006).

There were advantages to the use of a mixed methods approach. Firstly, the continued use of the SNM enabled comparisons across different participant groups during the analysis of Phase 2 as a whole. Secondly, the use of a more qualitative approach was less constrictive and allowed participants to explore and explain their experiences and associated needs. Thirdly, using an iterative approach, the first three interviews were predominantly about reviewing the SNM elements, provided as a deck of cards, sorting them into categories

relating to relevance and then scoring for importance. As the interviews progressed, so the format changed to a discussion about the participant's experiences followed by the card sort (participants 4 and 5). This moved to a less structured interview, where at the end, the researcher fed back the needs identified during the discussion, thus giving immediate feedback and validation of researcher's interpretation. This was followed by the participant reviewing the remaining cards to ensure nothing was missed.

One of the strengths of the focus groups was that by returning to the data generated in the interviews, there was the ability to gain some validation of the experiences and needs identified by the individual interviews of people who had experienced a TIA. The research is building on the findings of previous sub-studies to form a bigger picture. This process is known as triangulation and helps to confirm that findings obtained in one area, are relevant to other people in a similar, but not identical situation (Golafshani, 2003; Shenton, 2004). However, it must be recognised that small numbers were involved and it is possible that findings may only relate to local services, and local service users. The ability to review findings that included input from carers and professionals also enabled differing viewpoints to be considered.

Recruitment for the focus groups resulted in groups with participants who had a time span of between 7 and 20 weeks elapsed since their TIA. This helped to develop an understanding of how needs might change over time after a TIA. This was considered a strength of the research in that it clearly demonstrated that there are different needs according to how long ago the event occurred, but also demonstrated that in some cases some needs can persist.

A strength of the carer questionnaire was the method selected for this part of the research. The questionnaire was kept deliberately similar to the previous questionnaire utilised with nurses and other healthcare staff, and was based on the SNM (French *et al*., 2008). This allowed for comparison between the views of professionals and those of carers.

2c – Staff interviews

A semi-structured interview method was used to enable a depth of enquiry whilst still retaining common themes between interviews. The material provided for the discussion ensured that the issues, problems and needs identified by people experiencing a TIA remained the central feature of the discussion, but did not prevent new ideas or themes from emerging.

A modified snowball method of recruitment was used for the staff interviews. This enabled people to be interviewed who would not have otherwise been selected, thus giving a greater diversity of opinions and experiences. The personal introductions in some cases were very helpful. For example, the Community Stroke Co-ordinator had been engaged in some work on community stroke services, so she recommended the author speak to the Commissioner of Stroke Services at the Clinical Care Group. Her recommendation enabled easy access to both the commissioner and, through him, to a GP, who are historically difficult to interview due to their pressure of work.

Limitations

2a – Staff survey

By the nature of survey techniques, there were limitations imposed on the responses, based on the questions asked and response choices available. This was, to some extent, mitigated by the provision of a free text box for any other comments at the end of the survey, which allowed participants with strongly held views to share them. The survey tool also prompted free-text responses to outline any perceived gaps in identified needs following TIA.

Response rates below 60% are often considered unacceptable. This is particularly in relation to publication of research. The response rate at the conferences was limited by the number of computer terminals available for use in breaks and at lunch time. The sampling at regional conferences was well received, the computers were in almost continuous use during the times available, and sometimes there were even queues forming. In retrospect, it would have been better to have more computer stations available so as not to limit participation. Another strategy that could have been employed, to improve participation at the conferences, would have been to include the web address

on the participant information sheet. Those potential participants who were unable to access the computers during breaks at the conferences could then have participated from home after the event.

It is difficult to be sure exactly how many people received the invitation to participate in the on-line survey, or via post, since NSNF and SSNF membership lists are updated at most once a year (personal communication), and if members have moved to a new house, changed job or email address, they may not have received the questionnaire (Bandilla, *et al.,* 2012). Membership fees for both the groups is relatively low, which might mean that membership is perceived as having limited monetary value, and could account for members failing to ensure their current contact details are held. Members of the NSNF and SSNF who attended either conference, and completed the survey on line at that time, would not have been expected to respond to the invitation via their stroke forum.

Several of the survey participants also remarked on how difficult they found it to complete the questionnaire due to the strong bias towards stroke. Unfortunately, this was inevitable once the decision was made to include all the stroke needs identified, and not remove those relating to potential on-going problems. This decision may have been proved to be the correct one, based on the unexpectedly high rate of positive responses for many of these elements. It can be seen as a strength of the study, since there had been no prior editing of the potential needs documented in the SNM, and elements were provided in the format presented in the SNM, since the report had been aimed at a professional audience. Although there was overlap with the items on the SNM and staff perception of needs following TIA, there was perhaps a different emphasis. However, the survey method did not allow participants to clarify their responses other than via the free text box.

2b – Patient and carer views

The researcher sometimes found it difficult to inhabit the research role and not offer opinions, support or advice. The researcher's own experience as a stroke nurse practitioner, where she sees many patients in clinic in a similar one-to-one situation, required her to focus very hard on gathering people's experiences

and exploring their view of needs, rather than addressing those needs that were revealed. On reviewing the transcripts of the interviews, it was apparent that, particularly in the earlier interviews, there was some blurring of roles. It is important to be aware of researcher stance and biases, as they will impact on how the researcher will respond during the interaction (Walsh & Downe, 2006).

The interview with Participant Seven at her own home was interrupted by two telephone calls, following which it became apparent from her tone of voice and body language that she was no longer interested in finishing the interview. For this reason, the researcher cut the interview short. On reflection, it might have been better to face the situation head on and ask the participant whether she was willing to continue the interview, rather than picking up on non-verbal cues and interpreting them as the participant's desire to cease the interview (King & Horrocks, 2010). As part of that reflection on practice it was decided that any further situations of a similar nature would provoke the question '*Are you happy to continue with the interview / encounter?*', although this situation did not arise again.

One participant, following discussion with the supervisory team, was not included in the analysis and evaluation. This decision was reached because, when the potential participant screening was conducted, there was no evidence on this person's medical records of subsequent stroke. However, when the researcher was welcomed into the participant's home to conduct the interview, it became apparent that she had sustained a stroke, for which she was treated at a different hospital, shortly after her attendance in TIA clinic. A judgement was made at the time that to abort the interview at that point would be inappropriate and cause distress to the participant. For that reason, the interview was conducted, with a focus on the initial TIA. Unfortunately, the responses received during the interview demonstrated that it was difficult for the participant to tease out events and feelings relating solely to the TIA. Since the participant had been hospitalised for a couple of weeks and was told she had sustained a stroke, it was decided that it would not be appropriate to include the data. The decision was because the subsequent stroke was a pre-existing exclusion criterion. This demonstrated a limitation in the screening process used for the study, since there was no mechanism to capture data from other hospitals. On

reflection, this situation could easily have been avoided by checking the screening criteria with potential participants when discussing the study and arranging a meeting.

The focus groups were conducted with a small number of participants selected from two areas of the UK, Northwest and Southwest. It would not be possible to claim that the findings from these interviews are generalizable in any way, since, to some extent, perceived needs are likely to be related to the model of TIA service to which an individual has been exposed. Within the group sampled, data saturation appeared to be reached with the final interviews not revealing any new themes. However, it is not possible to state that patients drawn from another area, who had been exposed to other services, would only have the same views.

Sampling was based at two District General Hospitals, and was limited to potential participants who had received a TIA diagnosis during the preceding 13 months. Every eligible potential participant was contacted. There were surplus responses for interviews in the Southwest, but in the Northwest, there was very limited response to contact by mail. The difficulties experienced with recruiting to focus groups led to the use of interview methods, which changed the type of data obtained and very likely altered the longer-term trajectory of the research.

The biggest limitation to the carers' survey is the small sample number. However, it has produced some interesting results which would certainly bear further investigation. Attempts to increase recruitment met with an unfavourable opinion from the ethics committee, who felt the changes were too radical to warrant being considered a substantive amendment and recommended presenting the changes as a separate study. Another limitation was that it was not possible to probe further into some of the responses received, due to the anonymity offered to participants when they were recruited.

Using a qualitative research method would have potentially offered a deeper insight into carer views, but a far higher response rate had initially been anticipated. At the point, it became apparent that recruitment of carers was problematic, there was insufficient time to plan and execute a separate study specifically targeting them, rather than relying on 'co-recruitment' via potential

participants for other elements of the programme of research. However, the addition of the views of carers about the SNM element in relation to their experience of caring for someone following TIA adds a depth to the overall research that would otherwise be lacking.

2c – Staff interviews

Not all recommendations for interviews resulted in an agreement to be interviewed, and there were some professional groups the author was keen to talk to but was unable to secure an interview. One group were paramedics. They are often the first healthcare professional to be in contact with someone following TIA. The aim was to understand their thought processes during that very acute phase in the patient journey, clarifying which needs they felt people had, immediately following the index event. Several different routes were taken to access a paramedic. The local ambulance station lead was contacted and asked if any of the staff would be available to participate. Individual paramedics known to the Emergency Department Consultant were also contacted, but no response was forthcoming following a second approach.

Another group the author was very keen to talk to were opticians. Following the focus groups that formed an earlier sub-study of Phase 2b, it became apparent that opticians play a greater role in management of TIA than had previously been appreciated. The first opticians contacted were those who perform NHS retinal screening. It was thought that they were more used to working with the NHS and therefore might be more willing to be interviewed. This approach did not result in an interview. At that point, all interviewees were asked if they could recommend an optician who might be prepared to be interviewed. This did not result in an interview either. Local optician shops were approached in a general way to try and establish why recruitment was unsuccessful. It transpires that in the area local to the author, in the Southwest of England, all the opticians working in branches of the main chain-store opticians were locums, and therefore paid by the hour. The branch managers were not prepared to pass the invitation to participate in research to their opticians. The small independent opticians tended to be single practitioners and unwilling to participate due to workload. For this reason, no optician was interviewed despite this being highlighted as an area of interest. The inability to interview a paramedic and an

optician and include their insights in the analysis of the data collected is a limitation of this part of the research.

Implications for creating a model of needs

To create a model that would allow needs to be identified, and services to become more responsive, the data was reviewed in relation to time from event. Some novel needs were clearly time critical, and it could be seen that needs changed during the time course following the event. Four time-periods were identified, which fit with the patient experience and current service provision based on the NSS (DH, 2007) and the NICE Guideline 68 (NICE, 2008). The time-points are: Onset; diagnosis; Early (diagnosis - 28 days); Later (29+ days). Analysis of the views of need at each time-point will be considered.

5.6 Synthesis

Phase 2 has explored needs following TIA from the perspectives of patients, staff, and carers. The starting point in each case was the use of the SNM, based on the understanding that since TIA and stroke are part of the same disease continuum, it was thought likely that some needs were likely to be shared by those who have experienced both stroke and TIA.

In each sub-study, an iterative approach enabled the methods to develop, allowing the identification of TIA specific needs that are not to be found in the SNM. In the results section, the findings of each sub-study were reported in isolation. In the analysis section, results will be considered in relation to the aims of Phase 2. These were to explore how needs identified in people following stroke might also be relevant to people following TIA; to understand the views of patients, carers and staff about their perceptions of needs following TIA and identify areas of agreement and disagreement between groups; to identify and understand needs that were identified following TIA which appear distinct and unique to TIA and, finally, to develop a draft model of needs following TIA.

The mis-match in perception of needs between study groups is perhaps the clearest demonstration of how and why needs can remain unidentified and therefore un-met following TIA.

Relevance of SNM and mismatches between groups

Comparison has been made regarding the elements of the SNM that each group (patients, staff and carers) felt were relevant following TIA. To ensure that the output is as comprehensive as possible, those elements that were considered 'possibly relevant' were included with those elements considered 'definitely relevant'. The majority of the SNM needs (48) that were considered 'potentially relevant' following TIA were identified by patients, carers and staff (Figure 18, page 184). This suggests a recognition that a range of needs may arise following TIA. There was a total of 20 needs that the staff or carers thought 'might be relevant' that the patients themselves did not feel were potentially an issue. It is likely that, when considering a long list of possible needs, those people who have not experienced TIA for themselves were reluctant to discount needs that seemed possible in some circumstances. The patients appeared more comfortable excluding potential needs, possibly because they were able to speak from their own experiences. A number of the needs included by staff and carers were physical or practical needs e.g. cooking, using the toilet, washing / dressing / clothes. It may be that patients might have difficulties in these areas, but it would not be expected to be due to experiencing TIA, which would be expected to leave no physical deficit in function after the event resolved. It is possible that some responses identifying physical needs might relate to the TIA itself, when there could potentially be problems with, for example, mobility, if leg weakness was present. This explanation could account for some of the unexpected responses.

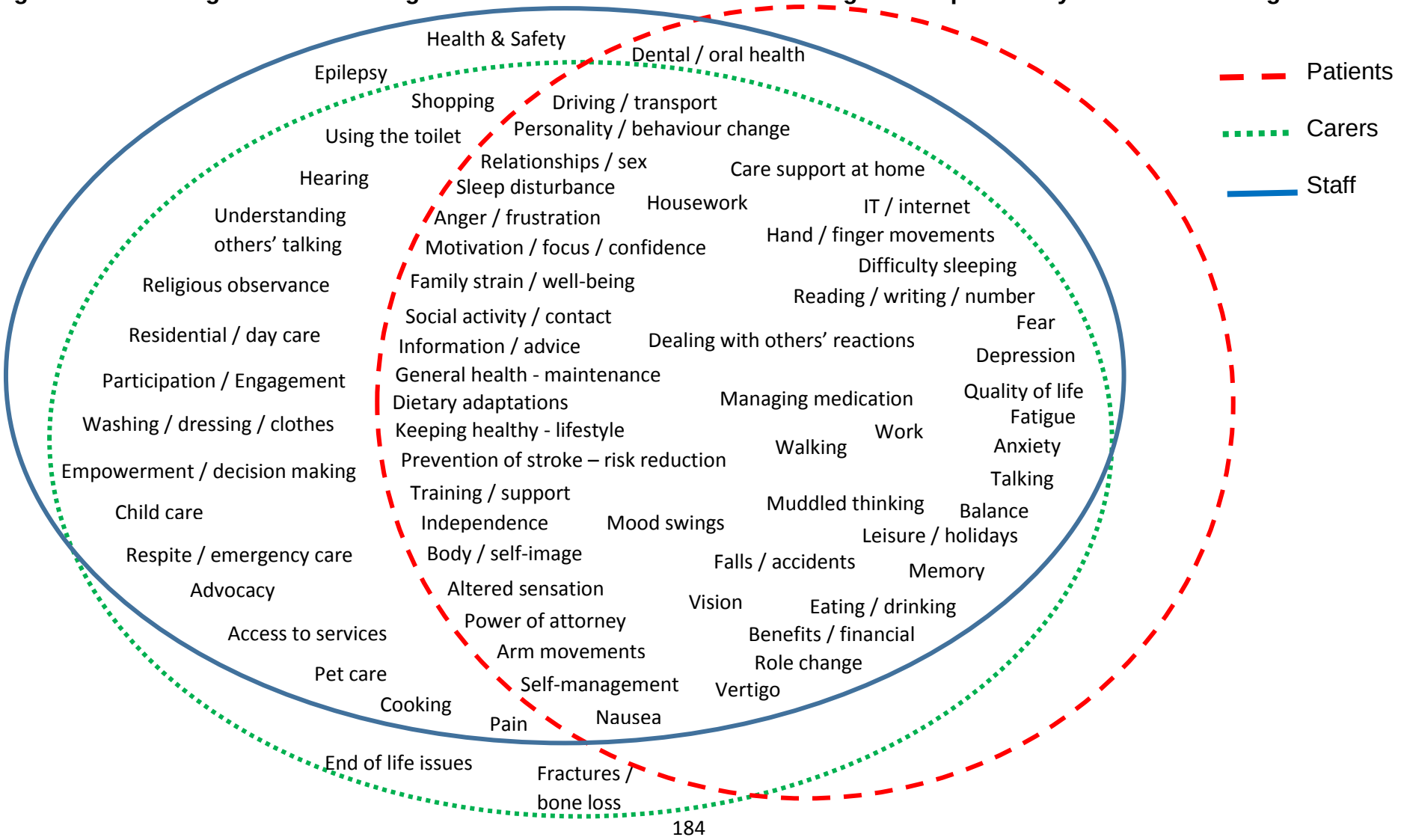
All the needs identified by the patients were also included within the responses from both staff and carers, with the exception of oral / dental care, which was not identified as a need by carers. This might be due to staff awareness regarding the link between dental infections and sub-acute bacterial endocarditis, which can potentially cause cardiac emboli. From a patient perspective one man (Participant 3), stressed the importance of dental care:

> *"I think that is most important…… I think it's an on-going…. I always make sure I go to the dentist every six months".* .

Within the card sort exercise this was considered relevant but it is not clear that it was considered a need specifically following TIA, rather an ongoing philosophy. This was not noticed or further explored at the time of the interview.

Overall there is a high level of agreement between the groups of participants in the research. There are no needs within the SNM that have been identified by patients alone. This suggests that recognition of the potential for needs to arise is present in all groups, and that the SNM provided a useful starting point for the research. Stroke and TIA are closely related conditions so it is unsurprising that there is such a degree of commonality.

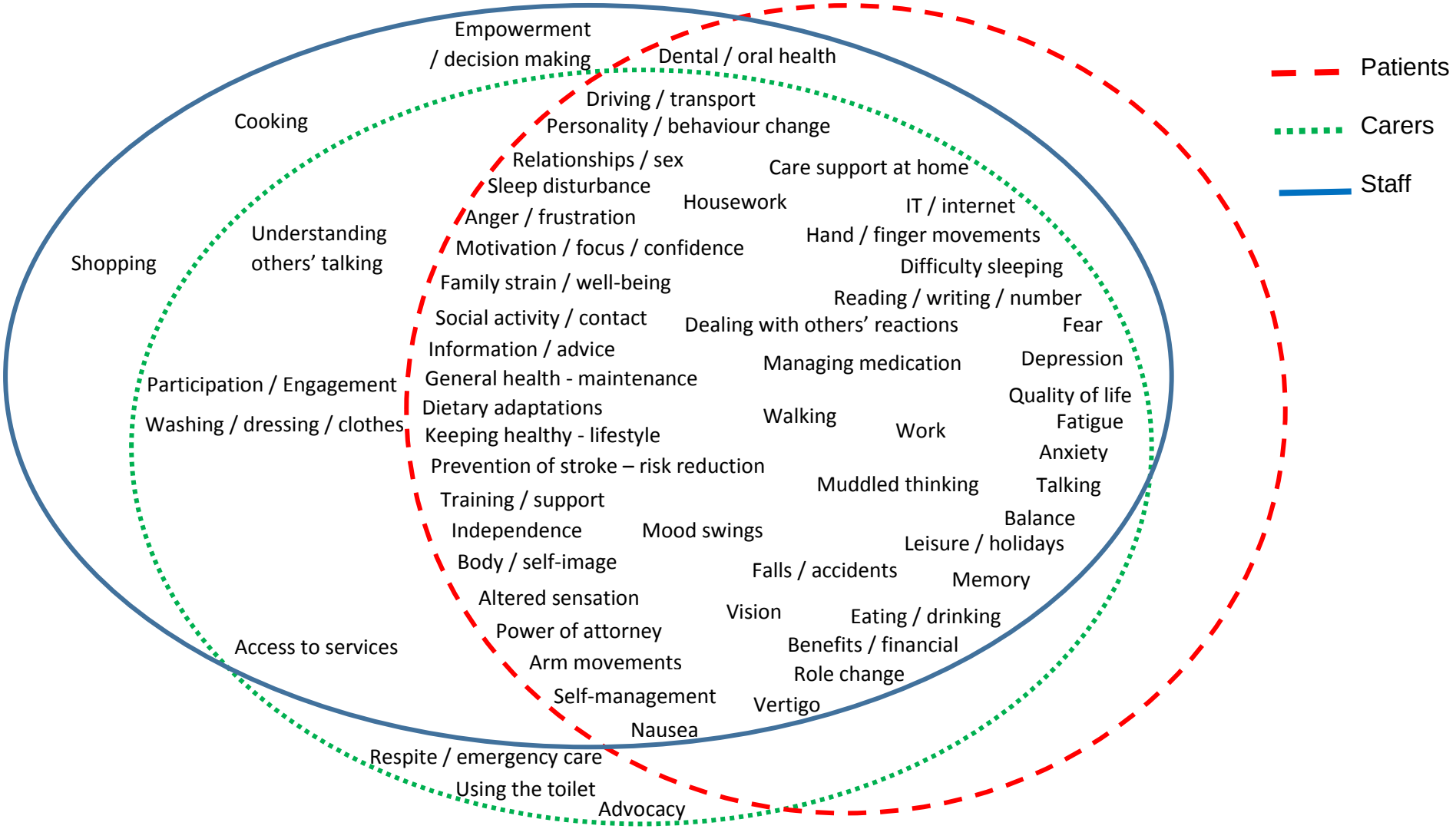
Figure 18 Venn diagram summarising all needs from the SNM that are thought to be potentially relevant following TIA



There is also a comparison between groups of those elements that are thought to be definitely relevant in each group (Figure 19). This relates to needs where there were less doubts about relevance, and it is demonstrated in a far greater level of agreement between groups. There were 49 needs identified by patients as 'definitely relevant', a further 11 needs were considered 'definitely relevant' by professionals or carers. This suggests that staff and carers might be trying to meet needs that don't exist. This could possibly explain patient reports of family "*fussing*", making them feel 'watched', 'smothered', or "*wrapped in cotton woo*l." This might be classified as 'reactions of others' which is found as a TIA only need.

.

Figure 19 Venn diagram summarising needs from the SNM that are thought to be definitely relevant following TIA



The majority of needs are recognised by all groups, but not all members of any of the groups will have identified all the needs. The most commonly identified needs considered important by each group of participants (patients, staff and carers), have also been identified and can be seen in Figure 20 (page 189). This clearly defines the mismatch between the priorities of each group. This figure shows that although professionals and carers have previously identified all the needs found in this Venn diagram, they haven't necessarily recognised the importance of them to patients.

Carers think 'washing / dressing / clothes' and 'independence' are very important, but patients do not agree. Healthcare professionals recognise three of the most important needs, 'General health – maintenance', 'Prevention of stroke – risk reduction' and 'Information / advice'. These needs are the needs professionals typically address, but of the 19 needs identified by patients, 16 have not been identified as highly important by healthcare professionals in the research. Carers do not appear to appreciate the perceived importance of information and advice.

There are a wide range of needs, some of which are physical, such as balance and vertigo, or talking, but most are concerned with emotions, cognition, or centred on strategies to optimise health. There are a few other needs such as driving and fatigue that do not naturally fit into those categories and will be considered separately. It is possible that needs associated with vertigo and balance could be caused by medication given to lower blood pressure. In some cases, lowering blood pressure can result in postural hypotension (Sathyapalan, Aye & Atkins, 2011; Zang, 2013), which presents as dizziness and light-headedness, and might be described as vertigo, and can impact on balance. The other physical need is about talking, and it may be that this relates to the experience of the presenting symptoms rather than an ongoing need.

Emotional needs include anxiety, fear and depression, but this category could be expanded to include dealing with others' reactions and family strain / well-being. Cognition includes memory and muddled thinking. These appear to be short-lived problems, which is backed up by recent research

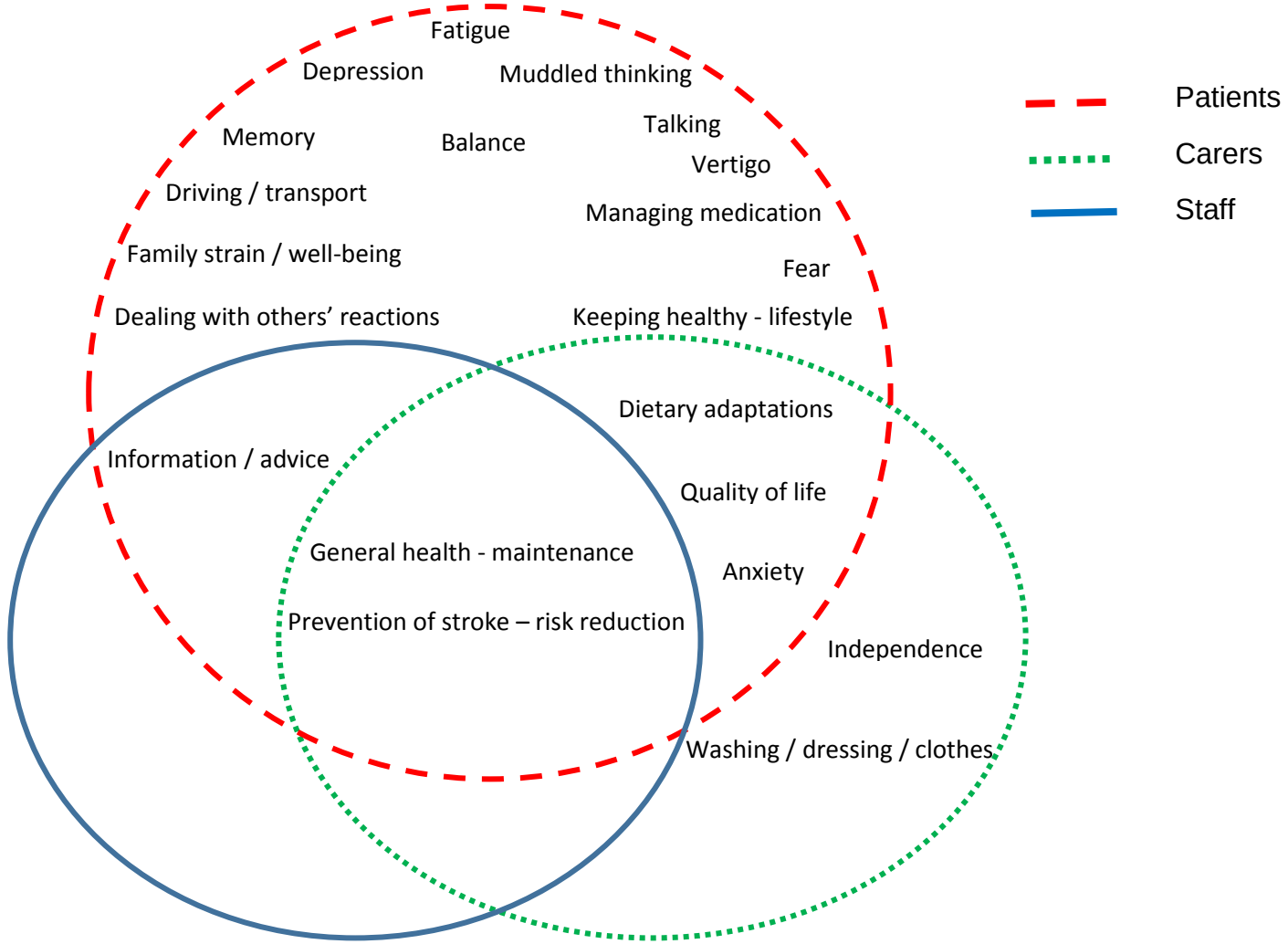
(Pendlebury *et al*., 2011; Sivakumar *et al.,* 2014a; 2014b) but consideration needs to be given to a TIA or minor stroke contributing to multi-infarct dementia (van Rooij *et al.,* 2014).

In terms of optimising health, this includes general health – maintenance, prevention of stroke – risk reduction, information / advice, dietary adaptations, keeping healthy – lifestyle, and managing medication. Some of the needs from the SNM have a specific meaning following TIA, for example dietary adaptations in the context of stroke related to the need for modified food and fluid textures to help with the management of dysphagia. In the context of TIA, it is used to reflect changes in eating habits in relation to the avoidance of high fat, salty and sugary foods.

Managing medication is another example. Following TIA, it appears to be more about concordance and understanding why treatment has been given, whereas there may be much more physical needs following stroke in relation to being able to identify medications, take them out of packaging and safely swallowing them.

Two needs in this category have not yet been considered, one is fatigue, which has only recently been documented as a sequela of TIA as well as stroke. The other need is driving and transport. Again, the context alters the meaning. For example, following TIA there is a brief 28-day suspension of driving privileges, whereas following a stroke there may be additional physical, sensory or cognitive difficulties that might affect someone's ability to drive. Also, the ability to use taxis and public transport might be impaired following a stroke due to general mobility issues, which would not be expected to be the case following a TIA.

Figure 20 Summary of needs from the SNM that are commonly identified as important following TIA Phase 2 a & b



Exploration of specific needs which are unique to TIA

A range of new needs were identified that appear to be specific to TIA, either entirely novel, or different interpretations of pre-existing SNM headings. These new interpretations are based on the different context that is present following TIA. These novel needs can be seen added to the SNM in Figure 21 (page 193).

Dealing with feeling a fraud. This was commonly described as '*not wanting to waste the doctor's time*', or minimising the extent and severity of the symptoms. It was interesting that one of the focus group members, who reported a brief episode of monocular blindness that resulted in major vascular surgery, still reported feeling like a 'fraud'.

Validation of experience. Patients appeared to want friends, family and medical staff to acknowledge that something serious had happened, that it was real, and that it really did require further action. This need links closely with **Encouragement to seek help,** which was the most common response, when patients shared their experiences with others. There was only one case where third parties did not prompt help-seeking behaviours, but that was the only example within the research. The sample size was very small and it may well be that with a bigger sample size, more examples would be found.

Avoidance of delay. Once a patient is seen by a TIA service, it often becomes apparent that time is critical in relation to stroke risk reduction. Some patients took a circuitous route into TIA care, and some people experienced considerable delays during their contacts with healthcare professionals. All patients involved in the research felt that rapid access was essential and felt this needed to be addressed in terms of public awareness (particularly since TIA can result in transient visual problems, which are not part of the FAST campaign). There was also a feeling that all members of the healthcare team should be aware that TIA is a medical emergency and requires rapid referral to specialists.

Denial. The need to reinforce the importance of the event, without inducing undue anxiety is great. TIA is diagnosis of exclusion and relies on clinical history taking, and the absence of other pathologies or explanations for the event. This makes it more difficult for patients to understand that although all

the tests have shown negative results, that does not mean that they have not had a TIA, in fact that is what makes the diagnosis more likely. When specific risks, such as atrial fibrillation or carotid stenosis can be identified, it enables treatment to be more targeted, but some people still find it difficult to come to terms with a change in health status.

Acceptance. This relates to acknowledging that the TIA event carries some significance and importance for the individual. It links with denial at onset of symptoms but may continue throughout the patient's journey, because they need to acknowledge that the event was real and requires appropriate intervention to reduce potential risk of stroke.

Coping with Self-monitoring / hypervigilance. Self-monitoring and hypervigilance are two sides of a single coin, in that self-monitoring enables people to take responsibility for themselves and so make decisions about the management of their health. This links to self-management found in the SNM. However, with hypervigilance, there are patients who become fixated on their TIA symptoms, constantly checking and behaving in a way that suggests they perceive constant threat. This is unique to TIA and is highly undesirable, it might feed anxiety and depression if the patient feels out of control in relation to their health. It is not clear whether the experience of TIA heightens anxiety, which may result in frequent checking for new or repeated symptoms and potentially lead to health anxiety disorder (Olatunji, Deacon & Abramowitz, 2009). Another explanation might be that the sudden and very transient nature of TIA prompts people who believe themselves to be well to become sensitised to any minor changes or sensations in their body, which they would not normally notice. A number of patients talked about how they check their limbs, speech and vision in response to various stimuli.

Positive attitude. Developing a positive attitude helped people to deal with the diagnosis and the realisation that they may not be as healthy as they had thought. By focussing on what could be done, and using the experience to allow a re-evaluation of priorities, it was felt that this could help in moving forward after a TIA.

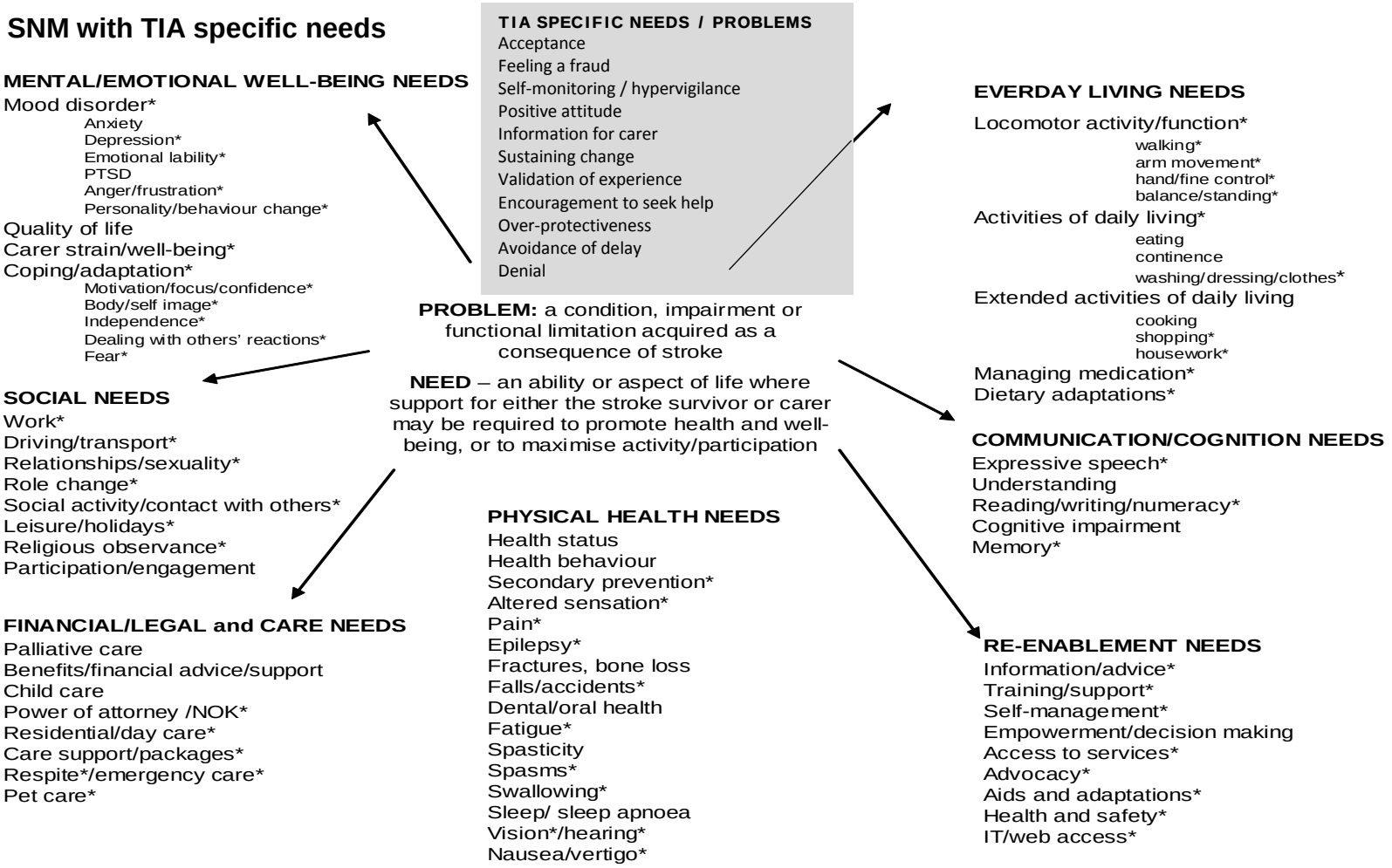
Sustaining change. As time passed after the event, the less anxious people felt, and therefore, maintaining the changes to lifestyle and continuing

medication when feeling well became less appealing, and more difficult to achieve.

Over-protectiveness. Many patients talked about how the people around them treated them differently after a TIA. They talked about family members suggesting they should do less, stop carrying out activities that they found enjoyable, and otherwise treating them as less capable. In discussion with carers when they attended an interview, it became apparent that this response was seen as a demonstration of love and concern by the carer rather than a bid to deprive the patient of their traditional role.

Information for carer. This is distinct from the information needs of the patients themselves. Information / advice is within the re-enablement needs in the SNM, but the context is to do with people feeling that their condition is either given too much importance by others or is not taken seriously enough, because they have recovered, and this can then contribute to the patient 'feeling a fraud'. This may be because they are aware that something significant has occurred but friends and family don't appear to appreciate the implications of the event. So information needs for family and friends post TIA is quite different and unique in the impacts if left as an unmet need.

Figure 21 SNM with TIA specific needs added



When the output from Phase 2c is included, together with TIA specific needs previously identified, a greater agreement between groups can be seen (Figure 22, page 196). In Phase 2c professionals were asked to prioritise needs, this data was added to Figure 21.

There are many more needs in common when the Specific TIA needs and professional priorities are also considered. Notably 'quality of life' moves into the intersection that represents all three participant groups. In Figure 19, there was only one need in common between patients and professionals alone. An additional six needs are in the 'patient / professional' intersection; 'family strain / well-being', 'keeping healthy' and 'managing medication' from the SNM and three new TIA specific needs; 'validation of the experience', 'encouragement to seek help' and 'sustaining change'.

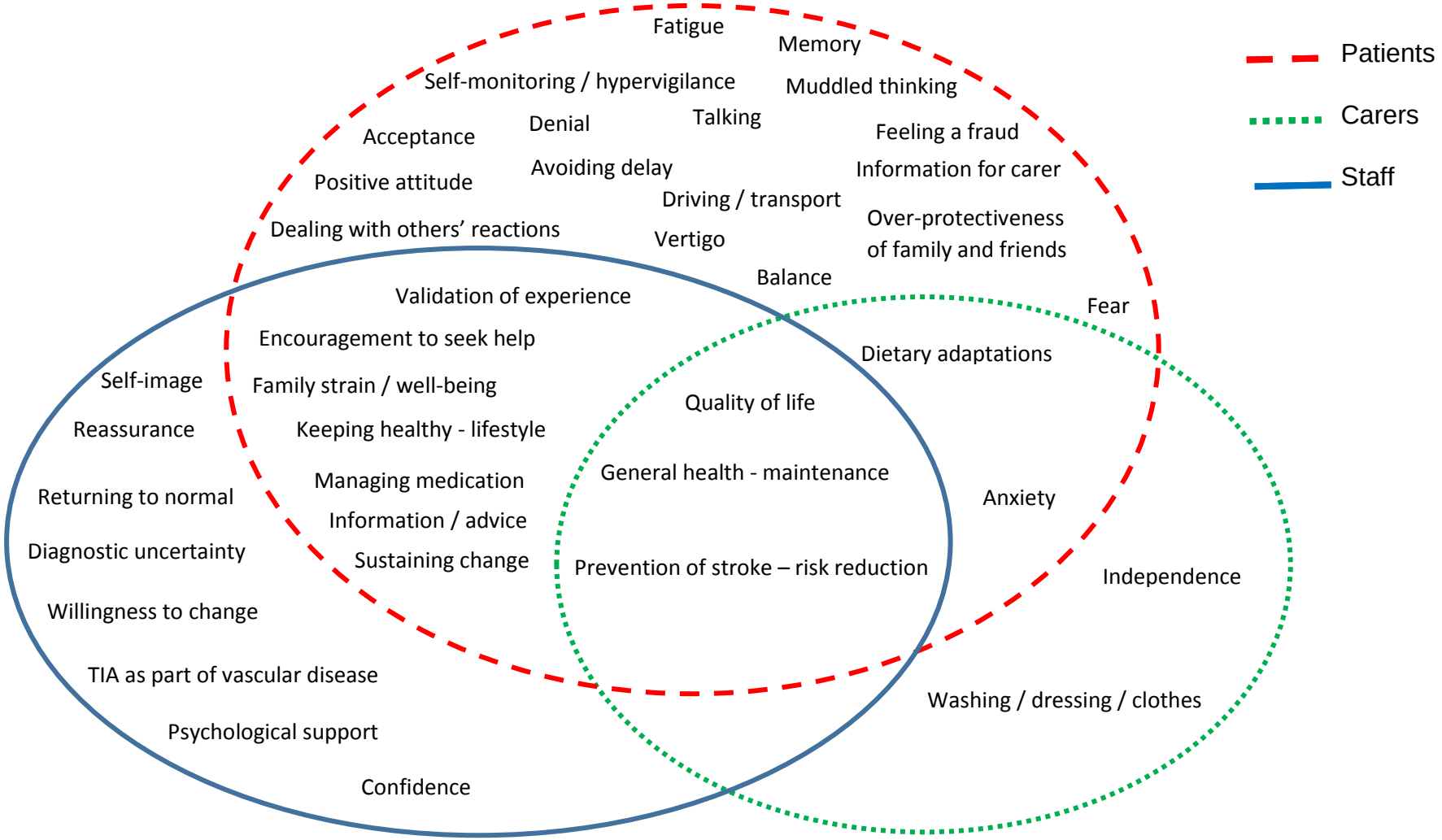
The professionals also talk about psychological support, which is likely to be a blanket term which might include many of the other needs identified by professionals and patients. Psychological support could encompass the following needs: the need to manage fear, anxiety, and depression, dealing with others' reactions, maintaining a positive attitude, learning acceptance, support with self-monitoring / hypervigilance, understanding 'feeling a fraud', developing confidence in self and future, reinforcing self-image and receiving reassurance.

Links could also be seen in relation to information giving. Within TIA, a specific need to provide information to carers has been identified, this potentially links with concerns about family / carer strain and the need to manage over-protectiveness in family and friends, which can impact on independence. So, in addition to psychological support that could also be an over-arching need in relation to information for both the patient and the family / carers.

A further category of need might be the need to reduce risk and recover. This could include quality of life, keeping healthy, managing medication, dietary adaptations, general health maintenance, secondary prevention, willingness to change, sustaining change and returning to normal. Also within this category could be driving and transport.

The next category would be the need to act appropriately from onset to diagnosis. This would include the need for validation of experience, encouragement to seek help, avoidance of delay, management of denial; and accepting diagnostic uncertainty. Several of the psychological needs are also likely to be linked to, or caused by, diagnostic uncertainty.

Figure 22 Venn diagram showing needs regarded as highly important or TIA specific from Phase 2 of the research



Development of a draft model of needs following TIA

From the patient data gathered in Phase 2, it was possible to identify at which time-point the identified significant needs arose. In some cases, there was blurring of boundaries; needs might be found in more than one time-point. Another set of elements were identified as 'bridges'. These were factors which patients felt had facilitated progress or helped to identify or meet needs. These needs and bridges as identified by the patients can be found in Figure 23 (page 205).

Analysis of the views of need at each time-point will be considered.

Onset. This is the point at which focal neurological symptoms are noticed or identified. Symptoms can be very short-lived and, as such, may not cause alarm or a recognition that a serious event has occurred. It is easy to dismiss symptoms once they have passed. This denial or avoidance behaviour would be less likely to be seen following stroke, since by the nature of stroke symptoms, they persist for over 24 hours. Shock appears to be one of the features at onset. This response is in relation to the sudden onset of the symptoms themselves, rather than the ongoing implications of having had a TIA.

Recognition of what the symptoms might represent was varied amongst the patients involved in the research. Many didn't realise the significance, others did, but most still required encouragement to seek medical advice. Staff were of the opinion that recognition was a problem, particularly with symptoms that don't fit the Stroke Association FAST campaign. The FAST campaign was designed to detect anterior cerebral circulation strokes (Wilson *et al.,* 2014). These are the more common site of cerebral events and have slightly more easily recognisable symptoms. Posterior cerebral circulation strokes can present in such a way as to mimic many other conditions and therefore it is more difficult to provide a public awareness message that is likely to have an acceptable level of sensitivity and specificity. It was also felt that improving public awareness of TIA would help to encourage early presentation to healthcare.

There were mixed experiences in relation to the acuity of response once patients had sought medical advice, with one patient not receiving a diagnosis until almost a month after the event, whereas other patients commented on how quickly things happened after first contact with a clinician. Current guidelines recommend rapid assessment following TIA. However, it is recognised that not all clinicians treat TIA with the necessary acuity. It was reported that most GPs will see less than five TIAs each year, which is likely to make initial suspicion of a TIA diagnosis potentially more challenging.

A 'bridge' was identified between Onset and diagnosis. This 'bridge' consisted of aspects of the patient experience that they felt helped them to move from 'onset of symptoms' to 'diagnosis'. Two main themes emerged across the transition: 'validation of experience' and 'help-seeking behaviours'. Validation of the experience was about confirming that the event was real and that it carried significance. In many cases, it was the confirmation from a third party that the symptoms experienced, although now resolved, did in fact merit further action. Even when the patient was anxious about the event, a third party often helped with decision making. There are also reports that third parties might in some cases delay presentation to health care. There was one example in the research of a patient's friends not encouraging her to seek immediate help, although if they had, she would probably have acted on their validation of the event. Previous research into potential delays in attending hospital following stroke have suggested that sometimes third parties might delay the process (Jones *et al*., 2007). Help-seeking behaviour is complex and the majority of data within the research suggested that third parties had a broadly positive impact on help-seeking behaviour and in many cases instigated it. Reluctance to act on what are perceived as minor events, appears to stem back to issues of denial and 'feeling a fraud'. By validating the experience and encouraging the individual to act, third parties can be instrumental in ensuring patients access health care.

Diagnosis. It is likely to be very worrying to discover brief symptoms that are readily dismissed can be a warning of the potential for serious illness. Patients report needs relating to accessing services and understanding the diagnosis,

professionals are also concerned with these issues, and also voice concerns about patients' ability to retain information following a TIA diagnosis.

Accessing services can be confusing for patients, if symptoms have resolved. There can be a reluctance to contact emergency services. However, when the urgency of response becomes apparent, it can be frightening. Many patients voiced the view that if they had a similar episode in the future they would react differently. This is also a concern for professionals.

Making a diagnosis of TIA is known to be clinically challenging (Brown, 2001; Johnston, 2002; Farhat *et al*., 2009; Catangui *et al*., 2013; Nadarajan, 2014), and is typically a diagnosis of exclusion, with tests that give negative rather than positive results to support the diagnosis. This can make it harder for patients to understand what has happened and what it will mean to them. Professionals also feel there are needs and issues surrounding diagnosis. This emphasises the impact on the patient's sense of self and well-being and the challenge to the patient's health beliefs. On the subject of making the diagnosis, there is an awareness that, when explaining the results of investigations to patients, there is a fine line between scaring the patient with the idea of having a stroke, balanced against the reassurance that test results were normal. In fact, the normal test results can be very worrying, because, if nothing specific can be identified as the cause, then it makes risk reduction seem less certain. Negative test results can also feed denial behaviours and cause the patient to doubt the diagnosis. One younger patient wanted a second opinion, because she was seen by a doctor from the elderly care department and she was worried the doctor might not understand the implications of having a TIA at a young age.

Information was also raised as a need by both professionals and patients. Professionals talked about the perceived difficulty absorbing information when anxious. Patients' views were slightly different. They reported feeling that they wanted to know and understand what had happened, what could be done about it, and what to expect next. One area of need was related to the information provision for family or carers. Patients reported a mixture of responses to news of their TIA. Some patients reported feeling restricted by well-meaning

relatives, while others felt their family had not appreciated the significance of the event since they appeared to have fully recovered.

A ‘bridge’ was identified between ‘diagnosis’ and ‘early recovery’. This ‘bridge’ was aspects of the patient experience that they felt helped them to move from ‘diagnosis’ to the ‘early’ phase of recovery. This consisted of three themes; medication, secondary prevention and stroke nurse. The professionals also identified ways to meet needs following TIA.

Medication seemed to be a reassurance for some patients whilst, other patients were less keen to take long term medication. Patients had previously considered themselves well, yet were given a range of long-term medications. In some cases, they did not believe they needed this treatment, since they were not convinced about the diagnosis, either due to denial or possibly due to a poorly explained diagnosis. One patient in the research was very unhappy with the lack of information about the side effects of the medication he was given.

Risk reduction, or management in relation to lifestyle, was also seen as a way to move forward following TIA, particularly initially following diagnosis. It seemed that some patients responded to lifestyle advice as though the changes would prevent, rather than reduce, the risk of further TIA or stroke. This is tied up with individual health beliefs (Grisolia *et al*., 2015). Lifestyle modification was seen as a positive step which might be protective. Initially after diagnosis, patients were keen to identify ways to minimise future risk.

A number of patients identified their interactions with a stroke nurse as being of help when moving from diagnosis to early recovery. This would be in addition to the follow-up appointment some patients receive from the stroke service as recommended by the National Stroke Strategy (DH, 2007).

Early recovery, diagnosis to 28-days. This is the time-period that appears to give rise to the most needs. Patients identified eight main needs and professionals identified one in common and an additional three needs.

The patient needs included issues around driving restrictions since the diagnosis of TIA carries a 28-day suspension of driving privileges. There were two main issues in relation to driving. One was the inconvenience and potential

cost of not being able to drive and the loss of independence. The other issue was concerned with the need for discipline and self-control in refraining from driving. This was particularly difficult when the patient did not believe in the diagnosis.

There were also needs relating to 'self-monitoring' or hypervigilance. This theme was about checking to see whether new symptoms had manifested themselves. Some people talked about checking for specific symptoms if not feeling well, others suggested that anxiety was prompting regular checking which might not be healthy and could slow recovery and alter self-perception. Professionals also recognise the potentially harmful effects of self-monitoring. There was a more helpful behaviour of self-management, where patients and medical staff could work together to manage risk. However, professionals acknowledged that support is needed for those people who feel able and willing to take ownership of their health, but patients should not be pushed into self-management if they were not comfortable with it.

Professionals reported that support for patients was perceived to be the 4-week follow-up appointment. In many cases this contact was provided by specialist nurses. Fatigue and memory loss are both phenomena that are recognised post-stroke, but until recently there was little research documenting these problems following TIA (Winward *et al*., 2009; Mackenzie *et al*., 2011; Fens *et al.,* 2012). Recent research suggests the mechanism that causes fatigue following TIA is likely to be centrally mediated (Barbour & Mead, 2012), since there should not be a physical cause of fatigue if all physical symptoms have resolved.

The financial impacts of TIA are not necessarily immediately apparent to patients or staff. People cannot drive for 28 days and this can cause additional transport costs, but more hidden costs are the implications for travel insurance, life insurance and other financial products.

Willingness to modify lifestyle was a final need identified by the professionals. They said they experience problems with those patients who remain in denial regarding the diagnosis, as those patients were typically less likely to change their behaviour.

One of the professionals' suggestions about how needs might be identified and addressed was through the use of a 'cardiac rehabilitation' model of aftercare. Both myocardial infarction or ischaemia, and stroke are vascular diseases. Messages about lifestyle modification, risk reduction and medication are similar for both cerebral and cardiac diseases. There is a strong tradition of the provision of structured aftercare following an ischaemic cardiac event. Cardiac rehabilitation typically consists of a structured programme of information giving, exercise and peer support. It has been suggested that people who have had a TIA or non-disabling stroke would benefit from a similar programme (Prior *et al.,* 2011; Kirk *et al*., 2014; Marzolini *et al*., 2014). The repeat contacts over a relatively short period would also help the organisers identify less obvious needs, and allow the group to support each other.

When the professionals were asked whether they could identify anything else that might help identify or address needs in the 'Early' stage after a TIA, they suggested review of current information to determine whether newer formats might make the information more accessible.

A 'bridge' was identified between 'early recovery' and 'later recovery' (29 days onwards). This 'bridge' comprised aspects of the patient experience that they felt helped them to move from 'early' to 'later' recovery. The two identified themes of this bridge were positive attitude and sustaining change.

Many people talked about how they had coped with receiving a diagnosis of TIA. They talked about how a positive attitude helped them. The positive attitude could be developed by acting to improve the situation and returning to normal levels of activity as soon as possible.

Sustaining change was the other bridge identified going forward after a TIA. That was about how the shock of the event made it relatively easy to make lifestyle changes. But as the event became less prominent, as time passed, it became more difficult to maintain the changes.

Later, 29 days onwards. Needs identified as being more prominent after the first month following a TIA really appear to be related to emotions or perceptions, either self-perception or the perceptions of others.

The perceptions of others concern people following TIA. The diagnosis doesn't typically carry a stigma, but some people feel they are treated differently after having a TIA. One man talked about how he and his partner are more vigilant, always keeping an eye on each other. Another participant talked about her concerns that disclosing her medical history might make potential partners reluctant to commit to a long-term relationship.

Four needs were identified in relation to how people feel after a TIA. The needs were described as 'quality of life', 'role change', 'fatigue', and 'return to work'. A patient, when asked about her quality of life talked about how her fear and anxiety impact her life now. A patient talked about role change in relation to driving and his self-confidence. He has ceased driving at the request of his family, but now feels that this has damaged his position in the family and he has lost his independence. Fatigue has been reported in the literature following TIA, despite there being no obvious physical changes (Winward *et al.,* 2009), although it has been reported that the fatigue improved over the weeks and months following the TIA. Linked to other people's perceptions is concern regarding security of employment. One patient talked at length about her concerns about keeping her job.

Professionals had other concerns regarding needs after the initial 28 days. These were about the availability of service provision. One professional talking about continued support in primary care, reported that patients are seen for just ten minutes. This consultation has to cover medical, psychological and social issues, so focus is given to Quality Outcome Framework objectives; blood pressure, anticoagulation for atrial fibrillation (AF), and cholesterol medication. Unless the patient highlights any other problems, needs are probably not identified or addressed. However, it could be argued that patients need to take a more pro-active approach in identifying and presenting needs to their GP. The problem with that argument, in the case of TIA, is the patient's inclination to down-play the initial symptoms, thus not connecting subsequent needs or difficulties as being related to the initial TIA. There is a recognised lack of ongoing support and access for patients to see the stroke team after the follow-up appointment at approximately 4 weeks.

Another concern that professionals had is in relation to what they called the 'drop-off effect'. This mirrors the patients' concerns regarding sustaining change and is about maintaining the changes made following TIA. It includes lifestyle changes and continued concordance with medication. This need might be mediated by the professionals. It is important that where patients have previously had a TIA, they should be given optimum secondary prevention. Sometimes patients become less anxious as time passes following a TIA, and doubts about the diagnosis persist, thus potentially prompting the patient to stop taking their medication or lose focus in maintaining lifestyle changes.

The professionals had a number of ideas about how needs might be recognised and addressed after the initial 28-day period. These included the availability of a Health Hub, where all services can be accessed and appropriate signposting can be offered from one central point. This would make the journey much easier for the patient, who would be seen by staff with a full awareness of the services available locally.

It was felt that more effort should be made to offer empowerment to patients, to encourage them to take responsibility for their health, but also to acknowledge that something serious and potentially life-changing has happened. Promoting self-efficacy was a way to address needs by supporting a desire to change, as was continued access back to the stroke service for advice. Some services offer longer term support via telephone contacts. This is not universally available, but appears to be on professionals' 'wish list'.

Figure 23 Shows the draft model of TIA needs based on key time points following TIA

	Onset	Diagnosis	Early (diagnosis to 28 days)	Later (After 28 days)
Needs that span the patient journey Fear & anxiety				
Needs / issues or problems identified by those who have experienced a TIA	Overcoming denial Recognition of symptoms Timely emergency response Dealing with shock Understanding there may be a range of symptoms Dealing with 'Feeling a fraud'	Faster access to health care Clarity regarding diagnosis Quality information	Coping with driving restrictions Self-monitoring Self-management Support Managing the financial impact Dealing with fatigue Returning to work Strategies to manage poor memory	Dealing with others' reactions Maintaining quality of life Dealing with role change Coping with fatigue Returning to work / other activities
'Bridges' identified by those who have experienced a TIA		Validation of experience Help-seeking behaviour	Risk reduction Medication Stroke Nurse	Positive attitude Sustaining change
Needs / issues or problems identified by staff	Poor recognition of problem Denial / avoidance behaviour Delay in seeking help	Difficulty absorbing information when anxious Diagnostic difficulty / uncertainty Lack of professional awareness	Willingness to modify lifestyle Active participation in recovery Hypervigilance Formal follow-up	Lack of primary care support Drop-off effect
Professional suggestions about how needs might be met	Improved public education and awareness	Improved staff training / awareness Improved clarity of communication	Vascular rehab programme New formats for health education and lifestyle promotion	Health Hub Empowerment Promote self-efficacy Continued access back to the stroke service for advice

5.7 Summary

Phase 2 has examined needs following TIA, based initially on the SNM as a starting point. It has used a variety of research methods drawing from both quantitative and qualitative paradigms. Participants have been drawn from a range of groups including patients, carers and professionals, and a range of geographical areas. This variety of enquiry and participants offers a richness to the data which helps to make it trustworthy and credible. A significant proportion of the needs identified in stroke patients via the SNM have also been demonstrated to be relevant after TIA. A range of needs unique to TIA have also been found. The development of a draft model of needs following TIA that is structured around the passage of time and the changing needs that someone might experience following a TIA, makes the research findings more accessible and potentially useful in clinical practice. The next phase of the program of research is review of the draft model of needs following TIA by an expert panel comprising a group of patients, professionals and carers.

6. PHASE 3: REFINEMENT OF A PREVIOUSLY DEVELOPED MODEL OF NEEDS FOLLOWING TIA USING FOCUS GROUP METHODS WITH AN EXPERT PANEL

6.1 Introduction

Phase 2 reported the development of a draft model of needs following TIA. The model was based on findings from patients, carers and professionals. In Phase 3 the draft model was presented to an expert panel comprising patients, carers and professionals together, to refine the model and develop ideas about how needs might be identified and met.

6.2 Background to Phase 3

Over the course of this programme of research, Phase 1 looked at the national context of TIA service provision in 2011. Phase 2 used the SNM (French *et al*., 2008), as a basis for exploring views of patients, carers and professionals. The findings from Phase 2 were synthesised to develop a draft model of needs following TIA. The model consists of two parts, a comprehensive list of potential needs and a temporally based model of common needs that change over time. Phase 3 of the research will review the model to establish whether it fits with people's experiences of TIA, either from a patient perspective or that of a professional or carer.

Phase 3 Aim

To synthesise and validate the findings of the research programme in relation to the draft model of needs.

Phase 3 Objectives

1. To identify where, within a timeline of the TIA journey, needs would be most prominent.
2. To ask the expert panel to consider the framework model of needs following TIA, sharing their views of whether the model fits with their experiences, or not.
3. To review ways in which needs might be identified and met, by health and social care staff, and by patients and carers.

4. To present a draft model of patients' needs following TIA to an expert panel of patients, carers and health and social care professionals, obtaining feedback and opinion to refine and validate the model.

6.3 Methods

This final phase of the planned research comprised a focus group using an expert panel that included patients, carers and professionals. The meeting lasted approximately three hours in total. Each group of people included in the expert panel had a variety of knowledge and experience to bring to the meeting. By aiming for maximum diversity within the group, the benefit of using a focus group method was the interaction and discussions that provided richness to the data (Krueger & Casey, 2009).

Professionals were from the South Central and Southwest regions of England. People with a diagnosis of TIA were recruited from a TIA clinic in an NHS Hospital in the Southwest of England. The meeting was conducted at the same hospital that hosted the TIA clinic from which potential participants were recruited.

This study was recruiting three types of people. Recruitment of people following TIA was from patients that had attended a TIA clinic at a hospital in the Southwest between 1st May 2014 and 31st October 2014, and had a confirmed diagnosis of TIA documented in their medical records. Carers were identified by those people contacted as potential participants, who felt they had received their support. Professionals who had previously been interviewed or contacted as part of the program of research were also potentially eligible to participate.

Sampling and recruitment

People following TIA

It was necessary to ensure that only suitable potential participants were recruited. Therefore, a set of screening criteria were developed.

Screening questions

- Did the person have a diagnosis of TIA? *(yes).*
- Is the person still alive? *(yes).*
- Is there evidence the person has not had a completed stroke since TIA diagnosis? *(yes).*
- Is there evidence the person has not had a formal diagnosis of dementia or terminal illness since TIA diagnosis? *(yes).*
- Is there evidence the person does not have a documented communication problem? (e.g. severe deafness, language problems). *(yes).*

The recruitment process used a dual approach, with some patients being contacted retrospectively, and others being invited to participate prospectively at TIA clinic by the consultant who saw them. The invitation contained an information sheet about the study.

To identify people retrospectively, clinical staff from the TIA clinic provided anonymised data from the TIA database for assessment against inclusion / exclusion criteria. Anonymised data had the TIA database number ascribed which was utilised as the key. All data relating to the TIA clinic attendance, other than demographics, was available for screening. This ensured only appropriate potential participants received an invitation by post.

People invited to participate retrospectively received information by post. The information contained a letter of introduction from the consultant who made the diagnosis, and a participant information sheet explaining the research project and what was expected of participants.

People who had experienced a TIA were asked to identify an individual whom they felt offered them practical, emotional or physical support either during or after, their event. The invitation was extended to these people (carers) too, (the

term ‘carers’ was avoided in the supporting literature, as this might be felt to imply the provision of direct personal care or help around the home). People following TIA, or their carers, could express their interest in participating or ask any questions by telephoning the researcher. They could also register their interest by completing a tear off slip and returning it in a prepaid envelope.

Inclusion criteria

People following TIA

- Diagnosis of TIA made since 1st May 2014.
- Aged 18 or above.
- Willing to participate.
- Able and willing to give consent.

Carers

- Identified as carers of someone who has been diagnosed with a TIA since 1st May 2014.
- Aged 18 or above.
- Willing to participate.
- Able and willing to give consent.

Exclusion Criteria

People following TIA

- Subsequent stroke diagnosis.
- Diagnosis of dementia or terminal illness.
- Not able to speak English fluently.

Carers

- Formal diagnosis of dementia or terminal illness.
- Not able to speak English fluently.
- Death of person to whom support was given.

Professionals

Professionals were drawn from those who participated in, or had been contacted, regarding the professional interviews reported in Phase 2. Professionals involved in interviews during an earlier phase of research and

professionals identified using a modified snowball recruitment technique, as experts in their field, were contacted by either post or email and invited to participate. A modified snowball recruitment method (Atkinson & Flint, 2001) was employed within Phase 2 of the research, and identified a range of professionals that might be expected to have a wide range of perspectives in relation to TIA care and support.

The professional cohort extended to people who work as part of a charitable or community organisation, where the person receives a salary for their work. These individuals had to offer support or help to people following TIA on a regular basis to be eligible to be included. A follow-up contact was made with professionals, if a response had not been received within two weeks of the original contact. No further contact relating to the study was made if the professional failed to respond on second contact.

Inclusion criteria

- Offer support or services to people following TIA in a professional capacity.
- Offer support or services to people following TIA as part of a charitable or community organisation.
- Willing to participate.

Exclusion Criteria

- Do not have regular contact with or provide services for patients following TIA.

Conduct

On arrival, the researcher gave all participants an opportunity to ask any further questions and answered any queries. Participants were reminded that the groups would be audio-recorded. They were also reminded that they could withdraw at any time without needing to give a reason, or take a break and come back. The group started with a welcome and a brief overview of the programme of research. Participants were introduced to the group. Ground rules were established (Roberts, 1997), such as confidentiality, respect for other people's views, the need to have only one conversation within the group, and

the importance of getting the group talking to each other, rather than answering questions. Establishing ground rules was led by the researcher, but participants were asked to contribute and share their views.

In the initial exercise, the group was split in two, and each group, with a facilitator, was asked to consider four time-points following TIA. Two facilitators assisted the two groups to consider the timeline and add issues, problems and needs to the appropriate sections. They were also asked to add any identified ways to address the needs where possible. The four time-points were: onset; diagnosis; early (diagnosis-28 days), and later (29 days +). For each time-point the sub-groups were asked to identify the problems and issues experienced, or potentially likely following TIA. When problems and issues were identified, the group was asked to phrase these as needs. The example given was, if the problem was pain, then the need might be for pain-relief. This exercise was conducted before any material was provided to the groups. This was to obtain open responses without causing potential bias by offering either the SNM or any of the findings from the current programme of research. Once the groups had completed this exercise, the facilitators fed the results back to the whole group and similarities and differences were discussed.

Material provided for expert panel discussion

Once the unstructured exercise relating to needs at different time-points following TIA, had been completed, the researcher presented the draft model of TIA needs as developed by the programme of research. Five tables were presented to the expert panel. The first was a summary of needs identified by people who have experienced TIA (Figure 23, Page 205). This first table included ‘patient bridges’. These are the needs or enablers which help people move from one time-point to the next. The next two tables contained source data in the form of quotes to illustrate the needs outlines in the summary. The final two tables summarised the professionals’ views of needs and their suggested solution to address unmet needs, also including illustrative quotes.

The researcher explained what the five tables represented, and then gave the group time to read and discuss the material. They were asked whether the needs identified made sense in light of their experiences and whether there was

anything missing, which should be added. Finally, they were asked their views on how needs should be met and by whom.

At the end of the discussion, the researcher summarised the session, to ensure clarity and probe for misunderstanding, consensus and outlying views. This helped to ensure the researcher's interpretation was correct and enable clarification where necessary. Finally, the group were invited to add any other thoughts or views not previously discussed in relation to the model, categorisation of needs or strategies to identify or meet the unmet needs. Briefing material for facilitators can be found in Appendix D1.

Data collection

The expert panel was audio-recorded using analogue (tape) and digital recorders. Following the expert panel meeting, the facilitators discussed and reflected on the information gathered and facilitation process. This reflection was also audio-recorded, transcribed and included in the analysis of the group. The reflection also enabled the researcher to obtain feedback on her facilitation of the whole group, and receive suggestions to further improve her performance.

Data analysis

The expert panel audio-tapes were subsequently transcribed in full. Transcription was reviewed for errors and to understand the dynamics of the group, (e.g. laughter, pauses, tone of voice). Theme identification was performed by the researcher, who immersed herself in the data, by means of repeated listening to the recordings whilst reading the transcripts. Using a key-concepts framework classic approach to analysis, units of meaning and themes were identified (Krueger & Casey, 2009). This was reviewed by a senior academic supervisor with experience in analysing focus group data. Where differences in interpretation occurred, these were discussed with the research team to reach agreement.

Ethical issues

Ground rules of confidentiality and respect were discussed at the start of the expert panel meeting. Due to the nature of the expert panel, complete anonymity could not be guaranteed. The expert panel meeting was audio-

recorded. The recordings were kept in a locked cupboard until they were transcribed, at the earliest possible opportunity. Once transcription was checked against the recordings, and was identified as being correct, the audio recordings on tape were destroyed; the electronic recording was retained for initial analysis and destroyed as soon as possible thereafter. All data was stored with no personal identifiers (just a participant number) in secure electronic storage at UCLAN.

Tacit consent was demonstrated by participants' attendance. Written consent was required from all group participants prior to involvement in research. Formal consent was taken at the group by the researcher following the principles of GCP. There were always at least two facilitators (one being the researcher) with the group, to provide support for any participant who needed it although this was not necessary on the day.

Since people were recruited via an NHS Hospital in the Southwest, it was necessary to obtain NRES approval for the research. An ethics submission was completed via IRAS and was reviewed and approved on 27th June 2014, NRES No. 14/EE/1017. Local Research and Development and University approval was also obtained. A full set of study documents can be found in Appendix D2.

6.4 Results

A total of fifty-one potential participants who had been given a diagnosis of TIA between May and October 2014 received invitations to participate in the research. Eighteen received the invitation prospectively at their first TIA clinic attendance, 33 received an invitation by mail. Five positive responses were received from people who had experienced a TIA. Three of these had a spouse identified as their carer. One identified a shop-worker as her supporter (carer) and one reported not having anyone she felt was a carer. The three spouses were also prepared to participate in the research as carers. Unfortunately, one couple were unable to attend on the date planned for the meeting. A further couple dropped out shortly before the group when a date was received for planned surgery. The group comprised three people who had TIA, one carer and four professionals, details can be found in Table 36. Thumbnail pen sketches of participants can be found in Appendix D3.

Table 36 Details of participants in the expert panel

Participant No.	Identity	Clinical symptoms
(i)	Emergency Department Consultant	
(ii)	Stroke Nurse Practitioner	
(iii)	46-year-old female TIA 7 weeks ago	Left arm weakness
(iv)	76-year-old female TIA 11 weeks ago	Left leg weakness
(v)	Specialist Stroke Consultant	
(vi)	Research Physiotherapist	
(vii)	86-year-old male TIA 9 weeks ago	Left sided weakness
(viii)	Wife of participant (vii)	

Newly identified needs

There was only one new need identified by the expert panel. This was 'protecting carers', which might link to information for carers and over-protective family and friends. The other needs identified are tabulated below (Table 39). The two groups also produced a representation of their views of needs and problems / issues at each time-point. These can be seen in Tables 37 and 38.

Table 37 Tabulated results of Group A discussions

Onset	Diagnosis	Early (0-28 days)	Later (after 28 days)
Problems / issues Unexplained tiredness Feeling unwell, not knowing why Sudden onset Who to go to, what to do Warning signals Other conditions Seeking help, accessing healthcare Recognition of symptoms Do the public know the symptoms Recognition, Access to healthcare – GP Vs ED Vs Ambulance Ambulance crew Frightened Wide range of presentations of symptoms – not readily understood	**Problems / issues** Quick service Hidden symptoms No follow-up with results of MRI First experience of ill health Lack of information Shock – out of the blue Didn't know when it would happen again Men find it psychologically challenging Shock, denial, upset, v. emotional Vulnerability Worried about severe stroke Loss of control	**Problems / issues** Going home No dietary advice Uncertainty of tests and waiting for results Bombarded with information Point of contact from someone who understands Taking medication, statins, side effects Health beliefs, smoking cessation, drinking Different age groups have different needs	**Problems / issues** Others needing to know you have TIA history Psychological aspects Side effects from drugs Guilty Lack of recognition of financial implications of TIA No option not to work Going back to work as a health professional – left as believed to already know – so no support Knocked confidence Look OK so believed to be OK No follow-up after 28 days
Needs Reassurance from health care professionals or lay-professionals Public need to recognise symptoms Training and Education with ambulance crews Someone to take charge and make decisions Signposting to access to healthcare for TIA	**Needs** Support from family members & friends Contact details for after event to speak to someone who knows Emotional support and reassurance	**Needs** How to access information Information re. ability to work – back to normal routines Contact details for stroke / TIA specialists More contact	**Needs** Reinforcement of health beliefs TIA identity / 'medilert' Review further down the line Later education programme post 28 days Knowing how to access help / IAPT Information about TIA / stroke support outside health system Lifelong access to TIA / stroke service TIA helpline

Table 38 Tabulated results of Group B discussions

<table>
<tr><th>Onset</th><th>Diagnosis</th><th>Early (0-28 days)</th><th>Later (after 28 days)</th></tr>
<tr><td>Proactive management of risk factors even before the event</td><td colspan="3">The need to validate the experience</td></tr>
<tr><td></td><td colspan="3">The need for signposting for information
The need for reassurance you are doing the right thing
The need for significant others to understand what is going on</td></tr>
<tr><td></td><td></td><td colspan="2">The need to understand when can return to work, driving, holidays
The need to manage emotions
The need to manage fatigue</td></tr>
<tr><td>The need for:
Patients to recognise symptoms in a timely manner
Speedy access to specialist medical opinion
Understanding that TIA symptoms can be very different to stroke
Understand the immediate actions: Not driving, Inform insurers, Contact healthcare professional</td><td>The need for :
Clarity
Understanding the implications of the diagnosis (likelihood of stroke)
Understanding why it happened</td><td>The need for:
Understanding what I could do to reduce the risks of it happening again
Understanding the implications of not being able to drive and whether that will be long-term</td><td>The need for:
Ongoing monitoring of risk factors e.g. Cholesterol
Ongoing lifestyle advice to avoid “slipping back”
Acceptance that medications should be life-long
Lifestyle advice for family members who might be at similar risk of vascular ill health</td></tr>
<tr><td></td><td colspan="3">Solutions: Explicitly invite significant others to attend at least part of a diagnostic consultation
Information sessions later post TIA to enable peer contact</td></tr>
</table>

Table 39 Consolidated needs, initially based on the SNM, with TIA only needs added

Stroke only	TIA and stroke common	TIA and stroke less common	TIA only
Using the toilet Washing/dressing/ clothes Cooking Shopping Pain Hearing Fractures / bone loss Epilepsy Spasticity / limb tightness Swallowing problems Understanding others' talking Religious observance Participation / engagement Access to services Advocacy Aids / adaptations Health & Safety Child care Training & support Residential / day care Respite / emergency care Pet care End of life issues	General Health maintenance Keeping healthy lifestyle Prevention of stroke risk reduction Managing medication Dietary adaptations Balance Fatigue Quality of life Anxiety Dealing with others' reactions Talking Driving / transport Information / advice Family strain / well being Depression Fear	Dental / oral health Eating and drinking Independence Housework Altered sensation Nausea Vertigo Walking Falls / accidents Arm movements Hand / finger movements Sleep disturbance Difficulty sleeping Mood swings Anger / frustration Personality / behaviour change Motivation / focus / confidence Body / self-image Reading/writing/ numbers Muddled thinking Memory Work Relationships / sex Role change Social activity / contact Leisure / holidays Training / support IT / internet Care support at home Benefits / financial Vision Power of attorney Self-management **Empowerment / decision making**	Self-monitoring / hypervigilance Over-protective friends and family Positive attitude Acceptance Validation of experience Encouragement to seek help Denial Avoid delay Sustaining change Feeling a fraud Information for carer **Symptom recognition** **Diagnostic uncertainty** **Willingness to change** **Returning to normal** **Continued access to advice** **Help to understand diagnosis** **Knowing how to access help** **Psychological support** **Professional understanding of TIA** ***Protecting carers***

Needs in bold represent needs moved from stroke only to stroke and TIA, or new TIA specific needs.

As the research progressed, so the newly identified needs have been added or moved from one section to another. The needs identified in Phase 2 have been added (Table 39).

Recommendations about how needs might be met

Eight suggestions were made regarding how needs might be addressed. These were

1. Life-long access to stroke team for advice.
2. Telephone support.
3. Cardiac rehabilitation model developed for TIA.
4. TIA education programme post 28 days.
5. Longer-term formal TIA follow-up.
6. Understanding healthcare options.
7. Primary prevention.
8. The use of a medic-alert.

6.5 Discussion

The expert panel confirmed that the TIA needs previously identified seemed reasonable. When given a blank canvas, except for one, all the needs identified had previously been included in the model of needs following TIA. The expert panel identified which time-points were most likely to be associated with specific needs. Finally, the expert panel made suggestions for how needs might be met, and by whom.

Recruitment for this study was easier. This could be that all the methods used for recruitment had already been used in previous studies. The response rate was also higher. It is not clear why this might be the case, but could be due to referring to the potential participants as experts, and demonstrating high regard for their knowledge and experiences. One couple withdrew shortly before the expert panel was to be held, but this was unavoidable because one of them received an appointment for planned surgery, for which they had been waiting some months. A 50% positive response rate from professionals was also very gratifying. The professionals were all known to the researcher from previous interviews. Their continued support suggests that the professionals

were interested in the research, and could see the value of it and therefore were prepared to make time to participate.

The use of facilitators with subgroups was a decision based on the desire to minimise bias. During the research, the researcher has developed clear views regarding the needs identified following TIA. By asking two skilled and impartial facilitators to conduct the first part of the expert panel, the risk of the researcher leading the group was reduced. The two facilitators were briefed prior to the meeting (briefing notes can be found in Appendix D1), and left to conduct the blank-canvas review of the TIA timeline however they wished. Differences in the approach used by each group was marked. Group A first identified problems and issues then looked at how they could translate into needs. Group B focused on needs from the start, and identified needs that they felt spanned more than one time-point.

The initial 'blank canvas' approach to the 'timeline' was essential, because throughout the research the discussions have been based upon the output of the SNM (French *et al.,* 2008) and any previously identified TIA only needs. A number of previous studies looking at emotional and psychological problems following TIA demonstrated a range of difficulties, including fatigue, memory problems and anxiety (Moran *et al*., 2014). However, the methodology was such that participants were provided with a range of options, rather than asking, without prompting, what difficulties had been experienced. This prompting could potentially introduce bias. The same could be said for the previous elements of this programme of research, since the majority is based on the SNM and the identified 'TIA only' needs. By asking for views without access to the previous work, it was possible to see whether the same issues, problems and needs were identified. The blank-canvas approach was somewhat confounded by including professionals who had previously had contact with SNM and TIA only needs. However, this contact was only during the interviews which occurred four to five months prior to the expert panel. It was felt unlikely that they would have detailed recall of the SNM after this time.

Saturation of data was suggested but not clearly demonstrated. No new needs or themes were identified within the timeline data. Timeline data were

considered in combination with the summary Venn diagram and the material presented following the initial exercise. That no new needs were identified was encouraging in that it suggests that the most prominent needs have been identified. The sample sizes for the research preclude claims of data saturation, but the use of a variety of research methods to produce similar results lends credibility to the findings.

The needs generated by the ‘blank canvas’ timeline exercise were considered in relation to the previously generated data, and each need was mapped against the closest previously identified need (Table 40). Although the two groups used slightly different ways of representing the data the findings were very similar and where they differed from each other, there was still a common thread with previously identified needs.

Table 40 Listed needs identified using the blank timeline exercise

Previously identified need	Needs
Returning to normal	Reassurance
Symptom recognition	Timely symptom recognition
Professional understanding of TIA	Training for paramedics
Validation of experience	Someone to take charge
Information / advice	Sign-posting through health provision
Avoidance of delay	Speedy access to specialist service
Help to understand diagnosis	Understand difference between TIA and stroke
Information and advice	Immediate actions re driving, insurance etc.
Information for carers	Support from family and friends
Continued access to advice	Contact details for knowledgeable person
Psychological support	Emotional support and reassurance
Diagnostic uncertainty	Clarity or diagnosis
Help to understand diagnosis	Implications of diagnosis – risk of stroke
Help to understand diagnosis	Understanding why it happened
Information / advice	Access to information
Returning to normal	Returning to normal
Continued access to advice	More contact with professionals
Prevention of stroke	Risk reduction
Driving	Driving
Sustaining change	Reinforcement of health beliefs
Validation of experience	Medic alert
Knowing how to access help	Review beyond 28 days
Knowing how to access help	Knowing how to access help
Social activity / contact	Support outside the health system
Knowing how to access help	Lifelong access to TIA / stroke service
Continued access to advice	TIA helpline
Knowing how to access help	Ongoing monitoring of risk factors
Knowing how to access help / sustaining change	Ongoing risk management – slipping back
Sustaining change	Acceptance that medication should be life-long
Risk reduction	Lifestyle advice for family who might be at risk.
Validation of experience	Validation of the experience
Information for carers	Significant others need to understand event
Fatigue	Fatigue management
Psychological support	Manage emotions.

The expert panel helped to confirm and validate the previous findings from throughout the programme of research. Over the course of the research, many needs initially identified within the SNM (French *et al.,* 2008), have also been found to be relevant to those people who have experienced a TIA. A reasonably high number of TIA only needs have also been identified. In some cases, these overlap with needs identified in the SNM, but the context or approach is different, making them distinct needs in their own right.

There were eight suggestions about how needs might be met.

Life-long access to stroke team for advice (1), is also linked to **Telephone support (2).** It was felt that there needs to be access back to the stroke service, either via self-referral or via a health care professional (GP or practice nurse). This would address a number of needs including help with sustaining change, emotional and psychological problems following TIA, access to quality information, reassurance, returning to normal discussions about secondary prevention and risk management, primary prevention for family members, information and support for carers and others.

Cardiac rehabilitation for TIA (3). It was suggested that provision of a rehabilitation programme similar to that provided following cardiac problems would encourage activity and provide a venue for **TIA education programme post 28 days (4).** The benefit of this model would be that individuals themselves and their carers can establish peer support during the rehabilitation programme, which is likely to be more effective than professionals dictating change (Dennis, 2003; Solomon, 2004). Another recommendation was for **Longer-term formal TIA follow-up (5),** a formal follow-up after the standard 28-day one, perhaps at six months, in a similar way to that of stroke survivors.

Understanding healthcare options (6). It was felt that people generally do not understand the variety of ways to access healthcare. In addition to their GP, or the Emergency department, there is also an Out of Hours GP service, and the medical helpline number 111, from which advice or referral can be obtained. The message of FAST is recognised to have had an impact on stroke presentation, but had not had significant impact on TIA. People who

still have symptoms present should be directed to hospital and attendance in the Emergency Department, since ongoing symptoms could represent stroke. If symptoms have resolved, people should see a doctor that same day. They should be referred into a specialist clinic within 24 hours for people at higher risk, and within one week for those at lower risk based on a stroke risk assessment tool (Johnston *et al.,* 2007; NICE, 2008).

Primary prevention (7), and public health messages to promote a healthy lifestyle and reduce all vascular risk, need to be more prominent in the media and within GP surgeries. One group suggested people who have experienced a TIA might like to wear a **Medic Alert (8)**, or carry a card stating that they have had a TIA. This was discussed but met a mixed response from other patients and professionals. It was agreed that carrying a card in your purse or wallet with details of current medication and health issues would be useful if at any time someone presented at hospital and was unable to speak.

It was also suggested that as a stroke community there should be a single term to represent TIA. TIA is also referred to as a 'mini-stroke', a 'minor stroke' an 'aborted stroke' and a 'transient ischaemic attack'. This causes confusion. One patient reported having had a mini-stroke and TIA on different occasions and did not appreciate that the two diagnoses were the same.

6.6 Conclusions

Overall the expert panel validated the previous findings of the research. Validation of the model and summary documents were obtained in that no entirely new needs were identified. The expert panel helped to refine the model by reviewing the needs previously identified and suggesting ways in which needs might be addressed. The expert panel were clear that they saw value in offering formal follow-up for longer than the current 28 days.

Implications for Practice

When setting up new services or reviewing current services for people with TIA, it might be helpful to consider the structure and content of the follow-up contact. Exploration of common and less common needs is important since the less common needs are potentially those that are most likely to be missed

and not identified. Peoples' needs change over time following TIA and although suggestions have been made of when needs are most likely to be felt, there is going to be variation based on individuals.

Longer term, people should have the details of a knowledgeable person who can answer questions and offer support and reassurance. This might be a member of the stroke team, but equally, they could be appropriately trained practice nurses, people from charities such as the Stroke Association, or dedicated others in the community. It was felt that setting up a group analogous to cardiac rehabilitation for people with TIA and minor stroke would offer a venue to provide training, support, and promote lifestyle changes (Kronish *et al.,* 2014). It would also potentially address a number of the needs based on moods and emotions.

Implications for further research

Within the research as a whole, there is little input from carers, and this is true also of the expert panel, where ultimately only one carer participated. Further research into the role and expectations of carers, along with an assessment of their needs, distinct from those of the person they are supporting would be helpful in identifying which needs these carers are currently addressing for people who have experienced TIA. This is important because carers appear not to recognise the role they play in relation to the person who has experienced a TIA. This means that the informal support provided is very hard to understand. Thus, for those people who do not have access to someone who can fulfil this role, there is likely to be greater needs experienced following TIA. This is due to the fact that the perception of need is actually the perception of unmet need, since once a need is addressed it no longer remains a need. By better understanding the role of carers it might be possible to predict the additional needs which are typically met by this group and therefore potentially not identified.

6.7 Summary

Within Table 39 the needs are presented in some cases as needs, but some are also presented as problems or issues. In the process of finalising and refining the model of needs following TIA, it will be necessary to turn the TIA only problems and issues into needs. This will be presented in Chapter Seven.

7. PRESENTATION OF A MODEL OF NEEDS AFTER TIA AND SUMMARY OF RESEARCH

7.1 Introduction

This chapter presents the final model of needs following TIA, that has been developed in this thesis. First, a brief summary of the research will be presented. After the model has been presented, a series of issues will be considered. These include, whether a model was able to capture the complexities of the topic; how Lee's framework of needs assessment supported the structure of the research; and how the SNM supported the content of the research. The strengths and limitations of the research as a whole will be considered and evaluation of the researcher's personal development will also be described. Finally, the contribution to knowledge will be demonstrated, together with recommendations for further research and suggestion for how the model might be used in clinical practice.

7.2 Summary of research

This thesis has presented a series of interlinked studies that have followed a path through needs analysis as outlined by (Lee *et al*., 2007a; 2007b).

Phase 1 of this research looked at the national picture of TIA service provision using a questionnaire distributed by BASP. The survey found that service provision across England, Scotland and Wales, for people with suspected TIA was highly variable in terms of frequency of clinics; duration of appointments; access to investigations; personnel involved in clinics, and whether patients could expect to have a second follow-up appointment, or not. Those services that did not provide a follow-up appointment, appeared to offer a less comprehensive service than the services that routinely followed-up patients following TIA.

Phase 1 demonstrated that very few (2/59) services offered all four key features of best practice, although if repeated today, it is likely that TIA services have continued to evolve and a far greater proportion would now meet all key features. At the time of the survey (2011), only 41% of services routinely offered follow-up to all people following TIA. This is likely to impact

on the ability of services to identify and address needs experienced following TIA, since the focus at initial contact was on making the diagnosis.

Phase 2 utilised a stroke needs mapping (French *et al.,* 2008) as the starting point to explore needs following TIA with patients, carers and staff via a multi-study iterative process. A model was constructed based on interviews and focus groups with patients, survey and interviews with staff and a questionnaire used with carers.

Phase 2 showed that although there are similarities between the needs experienced by people following TIA and stroke, there were some needs identified following TIA, which had not been previously identified following stroke. It was also noted that some needs that were found to be in common between stroke and TIA, held a different meaning for those who had experienced TIA, to the apparent meaning for people following a stroke. During Phase 2, it also became apparent that needs change over time from the index TIA, which led to the development of a draft model of TIA needs that reflected the changing needs over time. It was noted that the potential range of needs was great, and whilst there appeared to be a core group of needs that were relevant to most people following TIA, less common needs would be less likely to be identified (by either the patient or the professional) and therefore less likely to be addressed.

There is considerable overlap between needs identified following stroke and TIA. However, there are some needs that are unique to TIA. There are mis-matches between needs perceived by professionals and carers on behalf of patients and those actually reported by patients themselves. This mis-match could contribute to unmet needs. Needs following TIA can be grouped as common or rare, and emerge at different time-points after the initial event.

Phase 3 consisted of an expert panel that reviewed the draft model of needs following TIA and validated and refined the draft. The panel included representation from patients', carers and staff, and discussion of a proposed model of needs following TIA allowed a greater understanding these needs to be shared throughout the group. Phase 3 enabled the formulation of a final model of needs following TIA which is presented in this chapter.

Four validated time-points were identified as: 'onset of symptoms'; 'diagnosis; 'early' (0-28 days), and 'later' (29 days +). This led to a final model of needs following TIA being agreed based on each of those time-points. A number of needs that appear unique following TIA were identified. These included the need for encouragement to seek help, management of denial, dealing with diagnostic uncertainty, and managing hypervigilance. These needs have not been reported following stroke, at least not in the same context. Although there are a number of reports about delay in presentation following stroke (Harper *at al*., 1992; Feldmann *et al.,* 1993; Williams *et al*., 1997; Wester *et al.,* 1999; Parahoo *et al*., 2003; Carroll *et al*., 2004; Kleindorfer *et al*., 2006; Muller-Nordhorn *et al.,* 2009), the context is very different.

7.3 Presentation of final model

The final model of needs following TIA is a combination of the output from Phases 2 and 3 of the research. Needs have been presented using the words of participants. The needs have been split into the four time-points previously presented, and needs were refined to create a final model (Figure 24), which should be viewed in conjunction with the final Venn diagram (Figure 25). The final model of needs has identified a range of 'core' needs that most people are likely to experience and the Venn diagram that demonstrates the range of potential needs that might be experienced. Less common needs are potentially less likely to be identified, but may result in significant difficulties for the patient if they are not identified and addressed.

Needs following TIA have been demonstrated to be complex and specific to each individual. The use of multiple research methods, and participants from a range of time-points from the index event, has provided a richness of data which has illustrated a variety of potentially hidden needs following TIA. The wide range of presenting symptoms has contributed to the variation in experiences, as has each individual's coping strategies.

The needs presented in Figure 24 represent the more common needs and how they might change over time. It is recognised that the time-points are somewhat arbitrary, and individual patients may move more slowly (or quickly)

through the pathway, or may move backwards and forwards as their circumstances change.

The model of common needs (Figure 24), has also identified some needs that fit into more than one time-frame. The need to 'validate the experience' spans all four time-frames and seems to be a key on-going theme that impacts help-seeking behaviour, adoption of secondary prevention strategies and the long-term maintenance of those strategies. The other needs were felt to be equally relevant from obtaining a diagnosis, these include: the need for signposting for information and services; the need for reassurance you are 'doing the right thing'; and the need for significant others to understand what is going on. A further three needs were outlined after diagnosis has occurred, they were: the need to understand when you can return to work, drive and go on holiday; the need to manage emotion (the emotions of both the patient and those of the significant other); and the need to manage fatigue. In terms of what patients, carers and staff felt jointly would help people following TIA, three main suggestions were made:

- Explicitly invite significant others to attend at least part of a diagnostic consultation.
- Information sessions later post TIA to enable peer contact (similar to cardiac rehabilitation model).
- Contact details available for stroke / TIA specialists, for ongoing advice, support and signposting of services.

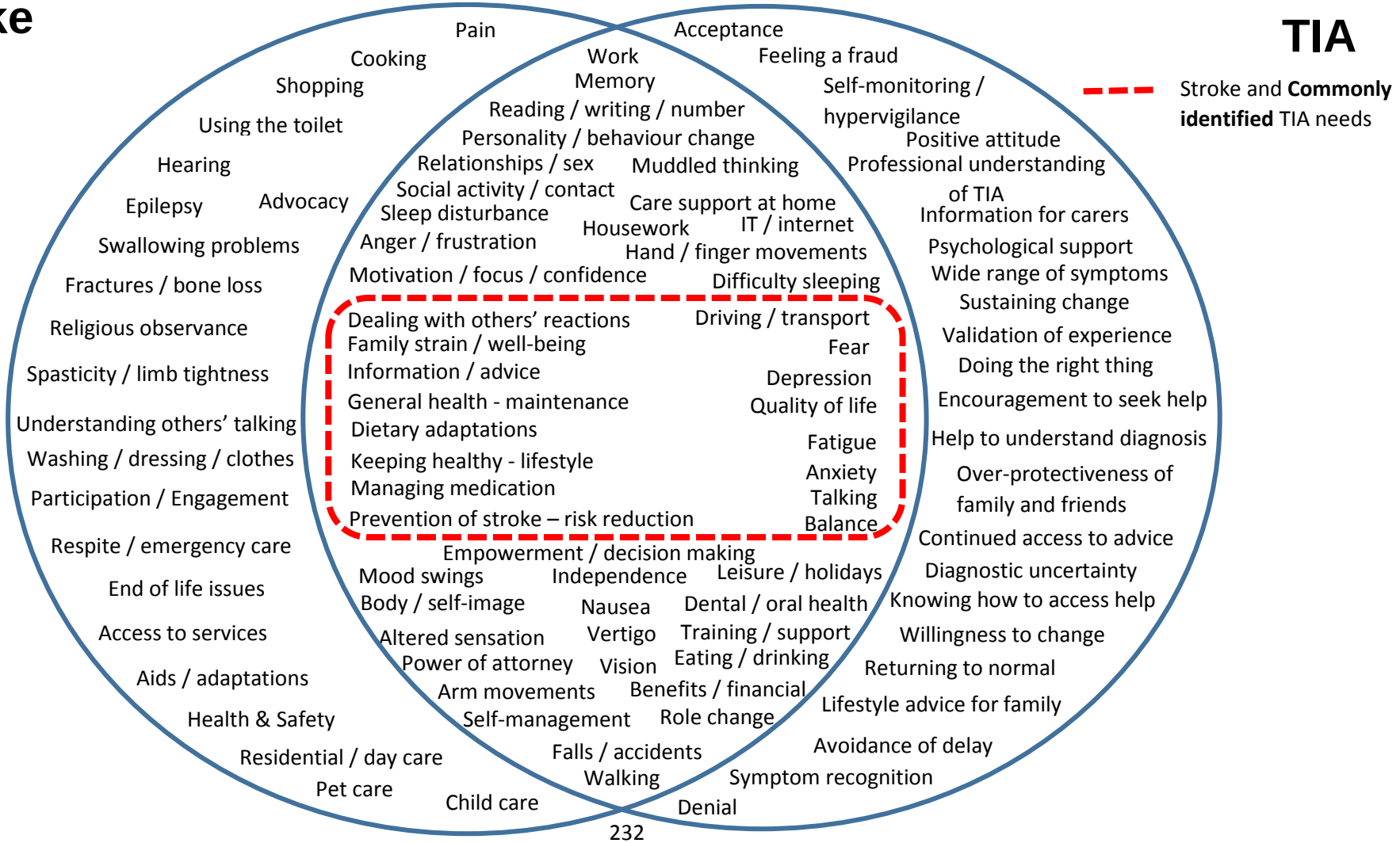
These potential solutions were thought to be relevant for all time periods except onset, before diagnosis has occurred.

Figure 25 highlights the significant overlap between stroke and TIA needs, but also demonstrates a wide range of needs that are currently unique following TIA. Clearly it would be unlikely for any one individual to experience all the needs identified in the Venn diagram attributed to having had a TIA. However, as a comprehensive review of potential needs, or problems following TIA, it offers an insight into just how wide ranging the needs might be.

Figure 24 Final model of common needs following TIA.

<table>
<tr><th>Onset</th><th>Diagnosis</th><th>Early (0-28 days)</th><th>Later (after 28 days)</th></tr>
<tr><td>Proactive management of risk factors even before the event</td><td colspan="3">The need to validate the experience</td></tr>
<tr><td></td><td colspan="3">The need for signposting for information and services
The need for reassurance you are doing the right thing
The need for significant others to understand what is going on</td></tr>
<tr><td></td><td></td><td colspan="2">The need to understand when you can return to work, driving, holidays
The need to manage emotions
The need to manage fatigue</td></tr>
<tr><td>The need for:
Patients to recognise symptoms in a timely manner
Speedy access to specialist medical opinion
Understanding that TIA symptoms can be very different to stroke
Understand the immediate actions: Not driving, contact knowledgeable healthcare professionals
Overcoming denial & feeling a ‘fraud’.</td><td>The need for:
Clarity regarding diagnosis
Understanding the implications of the diagnosis (likelihood of stroke)
Understanding why it happened
Support from family & friends
Emotional support and reassurance</td><td>The need for:
Understanding what could be done to reduce the risks of it happening again
Understanding the implications of not being able to drive and whether that will be long-term
Strategies to manage possible after effects; fatigue, memory loss, loss of confidence
Strategies to promote self-management and avoid hypervigilance
Being aware of financial implications</td><td>The need for:
Ongoing monitoring of risk factors e.g. Cholesterol
Ongoing lifestyle advice to avoid “slipping back”
Acceptance that medications should be life-long
Lifestyle advice for family members who might be at similar risk of vascular ill health.
Dealing with role change
Lifelong access back into TIA services if necessary</td></tr>
<tr><td></td><td colspan="3">Solutions: Explicitly invite significant others to attend at least part of a diagnostic consultation
Information sessions later post TIA to enable peer contact (similar to cardiac rehab model)
Contact details available for stroke / TIA specialists</td></tr>
</table>

Figure 25 Summarising final research findings relating to the relevance of stroke needs to people following TIA



7.4 Discussion

The development of a model of needs following TIA demonstrates that needs change over time, although there may be some overlap between time-points. The model is a simplified representation of needs post-TIA, but is based on the needs identified by patients, staff and carers. The draft model was validated and refined by a panel comprising patients, staff and carers. The final model shows the common needs that change over time. In addition, there is a diagram (Figure 25) demonstrating a comprehensive range of potential needs following TIA. This is important because less common needs are less likely to be recognised and therefore less likely to be met. Even the needs in the 'stroke only' section on the left of the Venn diagram (Figure 25) could still be relevant to some people following a diagnosis of TIA, but the participants involved in the research did not think they were relevant. Whilst the 'stroke only' items were unlikely to be relevant, it cannot be stated that they would never be considered relevant. The model will help clinicians to use the findings of this research to provide services that probe for un-met needs following TIA.

Process

Despite there being a wide range of established needs assessment tools available (McEwen *et al.,* 1995; Cowley *et al.,* 2000; Williams *et al*., 2000; Asadi-Lari *et al.,* 2003b; Low *et al.,* 2003; Williams *et al.,* 2007), the use of a novel framework enabled it to be used as a guide, rather than constraining the research as it developed. Lee's framework of needs assessment had only previously been used in educational settings (Lee *et al*., 2007b). The framework itself was based on a blend of previous work (Kaufman & English, 1979; Witkin & Altschuld, 1995), but was clearly described (Lee *et al*., 2007b). A strength of the framework was that it enabled a mixture of paradigms, methods and participant groups to be included (Lee *et al*., 2007a; 2007b), whilst plotting a focussed path through the research. The fit with this programme of research was good. Lee's framework facilitated a move away from a biomedical model, and thus enabled the focus of the research to be the needs experienced, rather than the condition that lead to potential needs. A weakness of this approach is that there is no precedent or validation for use of the framework in this way.

The use of a stroke needs mapping could be seen as both a strength and a weakness of this research. Although stroke and TIA can be seen as different parts of a cerebrovascular spectrum of disease, there are very distinct differences between the two conditions in terms of expected physical disability. It is possible that use of the SNM might have been directive or inhibited the natural expression of needs that might otherwise have been offered. To minimise that possibility, the first part of the expert panel was conducted with no reference to any material other than the four time-points (onset, diagnosis, 0-28 days, 29 days onwards), which were developed from the findings of Phase 2. The second part of the expert panel looked at the draft model developed from the programme of research. There was nothing entirely new presented at this point, although there were variations that reflected the personal experiences of the participants.

Another benefit of using the SNM is that it provided a common starting point for each participant group, which facilitated comparisons between the views of patients, staff and carers. A range of participants with different perspectives, have been included throughout the research. By eliciting the views of patients' staff and carers, triangulation of data sources was possible, which is thought to improve the validity of the data (Golafshani, 2003). The mis-match between groups offers insights into how the groups view needs following TIA. This illuminates how needs might fail to be recognised.

Further strengths of this research include the use of a mixture of quantitative and qualitative methods, which bring a breadth to the data. Within the qualitative elements more than one method of data collection has been used, which offers triangulation of methods (Shenton, 2004; Carter *et al*., 2014). Comparing the data obtained by interviews and focus groups showed many areas of agreement and similarities in the themes developed, however the interviews revealed more personal information than was obtained in a group setting, for example, one man during the interviews talked about the profound impact medication had on his libido and the sudden onset of impotence. This was not mentioned at all in any group setting, whereas individuals during interviews did not talk about the financial aspects of their TIA, but this was a common theme in the focus groups. All the interviews and focus groups (excluding the expert panel) had the same basic structure, based on the

SNM, which was reviewed in full during each encounter. This form of triangulation demonstrated that the data obtained was largely consistent across methods (Lambert & Loiselle, 2008; Carter *et al*., 2014).

A clear outline of study conduct at each stage enables the replication of the individual studies if required, indicating a transparent process and the provision of quotes allows assessment of the interpretation of data. Data were reviewed by the researcher and a senior academic with experience, initial coding and theme generation were discussed in detail, later coding and groupings were reviewed more generally as the research progressed and the researcher gained experience and confidence in using the research methods employed.

Limitations within this thesis include relatively low response rates to the two national surveys conducted, although response rates were in keeping with other findings within the literature (Nulty, 2008; Wiebe *et al*., 2012). Although there were four participants recruited from the Northwest of England, most of the participants lived or worked in the South of England (with the exception of a practice nurse from the Home Counties). This could potentially reduce generalisability of these findings to other areas of the UK, and would require further evaluation. The majority of patients were recruited from a single area in the Southwest of England, although their TIA care could have been delivered in any one of three local hospitals. Recruitment was more successful in the Southwest than the Northwest and it could be speculated that the service delivery models in each area could have influenced the response rate, since there was no follow-up provision in the Northwest and all patients in the Southwest were offered follow-up.

A further limitation was the inability to interview an optician and a paramedic, who, it might have been anticipated, would further add to the richness of the data collected and would have completed Phase 2c of the study more fully.

Searching the literature for this research and thesis was challenging due to the novel area of enquiry, and the breadth of potential topics. A wide range of residual problems and needs emerged during the conduct of this research. Data was published examining the experience of TIA, which added to the body of evidence, and required an iterative approach to the literature. An

important proportion of studies ten out of a possible 57, reported specific problems after TIA with mixed data from patients with minor stroke and TIA. This is either by design, or by virtue of using the WHO definition of TIA (WHO, 1975). The mixed data could be seen as both a strength and a limitation; a strength, since literature found was likely to be relevant to real world situations, and limitation in that mixing TIA and minor stroke might result in an over-estimation of problems or difficulties following TIA.

Finally, there is always a risk of self-selection when considering research of any kind (Mehra, 2002). It is not possible to determine whether the participants differed in any significant way from those who chose not to participate. In relation to TIA in particular there is also the potential that those patients who have not reported their TIA are very different to those that have reported it. Patients who have not reported their symptoms may possibly still worry about what the episode might have been, but equally, they might be exhibiting a more effective denial response. If a TIA has occurred but not been diagnosed, there is a very real risk that people will experience potential after effects such as fatigue or memory loss, but, without the TIA diagnosis, it is more difficult to explain the symptoms and potentially more alarming for symptoms to not have an attribution. Another disadvantage of patients not seeking help and receiving a diagnosis is, if they have in fact sustained a minor completed stroke, they miss out on the highly structured ongoing risk management, monitoring and regular follow-up available (DH, 2007).

Personal development

The process of post-graduate research teaches a range of skills, among them organisation and prioritisation skills, and the development of tenacity. The researcher has been a specialist nurse for nearly twenty years and it is second nature to want to identify patient problems and suggest solutions. Developing an awareness of perspective has been an important part of reflecting on the research process and findings (Walsh & Baker, 2004; Walsh & Downe, 2006). This is coupled with the experience of working in a less familiar paradigm, since previous research experience has been quantitative in nature. One of the hardest skills to adopt has been learning to listen, reflect, but not offer advice. In the early patient interviews, there was some

blurring of the research and clinical roles at times. This was identified on review of the data, and the researcher modified her behaviour and learned to avoid offering therapeutic suggestions. Transcripts of interviews were reviewed and the supervisory team critiqued performance and offered suggestions of other ways individual situations might have been dealt with. Later interviews utilised a greater degree of active listening and reflection, which also helped to validate the data obtained at the time of the interview. Facilitation skills have also been developed, enabling the researcher to confidently conduct focus groups, ensuring that all participants have an opportunity to contribute. An understanding of how to handle qualitative data has developed during the programme of research, with analysis reviewed and discussed with the supervisory team to ensure emerging themes are clearly based in the findings, not biased by the preconceptions of the researcher or team.

7.5 Contribution to knowledge

No previous needs mapping for people following TIA has been published. This thesis contributes to the knowledge base of TIA experience by providing a model of needs that might be found following TIA.

Needs have been identified by patients, carers and staff and cover physical, psychological, and social domains. The focus groups conducted in Phase 2 were the first to demonstrate how needs change over time, and this was key to the structure of the final model. The model of needs following TIA (Figure 24) provides an appreciation of how needs might change over time following TIA.

The whole range of identified needs have been categorised into common and less common ones (Figure 25). There are a number of unexpected problems or needs found in the stroke and TIA intersection, for example; arm movements, hand / finger movements, walking, falls / accidents, nausea, vertigo, and care / support at home. These all suggest incomplete recovery and possibly represent minor stroke rather than TIA. However, even if the patient receives a diagnosis of TIA, they still must manage the needs they perceive.

Some of the 'TIA only' needs have not previously been reported. These include concerns about 'feeling a fraud', the need to validate the experience, hypervigilance and the impact of diagnostic uncertainty. These have been explored within this thesis, together with a number of other 'TIA only' needs that, whilst referenced in the existing body of literature, were not prominent, or in some cases not present at all at the start of this research.

This thesis clearly demonstrates, for the first time, that people following TIA have extensive needs, despite complete symptom resolution. This adds to the growing knowledge that TIA is not a benign event which can be treated merely as a risk factor for stroke, but has far reaching consequences for patients, and offers opportunities to improve interventions for people following TIA.

There may be a case for abandoning TIA as an individual condition and combining it with stroke. The on-going nature of needs following TIA might mean that patients are better served if they were able to access the standard ongoing support that is available to people following stroke i.e. six-week, six month, then annual reviews. However, that is unlikely to happen quickly, so providing material that demonstrates the breadth of potential needs and how needs might change over time will give health care practitioners insight into how best to support this group of patients.

A further, methodological contribution, is the use of Lee's framework for needs assessment. This has not been used before in health, and has proven to be a useful roadmap through the needs assessment process.

7.6 Further research

Prior to the start of this programme of research the majority of research conducted into TIA was relating to TIA as a risk factor for stroke (Johnston *et al.,* 2000; Lovett *et al.,* 2003; Coull, Lovett & Rothwell, 2004; Giles & Rothwell, 2007b). There was also literature about secondary prevention, surgery, medication and lifestyle (Rothwell *et al*., 2007). There was some research about symptom recognition, but this was mainly mixed with stroke recognition for obvious reasons (Pancioli *et al.,* 1998; Rowe, Frankei & Sanders, 2001; Yoon *et al*., 2001; Reeves, Hogan & Rafferty, 2002; Johnston *et al*., 2003). There was even a limited amount of research about the

experience of TIA, and some recognition that some people had lasting difficulties following TIA (Rao *et al*., 2001; Chardavoyne & Frechette, 2006; Arts *et al.,* 2008). This thesis has looked specifically at the needs that might be experienced following TIA and, as such, has further explored the persistent after-effects of a diagnosis of TIA.

The role of the carer in TIA has not previously been explored. Within this thesis, the role has been alluded to, but due to difficulty accessing this participant group, more questions have been raised than answered. Further research into this role may suggest informal ways that patients may receive the help they require to meet their identified needs.

It would also be interesting to present the TIA needs model to patients following stroke, to see whether they identify with some of the needs that are currently considered 'TIA only'. It is certainly possible that considerable overlap may be found, because the SNM upon which the range of needs is based, was conducted with patients who had been discharged following stroke (French *et al.,* 2008). Therefore, some of the needs at onset or diagnosis may not have been captured by the methods used in the stroke needs mapping. Needs have been identified in a study population that was predominantly from one area. It would be important to determine whether the local service model has had an impact of the needs experienced following TIA. As previously discussed 'met needs' are often not perceived as needs by the individual concerned (Asadi-Lari *et al*., 2003a). Repeating elements of the research with patients from other geographical areas, where the service provision would not be identical, will help to establish the degree to which the care provided by TIA services impacts on the experience of TIA. If there are no new or different needs identified it would lend further credibility to the research presented in this thesis, and suggest the findings are generalizable. The findings of this research could be used as a starting point to look at possible interventions for people following TIA.

7.7 Recommendations for practice

The most important outcome of this research has been to highlight the wide range of potential needs that might be felt by someone who has experienced a TIA. The needs presented in the 'model of needs following TIA' are typically the more common needs, but the Venn diagram demonstrates the breadth of other problems that might be experienced.

Figure 25 shows the overlap between stroke and TIA needs. This is important in relation to which definition is used for TIA. Both require apparent complete resolution of symptoms, the difference is whether an ischaemic lesion has been excluded on MRI scanning (Easton *et al*., 2009). In practical terms, the needs most likely to arise, regardless of the presence or absence of ischaemia, would be expected to be those needs / problems found in the 'dotted box' situated with, in the intersection between stroke and TIA. Therefore, practitioners need to be aware of these and to screen for needs related to them, in addition to the needs identified within the timeline model. The less common needs are much more likely to be undetected, and therefore unmet, potentially leading to distress, sub-optimal recovery, or poor adherence to secondary prevention strategies. TIA follow-up services should probe for a range of potentially undisclosed needs.

One area of potential pathway development might be to create more formal links between commercial opticians and secondary care. By encouraging those opticians who suspect TIA to make a direct referral to stroke services, rather than opticians recommending patients should see their GP or attend the local eye hospital, delay can be avoided. This is clinically important since one in five patients with ocular TIA require vascular surgery, which is a time critical treatment (Lavallee *et al*., 2013; Wilson *et al.,* 2014).

If staff have a heightened awareness of the range of potential needs that might be present following TIA, it might encourage them to probe more carefully for unrecognised needs. Access to the new model of needs following TIA and comprehensive list of potential needs might help professionals consider needs, beyond the needs for diagnosis and secondary prevention. Identification of needs could help them to be met to improve patient outcomes and experience. An appreciation of how needs are likely to

change over time should also help healthcare staff to offer interventions and support when it is most needed. The TIA needs model should also be considered in relation to how TIA services generally are commissioned and provided.

7.8 Conclusion

This thesis has explored the needs experienced following TIA from the perspective of patients' carers and staff. It has contributed to knowledge by demonstrating the changing needs of patients over time following TIA, identifying the variety of needs that might be experienced, and looking at how needs might be addressed. In order to provide effective and individualised care, it is essential to incorporate an appreciation of how needs change over time, and also the potential breadth of needs experienced by people after TIA.

8.0 REFERENCES

Akhtar, N., Baumann, A and Cordingley, L. (2008). Q-methodology in nursing research. A promising method for the study of subjectivity. *Western Journal of Nursing Research, 30*(6), 759-773.

Albers, GW., Caplan, LR., Easton, JD., Fayad, PB., Mohr, JP., Saver, JL. and Sherman, DG. (2002). Transient Ischemic Attack – proposal for a new definition. *N Engl J Med, 347*(21), 1713-1716.

Albucher, JF., Martel, P. and Mas, LJ. (2005). Clinical practice guidelines: Diagnosis and immediate management of transient ischemic attacks in Adults. *Cerebrovasc Dis, 20*, 220-225.

Aldridge, A. and Levine, K. (2001). *Surveying the Social World: Principles and Practice in Survey Research*. Buckingham, UK: Open University Press.

Allen, KR., Hazelett, S., Jarjoura, D., Wickstrom, GC., Hua, K., Weinhardt J. and Wright K. (2002). Effectiveness of a post discharge care management model for stroke and transient ischemic attack: a randomized trial. *J Stroke Cerebrovasc Dis 11*(2), 88-98.

Amort, M., Furi, F., Schafer, J., Weisskopf, F., Katan, M., Burow, A., Bucher, HC., Bonati, LH., Lyrer, PA. and Englter, ST. (2011). Transient ischemic attack versus transaient ischemic attack mimics: Frequency, clinical characteristics and outcome. *Cerebrovasc Dis, 32*, 57-64.

Arts, ML., Kwa VI. and Dahmen R. (2008). High satisfaction with an individualised stroke care programme after hospitalisation of patients with a TIA or minor stroke: a pilot study. *Cerebrovasc Dis 25*(6), 566-571.

Asadi-Lari, M., Packham C. and Gray D. (2003a). Need for redefining needs. *Health and Quality of Life Outcomes*. *Biomed Central*, *1*(6), Doi: 10.1186/1477.7525-1-34.

Asadi-Lari, M., Packham C. and Gray D. (2003b). Is quality of life measurement likely to be a proxy for health needs assessment in patients with coronary artery disease? *Health Qual Life Outcomes, 1*(50), Doi: 10.1186/1477-7525-1-50.

Asadi-Lari, M. and Gray, D. (2005). Health needs assessment tools: Progress and potential. *Int J Tech Ass Health Care, 21*(3), 288-297.

Asch, DA., Jedrziewski, K. and Christakis, A. (1997). Response rates to mail surveys published in medical journals. *J Clin Epidemiol, 50*(10), 1129-1136.

Atkinson, R. and Flint, J. (2001). Accessing hidden and hard-to-reach populations: Snowball research strategies. *Social Research Update*, *33*, http://sru.soc.urrey.ac.uk/SRU33.pdf.

Ay, H., Arsava, EM., Johnston, SC., Vangel, M., Schwamm, LH., Furie, KL., Koroshetz WJ. and Sorensen AG. (2009). Clinical and imaging-based prediction of stroke risk after transient ischemic attack: the CIP model. *Stroke*, *40*(1), 181-186.

Aybek, S., Carita, A., Ghika-Schmid, F., Berney, A., Van Melle, G., Guex, P. and Bogousslavsky, J. (2005). Emotional behaviour in acute stroke study: The Lausanne emotion in stroke study. *Cog Behav Neurol, 18*(1), 37-44.

Backe, M., Larsson, K. and Fridlund, B. (1996). Patients' conceptions of their life situation within the first week after a stroke event: A qualitative analysis. *Intensive and Critical Care Nursing,* 12, 285-294.

Bailey, PH. (1997). Finding your way around qualitative methods in nursing research. *Journal of Advanced Nursing, 25*, 18-22.

Bakker, FC., Klijn, JM., Jennekens-Schinkel, A., van der Tweel, I., van der Grond, J., van Huffelen, AC., Tullenken, CAF. and Kappelle, LJ. (2003). Cognitive impairment is related to cerebral lactate in patients with carotid artery occlusion and ipsilateral transient ischemic attacks. *Stroke, 34*, 1419-1424.

Bandilla, W., Couper, MP. and Kaczmirek, L. (2012). The mode of invitation for web surveys. *Survey Practice e-journal, 5*(3) http://www.surveypractice.org/index.php/SurveyPractice/article/view/20html accessed 21/10/14.

Barbour, VL. and Mead, GE. (2012). Fatigue after Stroke: The Patient's Perspective. *Stroke Res Treat***,** *2012*, http://dx.doi.org/10.1155/2012/863031 .

Barriball, KL. and White, A. (1994). Collecting data using a semi-structured interview: A discussion paper. *J Adv Nurs, 19*, 328-335.

Batool, S., Roberts, AP., Kaira, L. and Manawadu, D. (2014). Health professionals' knowledge of driving restrictions following stroke and TIA: experience from a hyperacute stroke centre. *Postgrad Med J, 90*, 370-376.

Beech, P., Greenhalgh, J., Thornton, M. and Tyrrell, P. (2007). A survey of the practice of stroke doctors in developing transient ischaemic attack services in the UK. *J Eval Clin Pract, 13*, 395-399.

Bishop, FL. (2014). Using mixed methods research designs in health psychology: An illustrated discussion from a pragmatist perspective. *British Journal of Health Psychology, 20*, 5-20.

Blight, A., Pereira, AC. and Brown, MM. (2000). A single consultation cerebrovascular disease clinic is cost effective in the management of transient ischemic attack and minor stroke. *J R Coll Phys Lond, 34*(5), 452-455.

Boter, H. and Group HS. (2004). Multicenter randomized controlled trial of an outreach nursing support program for recently discharged stroke patients. *Stroke*, *35*(12), 2867-2872.

Boter, H., Rinkel G. and de Haan, R. (2004). Outreach nurse support after stroke: A descriptive study on patients' and carers' needs, and applied nursing interventions. *Clinical Rehabilitation, 18*, 156-163.

Bourque, LB. and Fielder, EP. (1995). *How to Conduct Self-administered and Mail Surveys.* Thousand Oaks, CA: Sage Publications Inc.

Bowling, A. (2002). *Research Methods in Health: Investigating Health and Health Services.* (2nd ed.) Maidenhead, UK: Open University Press.

Bradshaw, J. (1994). The conceptualisation and measurement of need: A social policy perspective. In Popay, J. and Williams, G. (Eds.), *Researching the People's Health* (pp.45-57). London, UK: Routledge.

British Medical Association [BMA]. (2013). BMA Position Paper: 7-day Services. British Medical Association; London. http://www.bma.org.uk/working-for-change/doctors-in-the-nhs/seven-day-services. Accessed 15th May 2016.

Brown, M. (2001). Difficult stroke and TIA syndromes identification and management of. *J Neurol Neurosurg Psychiatry*, *70*(suppl.), i17-i22.

Bruggimann, L., Annoni, JM., Staub, F., von Steinbuchel, N., Vander Linden, M. and Bogousslavsky, J. (2006). Chronic posttraumatic stress symptoms after nonsevere stroke. *Neurology, 66*, 513-516.

Calanchini, PR., Swanson, PD., Gotshall, RA., Haerer, AF., Poskanzer, DC., Price, TR., Conneally, PM. and Dyken, ML. (1977). Cooperative study of hospital frequency and character of transient ischemic attacks: IV. The reliability of diagnosis. *JAMA, 238*(19), 2029-2033.

Carroll, C., Hobart, J., Fox, C., Teare, L. and Gibson, J. (2004). Stroke in Devon: knowledge was good, but action was poor. *Journal of Neurology, Neurosurgery & Psychiatry 75*, 567-571.

Carruthers, J. (1990). A rationale for the use of semi-structured interviews. *J Educat Admin, 28*(1), http://dx.doi.org/10.1108/09578239010006046.

Carter, N., Bryant-Lukosius, D., DiCenso, A., Blythe, J. and Neville, A. (2014). The use of triangulation in qualitative research. *Oncology Nursing Forum, 41*(5), 545-547.

Castle, J., Mlynash, M., Lee, K., Caulfield, AF., Wolford, C., Kemp, S., Hamilton, S., Albers, GW. and Olivot, JM. (2010). Agreement regarding diagnosis of transient ischemic attack fairly low among stroke-trained neurologists. *Stroke*, *41*(7), 1367-1370.

Catangui, EJ. (2013). Time taken to seek and receive medical attention after TIA. *British Journal of Nursing, 22*(10), 562-565.

Chambers, JA., O'Carroll, RE., Hamilton, B., Whittaker, J., Johnston, M., Sudlow, C. and Dennis, M. (2011). Adherence to medication in stroke survivors: A qualitative comparison of low and high adherers. *Br J Health Psyc 16*, 592-609.

Chandratheva, A., Lasserson, DS., Geraghty, OC. and Rothwell, PM. (2010). Population-based study of behaviour immediately after transient ischemic attack and minor stroke in 1000 consecutive patients: lessons for public education. *Stroke 41*(6), 1108-1114.

Chang, E., Holroyd, BR., Kochanski, P., Kelly, KD., Shuaib, A. and Rowe, BH. (2002). Adherence to practice guidelines for transient ischemic attacks in an emergency department. *Can J Neurol Sci, 29*, 358-363.

Chardavoyne, J. and Frechette, V. (2006). Occult PTSD with panic attacks in a patient post-TIA: case report. *Int'l. J. Psychiatry in Medicine, 36*(4), 427-434.

Charmaz, K. (2006). *Constructing Grounded Theory: A Practical Guide Through Qualitative Analysis.* London, UK: Sage Publications Ltd.

Christiansen L. (2014). Patients' experience of quick diagnosing and treatment of Transient Ischemic Attack (TIA) including telephone follow-up by nurses. *Cerebrovascular Diseases, 37*, 422. Retrieved from http://ovidsp.ovid.com/ovidweb.cgi?T=JS&PAGE=reference&D=emed18b&NEWS=N&AN=614325387. 16th April 2017.

Cook, JV., Dickinson, HO. and Eccles, MP. (2009). Response rates in postal surveys of healthcare professionals between 1996 and 2005: an observational study, *BMC Health Serv Res 9*, 160. http://www.biomedcentral.com/1472-6963/9/160 .

Corbin, J. and Strauss, A. (2015). *Basics of Qualitative Research: Techniques and Procedures for Developing Grounded Theory*. Thousand Oaks, California: Sage Publications Inc.

Coull, AJ., Lovett, JK. and Rothwell, PM. (2004). Population based study of early risk of stroke after transient ischaemic attack or minor stroke: implications for public education and organisation of services. *BMJ 328*(7435), 326.

Courtnay, M. and Griffiths, M. (2005). *Independent and Supplementary Prescribing*. Cambridge, UK: Cambridge University Press.

Cowley, S., Bergan, A., Young, K. and Kavanagh, A. (2000). A taxonomy of needs assessment, elicited from a multiple case study of community nursing education and practice. *J Adv Nurs 31*(1), 126-134.

Creswell, JW. and Plano Clark, VL. (2007). *Designing and conducting mixed methods research*. Thousand Oaks, CA: Sage.

Creswell, JW. (2015). *A concise introduction to mixed methods research*. Thousand Oaks, CA: Sage.

Critical Appraisal Skills Programme (2017). CASP 10 questions to help you make sense of qualitative research Checklist. Accessed: http://www.casp-uk.net/checklists Date Accessed April 2017.

Croot E., Read J., Campbell F., Ryan T. and Venables G. (2012). Patients' experience of follow up after TIA: A qualitative study. *International Journal of Stroke, 7,* 18. doi:10.1111/j.1747-4930.2012.00961.x.

Croot E.J., Ryan T.W., Read J., Campbell F., O'Cathain A. and Venables G. (2014). Transient ischaemic attack: a qualitative study of the long term consequences for patients. *BMC family practice, 15,* 174. doi:10.1186/s12875-014-0174-9.

Crotty, M. (2003). *The foundations of social research: Meaning and perspective in the research process*. London, UK: Sage Publications Ltd.

Crowfoot GM, van der Riet PJ and Maguire JM. (2016). Living within stories: Exploring the experiences of people with transient ischemic attack. *Nursing & Health Sciences, 18,* 52-7. doi:10.1111/nhs.12227.

Curry, L. and Nunez-Smith, M. (2015). *Mixed methods in health sciences research: A practical primer*. Thousand Oaks, CA: Sage.

Dennis, M, Bamford, JM., Sandercock, PA., and Warlow, CP. (1989). Incidence of transient ischemic attacks in Oxfordshire, England. *Stroke 20*(3), 333–339.

Dennis, M., Bamford, J., Sandercock, P. and Warlow, C. (1990). Prognosis of transient ischemic attacks in the Oxfordshire Community Stroke Project. *Stroke 21*(6), 848–853.

Dennis, C-L. (2003). Peer support within a health care context: a concept analysis. *Int J Nurs Studies, 40*, 321-332.

Department of Health [DH]. (2007). *National Stroke Strategy*. London, UK: Department of Health.

Department of Health [DH]. (2013). Everyone Counts: Planning for Patients 2014 / 2015 to 2018 / 2019. Department of Health. Published to gov.uk, in PDF format only. www.gov.uk/dh.

Department of Health [DH]. (2014). *Living Well for Longer: National Support for Local Action to Reduce Premature Avoidable Mortality*. Department of Health. Published to gov.uk, in PDF format only. www.gov.uk/dh.

Department of Health [DH]. (2015*). 7-day NHS services: A Fact Sheet*. Department of Health. Published to gov.uk, in electronic format only. www.gov.uk/dh.

Doyle, L., Brady, A. and Byrne, G. (2009). An overview of mixed methods research. *Journal of Research in Nursing, 14*(2), 175-185.

Driver & Vehicle Licensing Agency [DVLA] (2016). *Assessing fitness to drive – a guide for medical professionals*. Swansea, UK: DVLA.

Drummond, JS. (2005). Relativism. *Nursing Philosophy, 6*, 267-273.

Dykema, J., Jones, NR., Piche, T. and Stevenson, J. (2013). Surveying clinicians by web: Current issues in design and administration. *Eval Health Professions 36*(3), 352-381.

Easton, JD., Saver, JL., Albers, GW., Chaturvedi, S., Feldmann, E., Hatsukami, TS., Higashida, RT., Johnston, SC., Kidwell, S., Lutsep, HL., Miller, E. and Sacco, RL. (2009). Definition and evaluation of Transient Ischemic Attack: A scientific statement for healthcare professionals from the American Heart Association / American Stroke Association stroke council; council on cardiovascular surgery and anesthesia; council on cardiovascular radiology and intervention; council on cardiovascular nursing; and the interdisciplinary council on peripheral vascular disease: The American academy of neurology affirms the value of this statements an educational tool for neurologists. *Stroke, 40*, 2276-2293.

Edwards, P., Roberts, I., Clarke, M., DiGuiseppi, C., Pratap, S., Wentz, R. and Kwan, I. (2002). Increasing response rates to postal questionnaires: systemic review. *BMJ, 324*, doi: http://dx.doi.org/10.1136/bmj.324.7347.1183.

Edwards, PJ., Roberts, I., Clarke, MJ., Diguiseppi, C., Wentz, R., Kwan, I., Cooper, R., Felix LM. and Pratap, S. (2009). Methods to increase response to postal and electronic questionnaires. *Cochrane Database Syst Rev*, (3): MR000008.

Eilertsen, G., Ormstad, H. and Kirkevold, M. (2013). Experiences of poststroke fatigue: qualitative meta-synthesis. *J Adv Nurs, 69*(3), 514-525.

Fan, YH., Mysak, TM., Jeerakathil, T. and Pearson, GJ. (2010). Secondary Stroke Prevention: Practice Patterns in a Tertiary Care Stroke Service. *Can. J. Neurol, Sci 37*, 245-251.

Farhat, H., Elhammady, M., Ziayee, H., Aziz-Sultan, M. and Heros, R. (2009). Eagle syndrome as a cause of transient ischemic attack. *Journal of Neurosurgery***.** *110*, 90-93.

Fassaert, T., van Dulmen, S., ois Schellevis, F. and Bensing, J. (2007). Active listening in medical consultations: Development of the active listening observation scale (ALOS-global). *Patient Education and counselling, 68*, 258-264.

Faugier, J. and Sargeant, M. (1997). Sampling hard to reach populations. *Journal of Advanced Nursing*, *26*(4), 790-797.

Feldmann, E., Gordon, N., Brooks, J., Brass, L., Fayad, P., Sawaya, K., Nazareno, F. and Levine, S. (1993). Factors Associated With Early Presentation of Acute Stroke. *Stroke 24*, 1805-1810.

Fens, M., van Heugten, CM., Beusmans, GH., Limburg, M., Haeren, R., Kaemingk, A. and Metsemakers, JF. (2013). Not as transient: patients with transient ischaemic attack or minor stroke experience cognitive and communication problems; an exploratory study. *Eur J Gen Pract 19*(1), 11-16.

Fink, A. (2009). *How to Conduct Surveys: A Step-by-step Guide* (4th ed.). California CA: Sage Publications Inc.

Flemming, K., Brown, R., Petty, G., Huston, I., Kallmes, JD. and Piepgras, D. (2004). Evaluation and Management of Transient Ischemic Attack and Minor Cerebral Infarction. *Mayo Clinic proc. 79*(8), 1071-1086.

Flemming, K. (2007). The knowledge base for evidence-based nursing: A role for mixed methods research? *Advances in Nursing Science, 30*(1), 41-51.

Forster, A., Brown, L., House, J., Knapp, P., Wrght, JJ. and Young, J. (2012). Information provision for stroke patients and their caregivers (review). *Cochrane Database of Syst Rev 11*. Doi:10.1002/14651858.CD001919.pub3.

Foss, C. and Ellefsen, B. (2002). The value of combining qualitative and quantitative approaches in nursing research by means of method triangulation. *Journal of Advanced Nursing, 40*(2), 242-248.

Foster, RL. (1997). Addressing epistemologic and practical issues in multimethod research: A procedure for conceptual triangulation. *Advances in Nursing Science, 20*(2), 1-12.

French, B., Leathley, M., Radford, K., Dey, P., McAdam, J., Marsden, J., Sutton, C. and Watkins, C. (2008). *UK Stroke Survivor Needs Survey Information Mapping Exercise Final Report*. Preston, UK: Stroke Association.

Friese, S. (2012). *Qualitative Data Analysis with Atlas.ti.* London, UK; Sage Publications Ltd.

Gibson, J. and Watkins, C. (2011). The use of formal and informal knowledge sources in patients' treatment decisions in secondary stroke prevention: qualitative study. *Health Expectations 16*, e13-e23.

Gibson, J. and Watkins, C. (2012). People's experiences of the impact of transient ischaemic attack and its consequences: qualitative study. *J Adv Nurs, 68*(8), 1701-1715.

Giddings, LS. and Grant, BM. (2007). A trojan horse for positivism? A critique of mixed methods research. Advances in Nursing Science, 30(1), 52-60.

Giles, MF., Flossman, E. and Rothwell, PM. (2006). Patient behaviour immediately after transient ischemic attack according to clinical characteristics, perception of the event, and predicted risk of stroke. *Stroke 37*(5), 1254-1260.

Giles, MF. and Rothwell, PM. (2007a). Substantial underestimation of the need for outpatient services for TIA and minor stroke. *Age and Ageing,* 36, 676-680.

Giles, MF. and Rothwell, PM. (2007b). Risk of stroke early after transient ischaemic attack: a systematic review and meta-analysis. *Lancet Neurology 6*, 1063-1072.

Gladstone, DJ., Bui, E., Fang, J., Laupacis, A., Lindsay, MP., Tu, JV., Silver, FL. and Kapral, MK. (2009). Potentially preventable; strokes in high-risk patients with atrial fibrillation who are not adequately anticoagulated. *Stroke, 40*, 235-240.

Gladstone, DJ., Spring, M., Dorian, P., Panzov, V., Thorpe ,KE., Math, M., Hall, J., Vaid, H., O'Donnell, M., Laupacis, A., Cote, R., Sharma, M., Blakely, JA., Shuaib, A., Hachinski, V., Coutts, SB., Sahlas, D., Teal, P., Yip, S., Spense, JD., Buck, B., Verreault, S., Casaubon, LK., Penn, A., Selchen, D., Jin, A., Howse, D., Mehdiratta, M., Boyle, K., Aviv, R., Kapral, MK. and Mamdani, M. (2014). Atrial fibrillation in patiets with cryptogenic stroke. *NEJM, 370*(26), 2467-2477.

Golafshani, N. (2003). Understanding reliability and validity in qualitative research. *The Qual Report 8*(4), 597-606.

Gommans, J., Barber, PA. and Fink, J. (2009). Preventing stroke: The assessment and management of people with transient ischaemic attack. *NZJM, 122*(1293), 50-60.

Goodyear, K. and Roseveare, C. (2003). Driving restrictions after stroke: doctors' awareness of DVLA guidelines and advice given to patients. *Clin Med, 3*(1), 86-87.

Green, BN., Johnson, CD. and Adams, A. (2001). Writing narrative literature reviews for peer-reviewed journals: Secrets of the trade. *Journal of Chiropractic Rehabilitation. 15*, 5-19.

Grisolia, JM., Longo, A., Hutchinson, G. and Kee, F. (2015). Applying health locus of control and latent class modelling to food and physical activity choices affecting CVD risk. *Soc Sci Med, 132*, 1-10.

Guba, EG. (1987). What have we learned about naturalistic evaluation? *Evaluation Practice. 8*(1), 23-43.

Guba, EG. and Lincoln, YS. (1994). Competing paradigms in qualitative research. In NK. Denzin & YS Lincoln (Eds*.), Handbook of qualitative research* 105-117. Thousand Oaks, CA: Sage.

Guyomard, V., Metcalf, AK., Naguib, MF., Fulcher, RA., Potter, JF. and Myint, PK. (2011). Transient ischaemic attack, vascular risk factors and cognitive impairment: a case-controlled study. *British Geriatrics Society*, DOI: 10.1093/ageing/afr079.

Harper, G., Haugh, RA., Potter, JF. and Castleden, CM. (1992). Factors delaying hospital admission after stroke in Leicestershire. *Stroke, 23*, 835-838.

Hillsdon, KM., Kersten, P. and Kirk, HJS. (2013). A qualitative study exploring patients' experiences of standard care or cardiac rehabilitation post minor stroke and transient ischaemic attack. *Clinical Rehabilitation, 27,* 845-853.

Hsia, AW., Castle, A., Wing, JJ., Edwards, DF., Brown, NC., Higgins, TM., Wallace, JL., Koslosky, SS., Gibbons, MC., Sanchez, BN., Fokar, A., Shara, N., Morgenstern, LB., and Kidwell, CS. (2011). Understanding reasons for delay in seeking acute stroke care in an underserved urban population. *Stroke*. doi: 10.10.1161/STROKEAHA.110.604736.

Howe, KR. (1988). Against the quantitative-qualitative incompatibility thesis: or dogmas die hard. *Educational researcher. November*, 10-16.

Intercollegiate Stroke Working Party [ISWP]. (2004). *National Clinical Guidelines for Stroke Second edition.* London, Royal College of Physicians of London.

Intercollegiate Stroke Working Party [ISWP]. (2006). *National Sentinel Stroke Audit Organisational Audit 2006 Report for England, Wales and Northern Ireland*. London, UK: Royal College of Physicians of London.

Intercollegiate Stroke Working Party [ISWP]. (2008). *National Sentinel Stroke Audit Organisational Audit 2008 Report for England, Wales and Northern Ireland*. London, UK: Royal College of Physicians of London.

Intercollegiate Stroke Working Party [ISWP]. (2008a). *National Clinical Guideline for Stroke Third edition incorporating the recommendations from Stroke: national clinical guideline for diagnosis and initial management of acute stroke and transient ischaemic attack (TIA).* National Institute for Health and Clinical Excellence. London, UK: Royal College of Physicians of London.

Intercollegiate Stroke Working Party [ISWP]. (2010). *National Sentinel Stroke Audit Organisational Audit 2010 Public Report for England, Wales and Northern Ireland.* London, UK: Royal College of Physicians of London.

Intercollegiate Stroke Working Party [ISWP]. (2011). *National Sentinel Stroke Audit 2010, Round 7 – National and Local Results for the Clinical Audit 2010*. London, UK: Royal College of Physicians of London.

Intercollegiate Stroke Working Party [ISWP], (2016a). *Sentinel Stroke National Audit Programme Annual Results Portfolio* [Online]. London. Available: https://www.strokeaudit.org/Documents/Results/National/Apr2015Mar2016/Apr2015Mar2016-AnnualResultsPortfolio.aspx. Accessed 16th April 2017.

Intercollegiate Stroke Working Party [ISWP]. (2016b). *National Clinical Guideline for Stroke. Fifth edition*. London, UK: Royal College of Physicians of London.

Ivankova, NV., Creswell, JW. and Sheldon, LS. (2006). Using mixed-methods sequential explanatory design: From theory to practice. *18(*1), 3-20.

Jackson, CJ. and Furnham, A. (2000*). Designing and Analysing Questionnaires and Surveys: A manual for Health Professionals and Administrators*. London, UK: Whurr Publishers.

Jagadesham, VP., Aparajita, R. and Gough, MJ. (2008). Can the UK guidelines for stroke be effective? Attitudes to the symptoms of a transient ischaemic attack among the general public and doctors*. Clin Med, 8*(4), 366-370.

Jepson, C., Asch, DA., Hershey, JC. and Ubel, PA. (2005). In a mailed physician survey, questionnaire length had a threshold effect on response rate. *J Clin Epidemiol***,** *58*(1), 103-105.

Johnson, RB. and Onwuegbuzie, AJ. (2004). Mixed methods research: A research paradigm whose time has come. *Educational Researcher, 33*(7), 14-26.

Johnston, S., Gress, DR., Browner, W. and Sidney, S. (2000). Short-term prognosis after emergency department diagnosis of TIA. *JAMA 284*(22), 2901-2906.

Johnston, S. (2002). Transient Ischemic Attack. *New England Journal of Medicine, 347*(21), 1687-1692.

Johnston, S., Fyad, P., Gorelick, PB., Hanley, D., Shwayder, P., van Husen, D. and Weiskopf, T. (2003). Prevalence and knowledge of transient ischemic attack among US adults. *Neurology 60*, 1429-1434.

Johnston, SC. (2007a). Short-term prognosis after a TIA: A simple score predicts risk *Cleveland Clinic Journal of Medicine 74*(10), 729-736.

Johnston, SC. (2007b). Towards FASTER treatment of TIA and minor stroke. *Lancet Neurology 6*(November), 941-943.

Johnston, SC., Rothwell, PM. and Nguyen-Huynh, M. (2007a). The ABCD, California, and unified ABCD2 risk scores predicted stroke within 2, 7, and 90 days after TIA. *Evidence Based Medicine 12*(June), 88.

Jones, S., Jenkinson, M., Leathley, M., Rudd, A., Ford, GA. and Watkins, C. (2007). The recognition and emergency management of suspected stroke and transient ischaemic attack. *Clinical Medicine 7*(5), 467-471.

Jordan, J. and Wright, J. (1997). Making sense of health needs assessment. *British Journal of General Practice, November*, 695-696.

Kalsner, J. and Kalsner, S. (1990). With TIAs, MDs cannot rely on patients to provide a meaningful history*. Can Med Assoc J, 143*(8), 790-791.

Kamaruzzaman, S., Watt, H., Carson, C. and Ebrahim, S. (2010). The association between orthostatic hypotension and medication use in the British women's heart and health study. *Age & Ageing 39*, 51-56.

Kar, A., Ellis, A., Guyler, P. and O'Brien, A. (2009a). Dual antiplatelet therapy for 1month following a transient ischaemic attack is associated with a low risk of stroke recurrence and a low incidence of adverse events at 30 days. 18th European Stroke Conference, *Cerebrovascular Diseases. 27***,** 70.

Kar, A., Ragavan, S., Brown, S., Ellis, A., Guyler, P. and O'Brien, A. (2009b). Intensive cardiac monitoring after transient ischaemic attack identifies a significant number of previously unknown paroxysmal atrial fibrillation. 18th European Stroke Conference, *Cerebrovascular Diseases. 27***,** 203.

Karkos, CD., McMahon, G., McCarthy, MJ., Dennis, MJ., Sayers, RD., London, NJ. and Naylor, AR. (2007). The value of urgent carotid surgery for crescendo transient ischemic attacks. *J Vasc Surg 45*(6), 1148-1154.

Karunaratne, PM., Norris, CA. and Syme, PD. (1999). Analysis of six months' referrals to a "one-stop" neurovascular clinic in a district general hospital: implications for purchasers of a stroke service. *Health Bull (Edinb) 57*(1), 17-28.

Kaufman, R. and English, FW. (1979). *Needs Assessment: Concept and Application.* Englewood Cliffs, NJ: Educational Technology Publications.

Kaufman, R. (1982). *Identifying and Solving Problems: A System Approach* (3rd ed.). San Diego, CA: University Associates Publishers.

Kellerman, SE. and Herold, J. (2001). Physician response to surveys: A review of the literature. *Am J Prev Med, 20*(1), 61-67.

Kelly, J., Hunt, B., Lewis, R. and Rudd, A. (2001). Transient ischaemic attacks: under-reported, over-diagnosed and under-treated. *Age & Ageing 30*(5), 379-381.

Kersten, P., Low, JT., Ashburn, A., George, SL. and McLellan, DL. (2002). The unmet needs of young people who have had a stroke: Results of a national survey. *Disabil Rehabil, 24*(16), 860-866.

Kessler, C. and Thomas, KE. (2009). An examination of economic outcomes associated with misdiagnosis or undertreatment of TIA. *Am J Managed Care, 15*(6), S170-S176.

King, N. and Horrocks, C. (2010). *Interviews in Qualitative Research.* London, UK; Sage Publications Ltd.

Kiphuth, IC., Utz, KS., Nobel, AJ., Kohrmann, M. and Schenk, T. (2014). Increase prevalence of posttraumatic stress disorder in patients after transient ischemic attack. *Stroke, 45*, 3360-3366.

Kirk, H., Kersten, P., Crawford, P., Keens, A., Ashburn, A and Conway, J. (2014). The cardiac mode; of rehabilitation for reducing cardiovascular risk factors post transient ischaemic attack and stroke: a randomized controlled trial. *Clinical Rehabilitation, 28*(4), 339-349.

Kirkpatrick, S., Locock, L., Giles, MF. and Lasserson, DS. (2013). Non-focal neurological symptoms associated with classical presentations of transient ischaemic attack: qualitative analysis of interviews with patients. *PLoS One 8*(6), e66351.

Kleindorfer, DO., Lindsell, CJ., Broderick, JP., Flaherty, ML., Woo, D., Ewing, I., Schmit, P., Moomaw, C., Alwell, K., Pancioli, A., Jauch, E., Khoury, J., Miller, R., Schneider, A. and Kissela, BM. (2006). Community socioeconomic status and prehospital times in acute stroke and transient ischemic attack: do poorer patients have longer delays from 911 call to the emergency department? *Stroke 37*(6), 1508-1513.

Koudstaal, PJ., Van Gijn, J., Staal, A., Duivenvoorden, H., Gerritsma, J. and Kraaijeveld, C. (1986). Diagnosis of transient ischemic attacks: improvement of interobserver agreement by a check-list in ordinary language. *Stroke 17*, 723-728.

Koudstaal, PJ., Gerritsma, J. and Van Gijn, J. (1989). Clinical disagreement on the diagnosis of transient ischemic attack: is the patient or the doctor to blame? *Stroke 20*, 300-301.

Kraaijeveld, C., Van Gijn, J., Schouten, H. and Staal, A. (1984). Interobserver agreement for the diagnosis of transient ischemic attacks. *Stroke 15*, 723-725.

Krishnamurthi, RV., Feigin, VL., Forouzanfar, MH., Mensah, GA., Connor, M., Bennett, DA., Moran, AE., Sacco, RL., Aderson, LM., Truelsen, T., O'Donnell, M., Venketasubramanian, N., Barker-Collo, S., Lawes, CMM., Wang, W., Shinohara, Y., Witt, E., Ezzati, M., Naghavi, M. and Murray, C. (2013). Global and regional burden of first-ever ischaemic and haemorrhagic stroke during 1990-2010. *Lancet Glob Health, 1,* http://dx.doi.org/10.1016/S2214-109X(13)70089-5.

Kronish, IM., Edmondson, D., Goldfinger, JZ., Fei, K. and Horowitz, CR. (2012). Posttraumatic stress disorder and adherence to medications in survivors of stroke and transient ischemic attacks. *Stroke, 43*, 2192-2197.

Kronish, IM., Goldfinger, JZ., Negron, R., Fei, K., Tuhrim, S., Arniella, G. and Horowitz, CR. (2014). Effect of peer education on stroke prevention: The prevent recurrence of all inner-city strokes through education randomized controlled trial. *Stroke, 45*, 3330-3336.

Kruger, RA. and Casey, MA. (2009). *Focus Groups: A Practical Guide for Applied Research* (4th ed.). Thousand Oaks CA: Sage Publications Inc.

Kuhn, TSW. (1996) *The structure of scientific revolutions*. New ed. Of Revised Ed. Chicago, ILL: University of Chicago Press.

Lambert, SD. and Loiselle, CG. (2008). Combining individual interviews and focus groups to enhance data richness*. Journal of Advanced Nursing. 62*(2), 228-237.

Lang, F., Floyd, MR. and Beine, KL. (2000). Clues to patients' explanations and concerns about their illnesses; a call for active listening. *Arch Fam Med, 9,* 222-227.

Lasserson, DS., Chandrathva, A., Giles, MF., Mant, D. and Rothwell PM. (2008). Influence of general practice opening hours on delay in seeking medical attention after transiwent ischaemic attack (TIA) and minor stroke: prospective population based study. *BMJ, 337*, doi: 10.1136/bmj.a1569.

Lavallee, PC., Cabrejo, L., Lebreuche, J., Mazighi, M., Meseguer, E., Guidoux, C., Abboud, H., Lapergue, B., Klein, IF., Olivot, J-M., Sirimarco, G., Gonzales-Valcarcel, J., Touboul, P-J. and Amerenco, P. (2013). Spectrum of transient visual symptoms in a transient ischemic attack cohort. *Stroke, 44*, 3312-3317.

Leathley, MJ., Fitzgerald, J., Fletcher, M., Golton, I., Jenkinson, D., Price, C., Quinn, T., Roffe, C., Williams, J. and Watkins, CL. (2012). Developing an educational framework for stroke. *Nursing Times, 108*(47), 20-21.

Lee, Y-F., Altschuld, JW. and White, JL. (2007a). Problems in needs assessment data: Discrepancy analysis. *Eval Program Planning, 30*, 258-266.

Lee, Y-F., Altschuld, JW. and White, JL. (2007b). Effects of multiple stakeholders in identifying and interpreting perceived needs. *Eval Program Planning, 30*, 1-9.

Leistner, S., Benik, S., Laumeier, I., Ziegler, A., Nieweler, G., Nolte, CH., Heuschmann, PU. and Audebert, HJ. (2012). Secondary prevention after minor stroke and TIA – usual care and development of a support program. *PLoS One 7*(12), DOI: 10.1371/journal.pone.0049985.

Lennon, O., Carey, A., Gaffney, N., Stephenson, J. and Blake, C. (2008). A pilot randomized controlled trial to evaluate the benefit of the cardiac rehabilitation paradigm for the non-acute ischaemic stroke population. *Clin Rehabil, 22*, 125-133.

Lennon, O. and Blake, C. (2009). Cardiac rehabilitation adapted to transient ischaemic attack and stroke (CRAFTS): a randomised controlled trial. *BMC Neurology 9*(9), DOI:10.1186/1471-2377-9-9.

Lovett, JK., Dennis, MS., Sandercock, PA., Bamford, J., Warlow, CP. and Rothwell, PM. (2003). Very early risk of stroke after a first transient ischemic attack. *Stroke 34*(8), e138-140.

Low, TJ., Kersten, P., Ashburn, A., George, SL. and McLellan, DL. (2003). A study to evaluate the met and unmet needs of members belonging to young stroke groups affiliated with the Stroke Association. *Disabil Rehabil, 25*(18), 1052-1056.

Luijendijk, HJ., Stricker, BH., Wieberdink, RG., Koudstaal, PJ., Hofman, A., Breteler, MM. and Tiemeier, H. (2011). Transient ischemic attack and incident depression. *Stroke 42*(7), 1857-1861.

MacKenzie, G., Gould, L., Ireland, S., LeBlanc, K. and Sahlas, DJ. (2011). Detecting cognitive impairment in clients with mild stroke or transient ischemic attack attending a stroke prevention clinic. *Canadian Journal of Neuroscience Nursing 33*(1), 47-50.

Magin, P., Dunbabin, J., Goode, S., Valderas, JM., Levi, C., D'Souza, M., Marshall, M., Barker, D. and Lasserson, D. (2015). Patients' responses to transient ischaemic attack symptoms: a cross-sectional questionnaire strudy in Australia general practices. *Br J Gen Pract,* doi: 10.3399/bjgp15X683125.

Mandelzweig, L., Goldbourt, U., Boyko, V. and Tanne, D. (2006). Perceptual, Social, and Behavioral Factors Associated With Delays in Seeking Medical Care in Patients With Symptoms of Acute Stroke. *Stroke, 37,* 1248-1253.

Manfreda, KL., Bosnjak, M., Berzelak, J., Haas, I. and Vehovar, V. (2008). Web surveys versus other survey modes: a meta-analysis comparing response rates. *Int J Mark Res, 50*(1), 79-104.

Mant, J., Wade, DT. and Winner, S. (2004). Health care needs assessment: stroke. In *Health Care Needs Assessment: The Epidemiologically Based Needs Assessment Review, First Series (2nd ed.).* Stevens, A., Raftery, J., Mant, J. and Simpson, S. editors. Oxford, UK: Radcliffe Medical Press. pp. 141–244.

Marinker, M. and Shaw, J. (2003). Not to be taken as directed: Putting concordance for taking medicines in practice. *BMJ, 326*, 348-349.

Markland, D., Ryan, RM., Tobin, VJ. and Rollnick, S. (2005). Motivational interviewing and self-determination theory. *J Soc Clin Psyc, 24*(6), 811-831.

Martin, P., Young, G., Enevoldson, T. and Humphrey, P. (1997). Overdiagnosis of TIA and minor stroke: experience at a regional neurovascular clinic. *QJ Med 90*, 759-763.

Marzolini, S., Tang, A., McIlroy, W., Oh, PI. and Brooks, D. (2014). Outcomes in people after stroke attending an adapted cardiac rehabilitation exercise program: Does time from stroke make a difference? *J Stroke Cerebrovasc Dis, 23*(6), 1648-1656.

McCarron, MO., Loftus, AM. and McCarron, P. (2008). Driving after transient ischaemic attack or minor stroke. *Emerg Med J*, 25, 358-359.

McEwan, J., Russell, EM. and Stewart, S. (1995). Needs assessment in Scotland: Collaboration in public health. *Public Health, 109*, 179-185.

McKevitt, C., Fudge, N., Redfern, J., Sheldenkar, A., Crichton, S. and Wolfe, C. D. (2010). *UK Stroke Survivor Needs Survey.* London, UK: The Stroke Association.

McSharry, J., Baxter, A., Wallace, LM., Kenton, A., Turner, A. and French, D.P. (2014). Delay in seeking medical help following transient ischemic attack (TIA) or "Mini-Stroke": A qualitative study. *PLoS One 9*(8), e104434.

Mehra, B. (2002). Bias in Qualitative Research: Voices from an Online Classroom. The Qualitative Report, 7(1), 1-19. Retrieved from http://nsuworks.nova.edu/tqr/vol7/iss1/2.

Milazzo, V., Di Stefano, C., Servo, S., Crudo, V., Fulcheri, C., Maule, S. and Veglio, F. (2012). Drugs and orthostatic hypotension: Evidence from the literature. *J Hypertens 1*(2), http://dx.doi.org/10.4172/2167-1095.1000104.

Moloczij, N., McPherson, KM., Smith, JF. and Kayes, NM. (2008). Help-seeking at the time of stroke: stroke survivors' perspectives on their decisions. *Health and Social Care in the Community, 16*(5), 501-510.

Moran, G., Fletcher, B., Calvert, M., Feltham, MG., Sackley, C. and Marshall, T. (2013). A systematic review investigating fatigue, psychological and cognitive impairment following TIA and minor stroke: protocol paper. *Systematic Reviews 2*, 72-78.

Moran, GM., Fletcher, B., Feltham, MG., Calvert, M., Sackley, C. and Marshall, T. (2014). Fatigue, psychological and cognitive impairment following transient ischaemic attack and minor stroke: a systematic review. *Eur J Neurol 21*(10), 1258-1267.

Moreau, F., Jeerakathil, T. and Coutts, S. (2012). Patients referred for TIA may still have persisting neurological deficits. *Can J Neurol Sci 39*, 170-173.

Moser, CA. and Kalton, G. (1971*). Survey Methods in Social Investigation*. Aldershott, UK: Dartmouth Publishing Company Limited.

Mosley, I., Nicol, M., Donnan, G., Patrick, I. and Dewey, H. (2007a). Stroke symptoms and the decision to call for an ambulance. *Stroke 38*(2), 361-366.

Mosley, I., M Nicol, M., Donnan, G., Patrick, I., Kerr, F. and Dewey, H. (2007b). The impact of ambulance practice on acute stroke care. *Stroke 38*(10), 2765-2770.

Muller-Nordhorn, J., Wegscheider, K., Nolte, C., Jungehulsing, GJ., Rossnagel, K., Reich, A., Roll, S., Villringer, A. and Willich, SN. (2009). Population-based intervention to reduce prehospital delays in patients with cerebrovascular events. *Arch Intern Med. 169*(16), 1484-1490.

Murphy, CA. (1993). Increasing the response rates of reluctant professionals to mail surveys. *Appl Nurs Res, 6*(3), 137-141.

Murray, SA. and Graham, LJ. (1995). Practice based health needs assessment: Use of four methods in a small neighbourhood. *BMJ, 310*, 1443-1448.

Murray, S., Bashir, K., Lees, K., Muir, K., MacAlpine, C., Roberts, M. and Langhorne, P. (2007). Epidemiological aspects of referral to TIA clinics in Glasgow. *Scottish Medical Journal 52*(1), 4-8.

Nadarajan, V., Perry, RJ., Johnson, J. and Werring, DJ. (2014). Transient ischaemic attacks: mimics and chameleons. *Pract Neurol 14*(1), 23-31.

National Audit Office [NAO]. (2005). *Reducing Brain Damage: Faster Access to Better Stroke Care.* London, UK: Department of Health.

National Institute for Health and Clinical Excellence [NICE]. (2008). *Diagnosis and Initial Management of Acute Stroke and Transient Ischaemic Attack (TIA): NICE Clinical Guideline 68.* Manchester, UK: Department of Health.

Newton. JN., Briggs, AD., Murray, CJ., Dicker, D., Foreman, KJ., Wang, H., Naghavi, M., Forouzanfar, MH., Ohno, SL., Barber, RM., Vos, T., Stanaway, JD., Schmit, JC., Hughes, AJ., Fay, DFJ., Ecob, R., Gresser, C., McKee, M., Rutter, H., Abubakar, I., Ali, R., Anderson, HR., Banerjee, A., Bennett, DA., Bernabe, E., Bhui, KS., Biryukov, SM., Bourne, RR., Brayne, CEG., Bruce, NG., Brugha, TS., Burch, M., Capewell, S., Casey, D., Chowdhury, Rajiv., Coates, MM., Cooper, C., Critchley, JA., Dargan, PI., Dherani, MK., Elliott, P., Ezzati, M., Fenton, KA., Fraser, MS., Furst, T., Greaves, F., Green, MA., Gunnell, DJ., Hannigan, BM., Hay, RJ., Hay, SI., Hemingway, H., Larson, HJ., Looker, KJ., Lunevicius, R., Lyons, RA., Marcenes, W., Mason-Jones, AJ., Matthews, FE., Moller, H., Muroch, ME., Newton, CR., Pearce, N., Piel, FB., Pope, D., Rahimi, K., Rodriguez, A., Scarborough, P., Schumacher, AE., Shiue, I., Smeeth, L., Tedstone, A., Valabhji, J., Williams, HC., Wolfe, CDA., Woolf, AD., and Davis, ACJ. (2015). Changes in health in England, with analysis by English regions and areas of deprivation, 1990-2013: a systematic analysis for the Global Burden of Disease Study 2013. *Lancet,* 386**,** 2257-74.

Nguyen-Huynh, M., Fayad, P., Gorelick, PB. and Johnston, SC. (2003). Knowledge and management of transient ischemic attacks among US primary care physicians. *Neurology 61*, 1455-1456.

NHS England (2008). *2009/2010 National Tariff Payment System*. London, UK: Monitor.

NHS England (2011). *2012/2013 National Tariff Payment System*. London, UK: Monitor.

NHS England (2012). '*Vital signs' Integrated Performance Measures Return (IPMR) – Commissioner Based*. London, UK: Department of health https://www.england.nhs.uk/?s=ipmr.

NHS England (2013). *2014/2015 National Tariff Payment System*. London, UK: Monitor.

Nulty, DD. (2008). The adequacy of response rates to online and paper surveys: what can be done? *Ass & Eval Higher Ed, 33*(3), 301-314.

Olatunji, BO., Deacon, BJ. and Abramowitz, JS. (2009). Ishypochondriasis an anxiety disorder? *British Journal of Psychiatry, 194,* 481-482.

O'Mahony, PG., Thomson, RG., Dobson, R., Rodgers, H. and James, OFW. (1999). The prevalence of stroke and associated disability. *J Public Health Med, 21*, 166-171.

Ovaisi, S., Oakeshott, P., Kerry, S., Crabtree, AE., Kyei, G. and Kerry, SM. (2013). Home blood pressure monitoring in hypertensive stroke patients: Aprospective cohort study following a randomized controlled trial. *Fam Pract, 30*, 398-403.

Oxford English Dictionary. (2012). Paperback Oxford English dictionary, Ed. Maurice Waite. Seventh Ed. Oxford, UK: Oxford University Press.

Pancioli, AM., Broderick, J., Kothari, R., Brott, T., Tuchfarber, A., Miller, R., Khoury, J. and Jauch, E. (1998). Public pertception of stroke warning signs and knowledge of potential risk factors. *JAMA, 279*(16), 1288-1292.

Parahoo, K., Thompson, K., Cooper, M., Stringer, M., Ennis, E. and McCollam, P. (2003). Stroke: Awareness of the signs, symptoms and risk factors – A population-based survey. *Cerebrovasc Dis, 16*, 134-140.

Pendlebury, ST., Wadling, S., Silver, LE., Mehta, Z. and Rothwell, P. (2011). Transient cognitive impairment in TIA and minor stroke. *Stroke*, *42*, 3116-3121.

Prabhakaran, S., Silver, AJ., Warrior, L., McClenathan, B. and Lee, VH. (2008). Misdiagnosis of transient ischemic attacks in the emergency room. *Cerebrovasc Dis 26*(6), 630-635.

Prior, PL., Hachinski, V., Unsworth, K., Chan, R., Mytka, S., O'Callaghan, C. and Suskin, N. (2011). Comprehensive cardiac rehabilitation for secondary prevention after transient ischemic attack or mild stroke I: Feasibility and risk factors. *Stroke, 42*, 3207-3213.

Prochaska, JO. and Velicer, WF. (1997). The transtheoretical model of behaviour change. *Am J Health Promot, 12*(1), 38-48.

Rao, R., Jackson, S. and Howard, R. (2001). Depression in older people with mild stroke, carotid stenosis and peripheral vascular disease: a comparison with healthy controls. *International Journal of Geriatric Psychiatry 16*, 175-183.

Reeves, MJ., Hogan, J. and Rafferty, AP. (2002). Knowledge of stroke risk factors and warning signs among Michigan adults. *Neurology 59*, 1547-1552.

Reynolds, T. (2011). Clinical trials: can technology solve the problem of low recruitment? *BMJ 342*, d3662.

Roberts, P. (1997). Planning and running a focus group. *Nurse Researcher*, *4*(4), 78-82.

Robinson, J. and Elkan, R. (1996). *Health needs assessment: Theory and practice*. London, UK: Churchill Livingstone.

Rochette, A., Racine, E., Lefe+bvre, H., Bastien, J. and Tellier, M. (2013). Actual and ideal services in acute care and rehabilitation for relatives post-stroke from three perspectives: relatives, stroke clients and health professionals. *J Rehabil Med 45*, Doi: 10.2340/16501977-1228.

Rodgers, H., Dennis, M., Cohen, D. and Rudd, A. (2003). British Association of Stroke Physicians: Benchmarking survey of stroke services. *Age and Ageing, 32*(2), 211-217.

Ross, M. and Nahab, F. (2009). Management of transient ischemia attacks in the twenty-first century. *Emerg Med Clin N Am 27*, 51-69.

Rothwell, PM., Coull, AJ., Giles, MF., Howard, S., Silver, L., Bull, L., Gutnikov, S., Edwards, PJ., Mant, D., Sackley, C., Farmer, A., Sandercock, PA., Dennis, M., Warlow, CP., Bamford, J. and Anslow, P. (2004). Change in stroke incidence, mortality, case-fatality, severity, and risk factors in Oxfordshire, UK from 1981 to 2004 (Oxford Vascular Study). *Lancet 363*, 1925-1935.

Rothwell, PM., Buchan, AM. and Johnston, SC. (2006). Recent advances in management of transient ischaemic attacks and minor ischaemic strokes*. Lancet Neurology 5*, 323-331.

Rothwell, PM., Giles, MF., Chandratheva, A., Marquardt, L., Geraghty, O., Redgrave, JNE., Lovelock, CE., Binney, LE., Bull, LM., Cuthbertson, FC., Welch, SJV., Bosch, S., Carasco-Alexander, F., Silver, LE., Gutnikov, SA. and Mehta, Z. (2007). Effect of urgent treatment of transient ischaemic attack and minor stroke on early recurrent stroke (EXPRESS study): a prospective population-based sequential comparison. *Lancet, 370*, 1432-1442.

Rowe, A., Frankei, M. and Sanders, K. (2001). Stroke awareness among Georgia adults: epidemiology and considerations regarding measurement. *Southern Medical Journal*, *94*(6), 613-618.

Rubin, H. and Rubin, I. (2012). *Qualitative Interviewing: The Art of Hearing Data* (3rd Ed.). Thousand Oaks CA: Sage Publications Inc.

Sadler, GR., Lee, H-C., Lim, RS-H. and Fullerton, J. (2010). Recruiting hard-to-reach United States population sub-groups via adaptations of snowball sampling strategy. *Nurs Health Sci, 12*(3), 369-374.

Sahlqvist, S., Song, Y., Bull, F., Adams, E., Preston, J. and Ogilvie, D. (2011). Effect of questionnaire length, personalisation and reminder type on response rate to a complex postal survey: randomised controlled trial. *BMC Med Res Methodol 11*, 62. Doi: 10.1186/1471-2288-11-62 .

Saldana, J. (2009). *The Coding Manual for Qualitative Researchers*. London, UK: Sage Publication Ltd.

Sandercock, PA. (2003). Should I start all my ischaemic stroke and TIA patients on a statin, an ACE inhibitor, a diuretic, and aspirin today? *Journal of Neurology, Neurosurgery & Psychiatry 74*, 1461-1464.

Sathyapalan, T., Aye, MM. and Atkin, SL. (2011). Postural hypotension. *BMJ* 342, doi: 10.1136/bmj.d3128.

Schmid, AA., Damush, TU., Plue, L., Subramanian, U., Bakas, T. and Williams, LS. (2009). Current blood pressure self-management: A qualitative study. *Rehab Nurs, 34*(6), 223-229.

Schrock, JW., Glasenapp, M., Victor, A., Losey, T. and Cydulka, RK. (2012). Variables associated with discordance between emergency physician and neurologist diagnoses of transient ischemic attacks in the emergency department. *An Emerg Med, 59*(1), 19-26.

Scott, A., Jeon, S-H., Joyce, CM., Humphreys, JS., Kalb, G., Witt, J. and Leahy, A. (2011). A randomised trial and economic evaluation of the effect of response mode on response rate, response bias, and item non-response in a survey of doctors. *BMC Medical Research Methodology, 11*(126), http://wwwbiomedcentral.com/1471-2288/11/126 Accessed 21/01/2014.

Shenton, AK. (2004). Strategies for ensuring trustworthiness in qualitative research projects. *Education for Information 22*, 63-75.

Sides, EG., Zimmer, LO., Wilson, L., Pan, W., Olson, DM., Peterson, ED. and Bushnell, C. (2012). Medication coaching program for patients with minor stroke or TIA: A pilot study. *BMC Public Health, 12*, http://www.biomedcentral.com/1471-2458/12/549.

Silver, B. (2003). Editorial comment--neuroimaging after TIA: a crystal ball? *Stroke 34*(12), 2898-2899.

Sim, J. (1998). Collecting and analysing qualitative data: issues raised by the focus group. *J Adv Nurs*, *28*(2), 345-352.

Simmons, BB., Cirignano, B. and Gadegbeku, AB. (2012). Transient ischemic attack: Part I. Diagnosis and evaluation. *Am Fam Physician, 86*(6), 521-526.

Sivakumar, L., Kate, M., Jeerakathil, T., Camicioli, R., Buck, B. and Butcher, K. (2014a). Serial Montreal Cognitive assessments demonstrate reversible cognitive impairment in patients with acute ischemic attack and minor stroke. *Stroke, 45*, 1709-1715.

Sivakumar, L., Camicioli, R. and Butcher, K. (2014b). Factors Associated with Cognitive Decline in Transient Ischemic Attack Patients. *Can J Neurol Sci 41*, 303-313.

Smith, JK. and Heshusius, L. (1986). Closing down the conversation: The end of the quantitative-qualitative debate among educational researchers. *Educational Researcher. 15*(1), 4-12.

Solenski, N. (2004a). Transient ischemic attacks: Part 1. Diagnosis and evaluation. *Am Fam Phys*, *69*(7), 1665-1674.

Solenski, N. (2004b). Transient ischemic attacks: Part 2. Treatment. *Am Fam Phys*, 69(7), 1681-1688.

Solomon, P. (2004). Peer support / peer provided services underlying processes, benefits and critical ingredients. *Psyc Rehab J, 27*(4), 392-401.

Sonni, S. and Thaler, DE. (2013). Transient ischemic attack: omen and opportunity. *Cleve Clin J Med 80*(9), 566-576.

Sprigg, N., Machili, C., Otter, E., Wilson, A. and Robinson, TG. (2009). A systematic review of delays in seeking medical attention after transient ischaemic attack. *J Neurol Neurosurg Psychiatry, 80*, 871-875.

Spurgeon, L., Humphreys, G., James, G. and Sackley, C. (2012). A Q-Methodology Study of Patients' Subjective Experiences of TIA. *Stroke Res Treat 2012*, 486261.

Spurgeon, L., James, G. and Sackley, C. (2013). Subjective experiences of transient ischaemic attack: a repertory grid approach. *Disabil Rehabil 35*(26), 2205-2212.

Stroke Association [SA]. (2014). *Not Just a Funny Turn, the Real Impact of TIA. Campaign Briefing Spring / Summer 2014.* London, UK: The Stroke Association.

Stroke Association [SA]. (2015). *State of the Nation Stroke Statistics – January 2016.* The Stroke Association. https://www.stroke.org.uk/sites/default/files/state_of_the_nation_2016_110116_0.pdf. Accessed June 2016.

Talbot, LR., Viscogliosi, C., Desrosiers, J., Vincent, C., Rousseau, J. and Robichaud, L. (2004). Identification of rehabilitation needs after a stroke: an exploratory study. *Health and Quality of Life Outcomes, 2*(53), doi: 10.1186/1477-7525-2-53.

Taylor, S. (2004). Understanding and treating health anxiety: A cognitive-behavioral approach. *Cognitive and Behavioral Practice, 11,* 112-123.

Tomasik, T., Windak, A., Margas, G., de Melker, RA. and Jacobs, HM. (2003). Transient ischaemic attacks: desires diagnosis and management by Polish primary care physicians. *Family Practice, 20*(4), 464-468.

Townsend, N., Wickramasinghe, K., Bhatnagar, P., Smolina, K., Nichols, M., Leal, J., Luengo-Fernandez, R. and Rayner, M. (2012). *Coronary Heart Disease Statistics 2012 Edition*. British Heart Foundation: London.

Tyrrell, P., Swain, S. and Rudd, A. (2010). Diagnosis and initial management of transient ischaemic attack. *Clinical Medicine 10*(2), 164-167.

Uehara, T., Kimura, K., Okada, Y., Hasegawa, Y., Tanahashi, N., Suzuki, A., Takagi, S., Nakagawara, J., Arii, K., Nagahiro, S., Ogasawara, K., Nagao, T., Uchiyama, S., Matsumoto, M., Lihara, K. and Minematsu, K. (2014). Factors associated with onset-to-door time in patients with transient ischemic attack admitted to stroke centres. *Stroke 45*(2), 611-613.

Van Geest, J. and Johnson, TP. (2011). Surveying Nurses: Identifying Strategies to Improve Participation. *Evaluation & the Health Professions 34*(4), 487-511.

van Rooij, FG., Schaapsmeerders, P., Maaijwee, NA., van Duijnhoven, DA., de Leeuw, FE., Kessels, RP. and van Dijk, EJ. (2014). Persistent cognitive impairment after transient ischemic attack. *Stroke 45*(8), 2270-2274.

Verbraak, M. E., Hoeksma, A.F., Lindeboom, R. and Kwa, V.I. (2012). Subtle problems in activities of daily living after a transient ischemic attack or an apparently fully recovered non-disabling stroke. *J Stroke Cerebrovasc Dis 21*(2), 124-130.

Vickery, BG. and Williams, LS. (2014). Posttraumatic stress disorder after cerebrovascular events: Broadening the landscape of psychological assessment in stroke and transient ischemic attack. *Stroke, 45*, 3182-3183.

Walsh, D and Baker, L. (2004). *Demystifying Qualitative Research in Pregnancy and Childbirth*. Chapter 5, (Eds.). Dykes F. in Lavender T., Edwards G., Alfirevic Z London, UK: Quay Books.

Walsh, D. and Downe, S. (2006). Appraising the quality of qualitative research. *Midwifery, 22*, 108-119.

Wang, Y., Rudd, AG. and Wolfe, CDA. (2013). Age and ethnic disparities in incidence of stroke over time*. Stroke, 44*, 3298-3304.

Wasserman, J., Perry, J., Dowlatshahi, D., Stotts, G., Stiell, I., Sutherland, J., Symington, C. and Sharma, M. (2010). Stratified, urgent care for transient ischemic attack results in low stroke rates. *Stroke, 41*, 2601-2605.

Watkins, C., Barron, T., Davis, D., Hatton, S., Jenkinson, D., Jones, S., Price, C., South, A., Quinn, T. and Leathley, M. (2011). The UK forum for stroke training and the stroke-specific education framework. *Journal Paramed Pract, 3*(9), 481-482.

Watkins, CL., Leathley, MJ., Chalmers, C., Curley, K., Fitzgerald, JE., Reid, L. and Williams, J. (2012). Promoting stroke-specific education. *Nurs Stand, 26*(39), 35-40.

Weibe, ER., Kaczorowski, J. and MacKay, J. (2012). Why are response rates in clinician surveys declining? *Can Fam Physician, 58*, e225-e228.

Wester, P., Radberg, J., Lundgren, B. and Peltonen, M. (1999). Factors associated with delayed admission to hospital and in-hospital delays in acute stroke and TIA: A prospective, multicentre study. *Stroke, 30*, 40-48.

White, JL. and Altschuld, JW. (2012). Understanding the “what should be condition” in needs assessment data. *Eval Program planning, 35*, 124-132.

Williams, L., Bruno, A., Rouch, D. and Marriott, DJ. (1997). Stroke Patients' Knowledge of Stroke. Influence on Time to Presentation. *Stroke, 28*, 912-915.

Williams, SE., Bond, CM., and Menzies, C. (2000). A pharmaceutical needs assessment in a primary care setting. *British Journal of General Practice, February*, 95-99.

Williams, H., Harris, R., and Turner-Stokes, L. (2007). Northwick Park care needs assessment: adaptation for inpatient neurological rehabilitation settings. *Journal of Advanced Nursing, 59*(6), 612-622.

Williamson, GR. (2005). Illustrating triangulation in mixed-methods nursing research. *Nurse Researcher, 12*(4), 7-18.

Wilson, AD., Coleby, D., Taub, NA., Weston, C. and Robinson, TG. (2014). Delay between symptom onset and clinic attendance following TIA and minor stroke: the BEATS study. *Age and Ageing, 43*, 253-256.

Winward, C., Sackley, C., Metha, Z. and Rothwell, PM. (2009). A population-based study of the prevalence of fatigue after transient ischemic attack and minor stroke. *Stroke***,** *40*(3), 757-761.

Witkin, BR. and Altschuld, JW. (1995). *Planning and Conducting Needs Assessments: A Practical Guide*. Thousand Oaks, CA: Sage Publications.

World Health Organisation [WHO]. (1975). *A classification and outline of cerebrovascular diseases, II*. *Stroke, 6*,564–616.

World Health Organisation [WHO]. (1989). Report of the WHO Task Force on Stroke and other cerebrovascular disorders stroke – 1989. Recommendations on stroke prevention, diagnosis, and therapy. *Stroke, 20*, 1407-1431.

Yoon, SS., Heller, RF., Levi, C., Wiggers, J. and Fitzgerald, PE. (2001). Knowledge of stroke risk factors, warning symptoms, and treatment among an Australian urban population*. Stroke, 32*, 1926-1930.

Zang, G. (2013). Antihypertensive drugs and the risk of fall injuries: A systematic review and meta-analysis. *J Int Med Res, 41*(5), 1408-1417.

DEVELOPING A MODEL OF PEOPLE'S NEEDS AFTER TRANSIENT ISCHAEMIC ATTACK

Appendices

Contents

Appendix A **3**

A1 Search strategy for literature review 3

Appendix B **7**

B1 Service Provision Survey – final version 7

B2 Cover letter and Information sheet to accompany the survey 14

B3 Full list of free text responses Initial contact 17

B4 Full list of free text from Follow-up 17

B5 Full list of free text re. staffing 18

B6 Full list of free text activities initial 19

B7 Full list of free text activities at follow-up 20

Appendix C **21**

C1 Final version of the nurses' survey and supporting documents for survey 21

C2 Patient interview guides (and patient information) 34

C3 Focus group template (and patient information) 41

C4 Carers Final Questionnaire 49

C5 Interview template for Professional interviews 61

C6 Table showing all free text comments clustered by main theme 62

C7 Screening Flowcharts Northwest and Southwest 64

C8 Patient interview participant thumbnail pen sketches 66

C9 Patient focus group participant thumbnail pen sketches 71

C10 Table Showing the TIA only concepts and supporting quotes. 74

C11 Table showing free text responses to the supporters' survey questions 75

C12 Professional participant thumbnail pen sketches 77

C13 High priority needs identified during professional interviews.....79

Appendix D **80**

D2 Facilitators briefing papers 80

D2 Full set of study documents 84

D3 Expert panel participant thumbnail sketches.....1122

Appendix A

A1 Search strategy for literature review

Database(s): **Ovid MEDLINE(R) Epub Ahead of Print, In-Process & Other Non-Indexed Citations, Ovid MEDLINE(R) Daily and Ovid MEDLINE(R)** 1946 to Present
Search Strategy:

#	Searches	Results
1	Ischemic Attack, Transient/	19696
2	ischemic attack, transient.mp.	19736
3	transient ischemic attack.mp.	7100
4	exp Ischemic Attack, Transient/	19696
5	ischaemic attack, transient.mp.	1
6	TIA.mp.	7266
7	"mini-stroke".mp.	23
8	1 or 2 or 3 or 4 or 5 or 6 or 7	27156
9	Personal Narratives/	3037
10	consequences.mp.	227112
11	problems.mp.	511688
12	impairment.mp.	251549
13	Experiences.mp.	163352
14	dysfunction.mp.	379644
15	9 or 10 or 11 or 12 or 13 or 14	1438839
16	8 and 15	1894
17	limit 16 to (english language and humans)	1063

Database(s): **Embase** 1974 to 2017 August 10

Search Strategy:

#	Searches	Results
1	Ischemic Attack, Transient/	7498
2	ischemic attack, transient.mp.	216
3	transient ischemic attack.mp.	34297
4	exp Ischemic Attack, Transient/	32486
5	ischaemic attack, transient.mp.	1
6	TIA.mp.	14797
7	"mini-stroke".mp.	36
8	1 or 2 or 3 or 4 or 5 or 6 or 7	41369
9	Personal Narratives/	36069
10	consequences.mp.	277252
11	problems.mp.	614705
12	impairment.mp.	445858
13	Experiences.mp.	186426
14	dysfunction.mp.	623191
15	9 or 10 or 11 or 12 or 13 or 14	2021377
16	8 and 15	4337
17	limit 16 to (english language and humans)	3501
18	qualitative.mp.	240627
19	17 and 18	24

Interface - EBSCOhost Research Databases
Search Screen - Advanced Search
Database - **CINAHL Complete**

#	Query	Results
S15	S7 AND S14	447
S14	S8 OR S9 OR S10 OR S11 OR S12 OR S13	539,791
S13	dysfunction	61,390
S12	experiences	233,282
S11	impairment	61,062
S10	problems	188,031
S9	consequences	51,449
S8	personal narrative	1,791
S7	(S1 OR S2 OR S3 OR S4 OR S5 OR S6)	4,057
S6	TIA	1,829
S5	transient ischemic attack (tia)	1,041
S4	transient ischaemic attack	3,365
S3	transient ischemic attack	3,365
S2	ischaemic attack, transient	3,365
S1	ischemic attack, transient	3,365

Interface - EBSCOhost Research Databases
Search Screen - Advanced Search Database - **PsycINFO**

S15	S7 AND S14	85
S14	S8 OR S9 OR S10 OR S11 OR S12 OR S13	1,170,017
S13	dysfunction	63,659
S12	experiences	497,961
S11	impairment	131,815
S10	problems	504,305
S9	consequences	127,853
S8	personal narrative	3,145
S7	(S1 OR S2 OR S3 OR S4 OR S5 OR S6)	2,247
S6	TIA	1,159
S5	transient ischemic attack (tia)	445
S4	transient ischaemic attack	1,686
S3	transient ischemic attack	1,686
S2	ischaemic attack, transient	1,687
S1	ischemic attack, transient	1,687

Appendix B

B1 Service Provision Survey – final version

1. TIA First contact

* **1. Which Hospital do you work for?**
(Name of Hospital and Stroke Network)
e.g. Lancashire Teaching Hospitals NHS Foundation Trust, Lancashire and Cumbria Network

* **2. Which days of the week are new TIA patients seen? (please tick all that apply)**

- ☐ Monday
- ☐ Tuesday
- ☐ Wednesday
- ☐ Thursday
- ☐ Friday
- ☐ Saturday
- ☐ Sunday

Other service provision (please specify)

3. How long are your new patient slots in TIA clinic? (or TIA new patient contacts if not in clinic setting)

- ◯ 5 Minutes
- ◯ 10 Minutes
- ◯ 15 Minutes
- ◯ 20 Minutes
- ◯ 30 Minutes
- ◯ 45 Minutes
- ◯ 60 Minutes
- ◯ Other

If other, please specify

*** 4. Which professionals see TIA patients at first attendance? (please tick all that apply)**

- [ ] Care of the Elderly Consultant
- [ ] Neurology Consultant
- [ ] Consultant General Physician
- [ ] Vascular Surgeon
- [ ] Junior Doctor (Specialist Trainee)
- [ ] Junior Doctor (Foundation Trainee)
- [ ] Stroke Specialist Nurse
- [ ] Clinic Nurse
- [ ] Other

If other, please specify

5. Who has overall responsibility for the clinic?

- ◯ Care of the Elderly Consultant
- ◯ Consultant General Physician
- ◯ Neurology Consultant
- ◯ Vascular Surgeon
- ◯ Junior Doctor (Specialist Trainee)
- ◯ Stroke Nurse Specialist
- ◯ Other

If other, please specify

*** 6. What activities occur at first clinic attendance? (please tick all that apply)**

	Performed prior to clinic	Performed in clinc	Results available during 1st clinic attendance?	Performed within 1 week following clinic
History taking	☐	☐	☐	☐
Physical examination	☐	☐	☐	☐
Brain imaging	☐	☐	☐	☐
Carotid imaging	☐	☐	☐	☐
Blood tests	☐	☐	☐	☐
BP measurement	☐	☐	☐	☐
12-lead ECG	☐	☐	☐	☐
Echocardiogram	☐	☐	☐	☐
Transcranial Doppler	☐	☐	☐	☐
24-hour ECG	☐	☐	☐	☐
Diagnosis given	☐	☐	☐	☐
Prognosis discussed	☐	☐	☐	☐
Lifestyle advice given and discussed	☐	☐	☐	☐
Antiplatelets started	☐	☐	☐	☐
Referral to vascular surgeon	☐	☐	☐	☐
Consultation with vascular surgeon	☐	☐	☐	☐

Other activities that occur at first visit (please specify)

2. TIA Follow-up

*** 1. Do TIA patients have routine follow-up after their initial contact?**

- ◯ Yes, all
- ◯ Some
- ◯ None

At what point after TIA first contact are patients followed up?

2. What duration are your planned TIA follow-ups?

- ◯ 5 Minutes
- ◯ 10 Minutes
- ◯ 15 Minutes
- ◯ 20 Minutes
- ◯ 30 Minutes
- ◯ 45 Minutes
- ◯ 60 Minutes
- ◯ Other
- ◯ No TIA follow-up

If other, please specify

*** 3. Who sees TIA patients at follow-up? (Please tick all that apply)**

- [ ] Care of the Elderly Consultant
- [ ] Neurology Consultant
- [ ] Consultant General Physician
- [ ] Vascular Surgeon
- [ ] Junior Doctor (Specialist Trainee)
- [ ] Junior Doctor (Foundation Trainee)
- [ ] Stroke Specialist Nurse
- [ ] Clinic Nurse
- [ ] GP
- [ ] Practice Nurse
- [ ] Community Stroke Nurse
- [ ] Community Matron
- [ ] No TIA follow-up available
- [ ] Other

If other, please specify

4. Who takes clinical responsibility for the follow-up episode?

- [ ] Care of the Elderly Consultant
- [ ] Neurology Consultant
- [ ] Consultant General Physician
- [ ] Vascular Surgeon
- [ ] Junior Doctor (Specialist Trainee)
- [ ] Junior Doctor (Foundation Trainee)
- [ ] Stroke Specialist Nurse
- [ ] Clinic Nurse
- [ ] GP
- [ ] Practice Nurse
- [ ] Community Stroke Nurse
- [ ] Community Matron
- [ ] No TIA follow-up
- [ ] Other

If other, please specify

*** 5. What activities occur at TIA follow-up? (Please tick all that apply)**

- [ ] Give test results
- [ ] Confirm diagnosis
- [ ] Discuss prognosis
- [ ] Modify medication
- [ ] Information giving
- [ ] Lifestyle counselling
- [ ] Answering questions
- [ ] No TIA follow-up
- [ ] Other

If other, please specify

*** 6. Where does follow-up activity occur? (Please tick all that apply)**

- ☐ Hospital Clinic (Out Patient Department)
- ☐ Stroke Ward
- ☐ GP Surgery
- ☐ Community Centre
- ☐ Patient's Own Home
- ☐ No TIA follow-up
- ☐ Other

If other, please specify

7. Are you willing to be contacted for further discussions around the responses you have made? If you are, please supply your contact details (Name, phone number or e-mail address)

Name

Phone number

email address

B2 Cover letter and Information sheet to accompany the survey

Cover letter for questionnaire

Dear Colleague,

I am writing to request your help with a research project. Your help will involve completing an on-line questionnaire. If you are willing to help, please follow the link, which will take you directly to the questionnaire. The research project is looking at what models of TIA care are currently available in England, Scotland and Wales.

This is the first phase of a programme of post graduate research. Attached is an information sheet, which explains more about the questionnaire. The on-line questionnaire should not take more than 6-7 minutes to complete.

Please click on link http://www.surveymonkey.com/s/FX88RDG and complete ASAP, but within 3 weeks of receipt.

Thank you for your help and co-operation.

Laura Gleave
Research Student
University of Central Lancashire
01202 263039 / 07970794788
LGleave1@uclan.ac.uk

Laura Gleave
Stroke Nurse Practitioner
Poole Hospital NHS Trust
Longfleet Road
Poole
Dorset
BH15 2JB

Supervisors:

Dr Jo Gibson

Senior Lecturer
Clinical Practice Research Unit Care
People's School of Health
University of Central Lancashire
PR1 2HE
01772 895144
PR1 2HE

Prof Caroline Watkins

Caroline Watkins
Professor of Stroke & Older
Brook 419
School of Health Preston
University of Central Lancashire
Preston
01772 893646/5542

Dr Michael Leathley
Clinical Practice Research Unit,
School of Health
University of Central Lancashire,
Preston, PR1 2HE.
01772 89 3647

What are patient needs after Transient Ischaemic Attack?

Chief Investigator: Laura Gleave

Supervisor: Dr Jo Gibson

What is the purpose of the questionnaire?

This questionnaire is the first phase of a research project that aims to answer the research question "What are patient needs after Transient Ischaemic Attack?" In the first instance the goal is to identify a range of TIA service delivery models, across England, Scotland & Wales.

Why have I been invited?

All members of BASP have been asked to contribute to this survey.

Do I have to take part?

As with any research, participation is voluntary.

What will I have to do?

Please follow the supplied link and complete the questionnaire. There are 13 questions, it should take no more than 6-7 minutes.

Will my taking part in the study be kept confidential?

The aim of this phase of the project is to identify different types of TIA service models. Once your service has been classified, the data will be stored on the mainframe computer at the University of Central Lancashire. Your data will not be directly identified and due care will be taken to maintain anonymity of responses.

Informed Consent?

Formal consent is not required for a survey of this nature. It is considered implicit consent if you complete the questionnaire.

What if there is a problem?

Complaints -If you have a concern about any aspect of this study, you should ask to speak to the researcher who will do her best to answer your questions (07970794788). If you remain unhappy and wish to complain formally, you can do this through the School Health, University of Central Lancashire, to the Head of School, Bernard Gibbon. bgibbon@uclan.ac.uk

What will happen to the results of the research study?
Service configurations will be clustered to form distinct service models. The results of the questionnaire will remain identifiable until the service has been classified. Data from the online survey will be downloaded and stored on the University secure server.

Who is organising and funding the research?
This research is funded by the University of Central Lancashire, Preston. The team working on the project are based in the School of Health. There is no payment to the team for including individuals in the study.

Who has reviewed the study?
This study has been internally reviewed by the research team of the School of Health, the Faculty of Health Ethics Committee, at University of Central Lancashire, and NHS R&D at Poole Hospital NHS Trust, to ensure that the highest standards of planning and conduct are applied to this project.

B3 Full list of free text responses Initial contact

Free text comments
plus results given at the end of clinic
Unspecified
Initial 30 minute slots; pts return as and when tests available
as required - can be 1-2hrs
20 mins initial assessment then 10 review post imaging (same day)
Including Ultrasound time in clinic
30 mins for consultant, 40 mins for Special Registrar
30-40mins with ANP then 30 mins with consultant
See 2 per day except for clinic

B4 Full list of free text from Follow-up

Free text comments
20 mins for Spr, 15 mins for consultant
Variable
may occur in separate general medical clinic depending on clinician

B5 Full list of free text re. staffing

Free text comments
Stroke Physician, TIA co-ordinator
Associate Specialist Care of the Elderly
vascular ultrasonographer
Associate Specialist
Vascular Ultrasound
specialist registrar (neurology)
HCA - trained in TIA service
First contact could be an A&E, Medical on-call junior doctor or a GP
Stroke Physician
Speciality doctor in stroke medicine - staff grade registrar level
TIA specialist nurse
Speciality doctors in stroke care
Vascular Lab Technician, ECG Technician
Clinical Pharmacologist with Specialist training in Stroke
i dont understand this question
Stroke Consultant-seems to be missing above!
Consultant Stroke Physician
Clinical Pharmacologists x2
Consultant or registrar in stroke medicine or vascular medicine

B6 Full list of free text activities initial

Free text comments
Other activities that occur at first visit (please specify)
consideration of randomisation into a clinical trial
Statin started if needed, CXR done, 24 hour BP if needed
MRI usually after 1 week
Discharged in most cases
This is a badly constructed question. Many of the answers depend on circumstances
transthoracic echo not routinely done. Where needed a bubble echo will be done within 1-2 weeks
24 hr ECG and ECHO only in selected cases
Business case for same day MRI-DWI in progress
chest x – ray
ECHO & 24 hr tape sometimes depending on service pressures. Vasc referral or consultation will depend on patient
consultation with vascular surgeon - surgeons not in clinic but on call vascular surgeon would then usually see on same day
CT is done urgently same day if necessary; but typically within 1-2 weeks. Echo and 24 tape not routinely done on everybody
Patient given leaflets and written instructions; stroke mimics appropriately managed
ABCD2 telephonic triage before clinic attendance by TIA specialist nurse
If high risk 2 slots are available for first clinic attendance day for carotid Doppler and referral is done appropriately
Not to drive for 1 month; To come to A&E if symptoms recur and last ~30 mins (for thrombolysis)
Driving advice given in clinic if appropriate. Echo usually carried out more than 1 week after clinic.
if investigation ie CT scan deemed necessary
Statins also commenced and anti-hypertensives in selected patients
Delays with some investigations
We consult immediately with the Vascular Surgeon (Consultant on-call), and those eligible for surgery get admitted immediately to the Surgical Assessment Unit.
Referral to vascular surgeon or radiologist in context of MDT

B7 Full list of free text activities at follow-up

Free text comments
Order any tests that haven't been done
Refer to post stroke group, arrange bubble echo, do further blood tests, re image, assess for depression etc. as needed.
Referral for further specialist treatment e.g. PFO Closure
Review of diagnosis if initially uncertain
Control risk factors
Referral on to other teams if appropriate eg to neurology, or haematology for thrombophilia screening
We often discuss MRs which we don't get same day

Appendix C

C1 Final version of the nurses' survey and supporting documents for survey

Introduction

This survey is to try and establish which issues nurses feel are relevant to patients following TIA.

A list of needs identified in patients following stroke has been compiled based on literature review and discussion. It is thought that some of these needs might be relevant to people following TIA.

The aim of this survey is to identify which of these identified needs are thought to be important to patients following TIA. Please consider the TIA in isolation, although we appreciate many patients with TIA will have other co-morbidities.

Your views are valuable and your help would be appreciated. The computer-based questionnaire will identify a range of issues relevant to stroke survivors, you are asked to rank these items as important, might be important and not important to patients following TIA.

The survey should not take long to complete and your participation will be considered as consent. No identifying data will be collected, but you will be asked about your job role.

All data will be stored at UCLAN in a secure manner, and no individuals will be identifiable.

Thank you for taking part.

Laura Gleave
Research Student UCLAN

1. Do you have contact with patients with TIA?

- ◯ Yes, regularly (most weeks)
- ◯ Yes, occasionally (most months)
- ◯ No

2. Which category most closely represents your professional role?

- ◯ Specialist nurse
- ◯ Stroke Unit nurse
- ◯ General ward nurse with interest
- ◯ Other

Other (please specify)

3. Which of the following physical health needs, would in your opinion be relevant / important to patients following TIA?

	Yes	Maybe	No
Health status	◯	◯	◯
Health behaviour	◯	◯	◯
Secondary prevention	◯	◯	◯
Altered sensation	◯	◯	◯
Pain	◯	◯	◯
Epilepsy	◯	◯	◯
Fracture, bone loss	◯	◯	◯
Falls / accidents	◯	◯	◯
Dental / oral health	◯	◯	◯
Fatigue	◯	◯	◯
Spasticity	◯	◯	◯
Spasms	◯	◯	◯
Swallowing	◯	◯	◯
Sleep / sleep apnoea	◯	◯	◯
vision / hearing	◯	◯	◯
Nausea / vertigo	◯	◯	◯

4. Which of the following Mental / emotional well-being needs would in your opinion be relevant / important to patients following TIA?

	Yes	Maybe	No
Mood disorders e.g.	◯	◯	◯
Anxiety	◯	◯	◯
Depression	◯	◯	◯
Emotional lability	◯	◯	◯
Post traumatic stress disorder	◯	◯	◯
Anger / frustration	◯	◯	◯
Personality / behaviour change	◯	◯	◯
Quality of life	◯	◯	◯
Carer strain / well-being	◯	◯	◯
Coping / adaptation e.g.	◯	◯	◯
Motivation / focus / confidence	◯	◯	◯
Body / self image	◯	◯	◯
Independance	◯	◯	◯
Dealing with others' reactions	◯	◯	◯
Fear	◯	◯	◯

5. Which of the following communication / cognition needs would in your opinion be relevant / important to patients following TIA?

	Yes	Maybe	No
Expressive speech	◯	◯	◯
Understanding	◯	◯	◯
Reading / writing / numeracy	◯	◯	◯
Cognitive impairment	◯	◯	◯
Memory	◯	◯	◯

6. Which of the following everyday living needs would in your opinion be relevant / important to patients following TIA?

	Yes	Maybe	No
Walking	◯	◯	◯
Arm movements	◯	◯	◯
hand / fine control	◯	◯	◯
Balance / standing	◯	◯	◯
Eating	◯	◯	◯
Continence	◯	◯	◯
Washing / dressing / clothes	◯	◯	◯
Cooking	◯	◯	◯
Shopping	◯	◯	◯
Housework	◯	◯	◯
Managing medication	◯	◯	◯
Dietary adaptations	◯	◯	◯

7. Which of the following re-enablement needs would in your opinion be relevant / important to patients following TIA?

	Yes	Maybe	No
Information / advice	◯	◯	◯
Training / support	◯	◯	◯
Self-management	◯	◯	◯
Empowerment / decision making	◯	◯	◯
Access to services	◯	◯	◯
Advocacy	◯	◯	◯
Aids and adaptations	◯	◯	◯
Health and safety	◯	◯	◯
IT / web access	◯	◯	◯

8. Which of the following social needs would in your opinion be relevant / important to patients following TIA?

	Yes	Maybe	No
Work	◯	◯	◯
Driving / transport	◯	◯	◯
Relationships / sexuality	◯	◯	◯
Role change	◯	◯	◯
Social activity / contact with others	◯	◯	◯
Leisure / holidays	◯	◯	◯
Religious observance	◯	◯	◯
Participation / engagement	◯	◯	◯

9. Which of the following financial / legal and care needs would in your opinion be relevant / important to patients following TIA?

	Yes	Maybe	No
Palliative care	◯	◯	◯
Benefits / financial advice / support	◯	◯	◯
Child care	◯	◯	◯
Power of attorney / NOK	◯	◯	◯
Residential / day care	◯	◯	◯
Care support / packages	◯	◯	◯
Respite / emergency care	◯	◯	◯
Pet care	◯	◯	◯

10. Are there any other needs, that have not been covered elsewhere in this survey, that would, in your opinion, be relevant / important to patients following TIA?

Please specify

Survey of nurses' perceptions of patients' needs following TIA

Survey cover sheet

This survey is part of a programme of post graduate research working towards a PhD. The overall aim is to understand 'what are patient needs after Transient Ischaemic Attack?'

Previous research conducted at the University of Central Lancashire (UCLAN) has identified a range of potential needs following stroke. The aim of this survey is to determine which of these identified needs are thought to be important to patients following TIA.

Your views are valuable and your help would be appreciated. The computer-based survey will identify a range of issues relevant to stroke survivors, you are asked to rank these items as 'important', 'might be important' and 'not important' to patients following TIA.

The survey should not take long to complete and your participation will be considered as consent. No identifying data will be collected, but you will be asked about your job role. All data will be stored at UCLAN in accordance with data protection principles and no individuals will be identifiable.

Thank you for taking part.

Laura Gleave
Research Student
University of Central Lancashire
01202 263039 / 07970794788
LGleave1@uclan.ac.uk

Laura Gleave
Stroke Nurse Practitioner
Poole Hospital NHS Trust
Longfleet Road
Poole
Dorset
BH15 2JB

Supervisors:

Dr Jo Gibson

Senior Lecturer
Clinical Practice Research Unit
People's Care
School of Health
University of Central Lancashire
Preston PR1 2HE
01772 895144

Prof Caroline Watkins

Caroline Watkins
Professor of Stroke & Older

Brook 419
School of Health
University of Central Lancashire
Preston
PR1 2HE
01772 893646/5542

Dr Michael Leathley

Clinical Practice Research Unit,

School of Health
University of Central Lancashire,

Preston, PR1 2HE.
01772 89 3647

What are patient needs after Transient Ischaemic Attack?

Chief Investigator: Laura Gleave

Supervisor: Dr Jo Gibson

What is the purpose of the survey?

To identify which needs identified following stroke are also thought to be important to patients following TIA, in the opinion of nurses.

Why have I been invited?

Nurses attending this conference are invited to participate

Do I have to take part?

As with any research, participation is voluntary.

What will I have to do?

Complete the computer based survey, stating which needs you feel are important, might be important or are not important to patients following TIA. This will take 3-4 minutes.

Will my taking part in the study be kept confidential?

You will not need to identify yourself during the survey, but you will be asked whether you are a 'specialist nurse', 'stroke unit nurse' or 'general nurse with an interest'.

Informed Consent?

Formal consent is not required for a survey of this nature. It is considered implicit consent if you complete the questionnaire.

What if there is a problem?

Complaints -If you have a concern about any aspect of this survey, you should ask to speak to the researcher who will do her best to answer your questions (07970794788). If you remain unhappy and wish to complain formally, you can do this

through the School Health, University of Central Lancashire, to the Head of School, Bernard Gibbon. bgibbon@uclan.ac.uk

What will happen to the results of the research study?
The aim is to develop a comprehensive list of potential needs following TIA which will help to inform interview guides for later research in focus groups and semi-structured interviews.

Who is organising and funding the research?
This research is funded by the University of Central Lancashire, Preston. The team working on the project are based in the School of Health. There is no payment to the team for including individuals in the study.

Who has reviewed the study?
This study has been internally reviewed by the research team of the School of Health, the Faculty of Health Ethics Committee, at University of Central Lancashire, to ensure that the highest standards of planning and conduct are applied to this project.

Survey of nurses' perceptions of patients' needs following TIA

Survey invitation

The survey is part of a wider programme of post graduate research. The overall aim is to understand what patient needs are following a Transient Ischaemic Attack.

Previous work conducted at the University of Central Lancashire (UCLAN) has identified a range of potential needs following **stroke**. The aim of this survey is to determine which of these identified needs are thought to be important to patients following **TIA**.

Your views are valuable and your help would be appreciated. The on-line survey will present a range of issues identified as relevant to stroke survivors. You will be asked to rank these items as 'important', 'might be important' and 'not important' to patients following TIA.

The survey should not take long to complete and your participation will be considered as consent. No identifying data will be collected, but you will be asked about your job role. All data will be stored at UCLAN in accordance with data protection principles and no individuals will be identifiable.

Remember, this survey is anonymous and it will not be possible to identify or link any responses to individuals.

Laura Gleave

Research Student

University of Central Lancashire

01202 263039 / 07970794788

LGleave1@uclan.ac.uk

Laura Gleave

Stroke Nurse Practitioner

Poole Hospital NHS Trust

Longfleet Road

Poole

Dorset

BH15 2JB

Supervisors:

Dr Jo Gibson

Senior Lecturer
Clinical Practice Research Unit
People's Care
School of Health
University of Central Lancashire
Preston PR1 2HE
01772 895144

Prof Caroline Watkins

Caroline Watkins
Professor of Stroke & Older

Brook 419
School of Health
University of Central Lancashire
Preston
PR1 2HE
01772 893646/5542

Dr Michael Leathley

Clinical Practice Research Unit,

School of Health
University of Central Lancashire,

Preston, PR1 2HE.
01772 89 3647

Survey of nurses' perceptions of patients' needs following TIA

Dear SSNF Member,

I am a research student at the University of Central Lancashire looking into patient needs following Transient Ischaemic Attack (TIA). The survey is part of a wider programme of post graduate research. The overall aim is to understand what patients' needs are following a TIA.

Previous work conducted at the University of Central Lancashire (UCLAN) has identified a range of potential needs following **stroke**. The aim of *this* survey is to determine which of these identified needs are thought to be important to patients following **TIA**.

I am writing to ask for your help. Your views are valuable and your help would be appreciated. The on-line survey will present a range of issues identified as relevant to stroke survivors. You will be asked to rank these items as 'important', 'might be important' and 'not important' to patients following TIA.

The survey should not take long to complete and your participation will be considered as consent. No identifying data will be collected, but you will be asked about your job role. All data will be stored at UCLAN in accordance with data protection principles and no individuals will be identifiable. Could I ask you to complete the survey by 31st March 2012.

Remember, this survey is anonymous and it will not be possible to identify or link any responses to individuals.

Survey link: https://www.surveymonkey.com/s/TIA_nurses_survey

Thank you very much for your help in this matter,

Laura Gleave

Research Student

Laura Gleave

Research Student

University of Central Lancashire

01202 263039 / 07970794788

LGleave1@uclan.ac.uk

Laura Gleave

Stroke Nurse Practitioner

Poole Hospital NHS Trust

Longfleet Road

Poole

Dorset

BH15 2JB

Supervisors:

Dr Jo Gibson

Senior Lecturer
Clinical Practice Research Unit
People's Care
School of Health
University of Central Lancashire
Preston PR1 2HE
01772 895144

Prof Caroline Watkins

Caroline Watkins
Professor of Stroke & Older

Brook 419
School of Health
University of Central Lancashire
Preston
PR1 2HE
01772 893646/5542

Dr Michael Leathley

Clinical Practice Research Unit,

School of Health
University of Central Lancashire,

Preston, PR1 2HE.
01772 89 3647

C2 Patient interview guides

Initial interview guide

Introduce research

Obtain consent

Explain card sort

Conduct card sort

Discuss needs identified as relevant and possibly relevant

Probe for any TIA only needs

Modified interview guide

Introduce research

Obtain consent

Ask about TIA experience

Ask about needs experienced / identified

Ask about what might have helped

Sort through the SNM needs cards and present those thought to be relevant to patient and discuss.

Give remaining cards to patient to pick out any others thought to be relevant

Discuss any additional cards identified

Probe for any TIA only needs

Summarise discussion to check understanding

What are patient needs after Transient Ischaemic Attack?

An exploratory focus group of people with a recent diagnosis of TIA.

(Interviews)

Please keep for future reference.

Chief Investigator / Researcher: Laura Gleave.

Supervisor: Dr Jo Gibson.

Part 1

We would like to invite you to take part in a research study. Before you decide you need to understand why the research is being done and what it would involve for you. Please take time to read the following information carefully. Talk to others about the study if you wish. (Part 1 tells you the purpose of this study and what will happen to you if you choose to participate. Part 2 gives you more detailed information about the conduct of the study).

Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

What is the purpose of the study?

The purpose of the study is to explore patients' perceived needs after a **mini-stroke** or TIA (Transient Ischaemic Attack). We want to know what you felt your needs

were following your TIA. This study is being undertaken entirely independently from your hospital doctors and GP, as part of a postgraduate research degree based at the University of Central Lancashire.

To date there has been no comprehensive review of patient needs following TIA. This study is part of a programme of work that aims to fully explore TIA patients' needs so that they can be identified and assessed. By fully understanding patients' needs after TIA, it might be possible to propose strategies to meet these identified needs.

Why have I been invited?

You have been given the diagnosis of TIA, within the past 15 months and have been selected at random to be invited to participate in this research.

Do I have to take part?

It is up to you to decide. You will be asked to read this information sheet and decide whether you would like to take part. If you are willing to participate, we will ask you to sign a consent form before you participate, to show you have agreed to take part. You are free to withdraw at any time, without giving a reason. This would not affect the standard of care you receive.

What will happen to me if I take part?

If you did not feel able to participate in focus groups at the University of Central Lancashire in Preston, you might consider an individual interview, which could be held face to face in your home, at the University in Preston, at another venue of your choosing or via the telephone.

You are still encouraged to identify someone, a family member or friend, who helped you following your TIA. The person you identify will have the opportunity to contribute to our research by completing a survey. Please give them the '**Exploratory survey'** information sheet to read and consider (Printed on lilac paper). If they are interested and willing to participate, please ask them to complete the tear off reply slip and include it with yours in the prepaid envelope. It is up to you whether you wish to invite someone or not.

Expenses and payments

You will be offered reimbursement for reasonable travel and parking costs to a maximum of £20.

What will I have to do?

You will be asked about your experiences after being given a TIA diagnosis. You will be given materials that are also being used with the focus groups, and asked your opinion about what is important to you after a diagnosis of TIA.

The interview will be audio recorded. After the interview, a written record of the recording will be made, and the audio recording destroyed as soon as possible. Interviews will not last more than 90 minutes.

What are the possible disadvantages and risks of taking part?

Some people may find talking about their TIA experiences upsetting. It is entirely up to you what needs and concerns you share with the researcher. If you do become upset, the interview will be stopped and there is no obligation for you to continue if you do not want to.

What are the possible benefits of taking part?

We cannot promise the study will help you, but the information we obtain from this study will help improve our understanding of the experiences of people following TIA.

What happens when the research study stops?

We will look very carefully at all that has been discussed, to identify patterns. All data will be held anonymously and stored on the Mainframe computer at the University of Central Lancashire, in a password protected file. Your confidentiality will be maintained by storing identifiable data separate from the written record of the group discussion.

What if there is a problem?

Any complaint about the way you have been dealt with during the study or any possible harm you might suffer will be addressed. The detailed information on this is given in Part 2.

Will my taking part in the study be kept confidential?

Yes. We will follow ethical and legal practice and all information about you will be handled in confidence. The details are included in Part 2.

If the information in Part 1 has interested you and you are considering participating, please read the additional information in Part 2 before making any decision.

Part 2

What will happen if I do not want to carry on with the study?

You can choose to stop participating at any time during the study. It will not affect your medical care.

What if there is a problem?

Complaints - If you have a concern about any aspect of this study, you should ask to speak to the researcher who will do their best to answer your questions (07970794788). If you remain unhappy and wish to complain formally, you can do this through PALS at Royal Preston Hospital (Tel. 01772 522972), details can be obtained from the hospital, or contact Nigel Harrison Acting Dean of the School of Health, at the University of Central Lancashire (Tel. 01772 893701).

Harm, NHS based research - In the event that something does go wrong and you are harmed during the research and this is due to someone's negligence then you may have grounds for a legal action for compensation but you may have to pay your legal costs. The normal National Health Service complaints mechanisms will still be available to you (if appropriate).

Will my taking part in this study be kept confidential?

All information which is collected about you during the course of the research will be kept strictly confidential, and any information about you that is used or published, will have your name and address removed so that you cannot be recognised.

Involvement of the General Practitioner/Family doctor (GP)
It is standard practice to inform a patient's GP of their participation in a research study. However, it is your decision whether you would like your GP informed of your participation in this study. There is no medical intervention, so it would be unlikely for participation to have a direct effect on your health care. Neither your GP, nor any other person involved in your care will be informed of anything discussed in the interview, unless you disclose something that would be harmful to yourself or others.

What will happen to the results of the research study?
All data will be stored with no personal identifiers (just a participant number) in secure electronic storage at the University of Central Lancashire. Any paper based information generated during the interview will be scanned and saved electronically. Electronic data will be password protected and stored on the University's mainframe computer. Access to any data is restricted to the research team only and no information that could identify you will be made public. Any publications or reports arising from this study will include only anonymised information. Audio recordings will be written up and original recordings destroyed. We may use the anonymised data and the report in other related research projects. It will not be possible for any participant to be identified by this anonymised data. Anonymised direct quotes may be used may be used in the write up of the study.

Who is organising and funding the research?
The study is to be undertaken as part of a postgraduate research degree and has no external funding. The University of Central Lancashire is the institution hosting the researcher.

Who has reviewed the study?
This study has been internally reviewed by the research team at the School of Health, and the Faculty of Health Ethics Committee at the University of Central Lancashire, and has also been reviewed by an NHS Ethics Committee to ensure that the very highest standards of planning and conduct are applied to this project. All associated documents such as this information sheet and letter of invitation have also been reviewed.

Why might I not be selected for the research?

Depending on the level of responses, it is possible that we will reach the numbers needed to answer our questions without asking you to participate. If you are not needed, I would like to take the opportunity to thank you for your interest.

If you have any further questions and would like to discuss the research further, please contact Laura Gleave on 07583342448. I will then call you back.

You can also contact me by email at LGleave1@uclan.ac.uk,

or by post at:

Laura Gleave,
C/o. RANVC / Rockley Ward
Poole Hospital,
Longfleet Road
Poole,
Dorset.
BH15 2JB

Thank you for taking the time to read through this information and for considering this request.

If you have decided you would like to participate, please contact the researcher on **07583342448**.

C3 Focus group template

Opening question (to get everyone speaking)	"Please tell us who you are, and how long ago you had your TIA?"	*10 Minutes*
Introductory question (to the subject)	"Please work in pairs with someone you don't already know. Have a brief (5 minute) chat and then tell the group two things you have found out about the person you were talking to, in relation to their TIA experience."	*20 Minutes*
1st Key question (exercise)	"Please sort the following cards into three columns as a group. Those things that are 'definitely relevant' for most people after TIA, those that 'might be relevant' for most people after TIA, and those that are 'not relevant' after a TIA."	*20 Minutes*
2nd Key question (consideration)	"Which needs do you think are essential? Please place them in order."	*20 Minutes*
3rd Key question (summary)	"If you could give doctors, nurses and others in the NHS advice about helping people after a TIA, what would you suggest?"	*20 Minutes*
Ending question	"Is there anything we should have talked about, but didn't in relation to your needs following TIA?"	*15 Minutes*
Summary	"These are the key points we have picked up from today's discussions. Is there anything we have missed, or misunderstood?"	*10 Minutes*

Table of needs provided for Focus Group

Stroke only	TIA and stroke common	TIA and stroke less common	TIA only
Using the toilet Washing/dressing/clothes Cooking Shopping Pain Vision Hearing Fractures / bone loss Epilepsy Spasticity / limb tightness Swallowing problems Understanding others' talking Religious observance Participation / engagement Self management Empowerment / decision making Access to services Advocacy Aids / adaptations Health & Safety Benefits / financial Advice & support Child care Power of attorney Residential / day care Respite / emergency care Pet care End of life issues	General Health maintenance Keeping healthy lifestyle Prevention of stroke risk reduction Managing medication Dietary adaptations Balance Fatigue Quality of life Anxiety Dealing with others' reactions Talking Driving / transport Information / advice Family / supporter strain / well being Depression Fear	Dental / oral health Eating and drinking Independence Housework Altered sensation Nausea Vertigo Walking Falls / accidents Arm movements Hand / finger movements Sleep disturbance Difficulty sleeping Mood swings Anger / frustration Personality / behaviour change Motivation / focus / confidence Body / self image Reading/writing/numbers Muddled thinking Memory Work Relationships / sex Role change Social activity / contact Leisure / holidays Training / support IT / internet Care support at home	Self monitoring / hypervigilance Over-protective Positive attitude Acceptance Validation of experience Encouragement to seek help Denial Avoid delay

What are patient needs after Transient Ischaemic Attack?

Exploration of previously identified needs using focus group techniques.

Please keep for future reference.

Chief Investigator / Researcher: Laura Gleave.

Supervisor: Dr Jo Gibson.

Part 1

We would like to invite you to take part in a research study. Before you decide you need to understand why the research is being done and what it would involve for you. Please take time to read the following information carefully. Talk to others about the study if you wish. (Part 1 tells you the purpose of this study and what will happen to you if you choose to participate. Part 2 gives you more detailed information about the conduct of the study).

Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

What is the purpose of the study?

The purpose of the study is to explore patients' perceived needs after a **mini-stroke** or TIA (Transient Ischaemic Attack). We want to know what you feel your needs are following your TIA. This study is being undertaken entirely independently from your hospital doctors and GP, as part of a postgraduate research degree based at the University of Central Lancashire.

To date there has been no comprehensive review of patient needs following TIA. This study is part of a programme of work that aims to fully explore TIA patients' needs so that they can be identified and assessed. By fully understanding patients' needs after TIA, it might be possible to propose strategies to meet these identified needs.

Why have I been invited?

You have been given the diagnosis of TIA, within the past 15 months and have been selected at random to be invited to participate in this research.

Do I have to take part?

It is up to you to decide. You will be asked to read this information sheet and decide whether you would like to take part. If you are willing to participate, we will ask you to sign a consent form before you participate, to show you have agreed to take part. You are free to withdraw at any time, without giving a reason. This would not affect the standard of care you receive.

What will happen to me if I take part?

If you agree to take part, you may be invited to attend a group meeting to discuss your experiences with others who have also had a TIA. The meeting will last up to three hours.

Light refreshments will be provided.

Expenses and payments

You will be offered reimbursement for reasonable travel and parking costs incurred in relation to the focus group, to a maximum of £20.

What will I have to do?

At the meeting you will meet with others who have also had a TIA. As a group, you will be asked to consider needs identified by people following TIA in relation to your own experience. This will help us to understand what needs are important to people who have had a TIA. You can help by talking and listening to others and sharing your experiences. You do not have to share anything you do not feel comfortable with.

The focus group will be audio recorded. After the group finishes, a written record of the recording will be made, and the audio recording destroyed as soon as possible.

What are the possible disadvantages and risks of taking part?

Some people may find talking about their TIA experiences, or listening to others' experiences upsetting. It is entirely up to you what needs and concerns you share with the group. As part of the 'ground rules' of the focus group, the discussion should remain confidential within the group, and not be discussed with others later, however due to the nature of focus groups complete anonymity cannot be guaranteed.

What are the possible benefits of taking part?

We cannot promise the study will help you, but the information we obtain from this study will help improve our understanding of the experiences of people following TIA.

What happens when the research study stops?

We will look very carefully at all that has been discussed, to identify patterns. All data will be held anonymously and stored on the hospital Mainframe computer and on the Mainframe computer at the University of Central Lancashire, in a password protected file. Your confidentiality will be maintained by storing identifiable data separate from the written record of the group discussion.

What happens if I am treated by the researcher?

Where possible this will not happen. However, if the researcher does participate in your care between you agreeing to participate in a focus group and the group itself, you will be offered to opportunity to withdraw from the group, if you feel participating might be uncomfortable or awkward for you.

What if there is a problem?

Any complaint about the way you have been dealt with during the study or any possible harm you might suffer will be addressed. The detailed information on this is given in

Part 2.

Will my taking part in the study be kept confidential?

We will follow ethical and legal practice and all information gathered will be handled in confidence. The details are included in Part 2.

If the information in Part 1 has interested you and you are considering participating, please read the additional information in Part 2 before making any decision.

Part 2

What will happen if I do not want to carry on with the study?

You can choose to stop participating at any time during the study. It will not affect your medical care.

What if there is a problem?

Complaints - If you have a concern about any aspect of this study, you should ask to speak to the researcher who will do their best to answer your questions (07583342448). If you remain unhappy and wish to complain formally, you can do this through PALS at Poole Hospital NHS Foundation Trust (Tel. 01202 448499), details can be obtained from the hospital, or contact Dr Nigel Harrison Dean of the School of Health, at the University of Central Lancashire (Tel. 01772 893701).

Harm, NHS based research - In the event that something does go wrong and you are harmed during the research and this is due to someone's negligence then you may have grounds for a legal action for compensation but you may have to pay your legal costs. The normal National Health Service complaints mechanisms will still be available to you (if appropriate).

Will my taking part in this study be kept confidential?

As previously stated, it is not possible to guarantee complete confidentiality since there will be other participants in the group, however all participants will be asked to treat the group discussion as confidential to the group members and not talk about the meeting with others after the event.

All information which is collected about you during the course of the research will be kept strictly confidential, and any information about you that is used or published, will have your name and address removed so that you cannot be recognised.

Involvement of the General Practitioner/Family doctor (GP)

It is standard practice to inform a patient's GP of their participation in a research study. However, it is your decision whether you would like your GP informed of your participation in this study. There is no medical intervention, so it would be unlikely for participation to have a direct effect on your health care. Neither your GP, or any other person involved in your care will be informed of anything discussed in the group.

What will happen to the results of the research study?

All data will be stored with no personal identifiers (just a participant number) in secure electronic storage at the University of Central Lancashire and at Poole Hospital NHS Trust. Any paper based information generated during the group will be scanned and saved electronically. Electronic data will be password protected and stored on the University's mainframe computer. Access to any data is restricted to the research team only and no information that could identify you will be made public. Any publications or reports arising from this study will include only anonymised information. Audio recordings will be written up and original recordings destroyed. We may use

the anonymised data and the report in other related research projects. It will not be possible for any participant to be identified by this anonymised data.

Who is organising and funding the research?
The study is to be undertaken as part of a postgraduate research degree and has no external funding. The University of Central Lancashire is the institution hosting the researcher.

Who has reviewed the study?
This study has been internally reviewed by the research team at the School of Health, and the Faculty of Health Ethics Committee at the University of Central Lancashire, and has also been reviewed by South Central - Berkshire NHS Ethics Committee to ensure that the very highest standards of planning and conduct are applied to this project. All associated documents such as this information sheet and letter of invitation have also been reviewed.

If you have any further questions and or would like to discuss the research further, please contact Laura Gleave on 07583342448.

Thank you for taking the time to read through this information and for considering this request.

TIA Supporter Questionnaire

A TIA (transient ischaemic attack) is the medical term for a 'mini-stroke'. You have been invited to participate in this survey because someone who has had a TIA has identified you as a person who offered practical or emotional support to them, when they were having a TIA or afterwards.

Please answer all questions. Remember all responses are anonymous, and nothing that you disclose in this survey will be made public in any way that would allow you to be identified. You do not need to write your name on the questionnaire.

If you would like some help to fill in the survey, or perhaps are unsure about what some of the terms mean, please ask the researcher who will be happy to help.

The first few questions are about **you**, as the person who offered practical or emotional support to someone following their TIA diagnosis.

Q1. Are you male or female?

Male ☐

Female ☐

Q2. In what age range are you?

18 – 30 ☐

31 – 45 ☐

46 – 60 ☐

61 – 75 ☐

76 + ☐

Q3. Would you rate your **OWN** general health as

Very good ☐

Good ☐

Poor ☐

Very poor ☐

Q4. Do you live with the person who has had a TIA?

Yes ☐ No ☐

Q5. What is your relationship to the person who has had a TIA?

Spouse / partner ☐

Friend ☐

Relative ☐ (Please state) ……

The next questions are about needs that have been identified as important to many people who have had a stroke. Needs can be considered as **problems, difficulties or concerns**. The person you accompanied to the meeting today has **not** had a stroke. We are asking your opinion about **which of the following needs you think are, or might be relevant to people who have had a TIA.**

Some of the items that follow may seem odd. That is because we have included all the needs that have been identified as important after

stroke. TIA is a different condition from stroke, but we want to know what the similarities and differences are between people's needs after stroke and TIA. There are no right or wrong answers to the following questions, we are interested in your experiences.

Q6. Which of the following **everyday living needs** do you think are important or relevant following a diagnosis of TIA?

	Yes	Maybe	No
General health (maintenance)	☐	☐	☐
Keeping healthy (lifestyle)	☐	☐	☐
Prevention of stroke (risk reduction)	☐	☐	☐
Dental / oral health	☐	☐	☐
Eating and drinking	☐	☐	☐
Using the toilet	☐	☐	☐
Washing / dressing / clothes	☐	☐	☐
Cooking	☐	☐	☐
Shopping	☐	☐	☐
Housework	☐	☐	☐
Managing medication	☐	☐	☐
Dietary adaptations	☐	☐	☐
Independence	☐	☐	☐

Comments:

Please continue on a separate sheet if necessary. Please state Q6

Q7. Which of the following **physical needs** do you think are important or relevant following a diagnosis of TIA?

	Yes	Maybe	No
Senses			
Altered sensation (e.g. numbness)	☐	☐	☐
Pain	☐	☐	☐
Vision	☐	☐	☐
Hearing	☐	☐	☐
Nausea	☐	☐	☐
Vertigo (dizziness)	☐	☐	☐
Movement			
Walking	☐	☐	☐
Balance / standing	☐	☐	☐
Falls / accidents	☐	☐	☐
Fractures / bone loss	☐	☐	☐
Arm movement	☐	☐	☐
Hand and finger movement	☐	☐	☐
Possible complications			
Epilepsy (fits or seizures)	☐	☐	☐
Spasticity / limb tightness	☐	☐	☐
Swallowing problems	☐	☐	☐
Sleep disturbance	☐	☐	☐
Fatigue (tiredness)	☐	☐	☐

Comments

Please continue on a separate sheet if necessary. Please state Q7

Q8. Which of the following **emotional needs** do you think are important or relevant following a diagnosis of TIA?

	Yes	Maybe	No
Quality of life	☐	☐	☐
Difficulty sleeping	☐	☐	☐
Anxiety	☐	☐	☐
Depression	☐	☐	☐
Mood swings	☐	☐	☐
Anger / frustration	☐	☐	☐
Personality / behaviour change	☐	☐	☐
Motivation / focus / confidence	☐	☐	☐
Body image / self image	☐	☐	☐
Dealing with others' reactions	☐	☐	☐
Fear	☐	☐	☐

Comments

Please continue on a separate sheet if necessary. Please state Q8

Q9. Which of the following **communication / thinking needs** do you think are important or relevant following a diagnosis of TIA?

	Yes	Maybe	No
Talking	☐	☐	☐
Understanding others' talking	☐	☐	☐
Reading/writing/numbers	☐	☐	☐
Muddled thinking	☐	☐	☐
Memory	☐	☐	☐

Comments

Please continue on a separate sheet if necessary. Please state Q9

Q10. Which of the following **social needs** do you think are important or relevant following a diagnosis of TIA?

	Yes	Maybe	No
Work	☐	☐	☐
Driving / transport	☐	☐	☐
Relationships / sex life	☐	☐	☐
Role change	☐	☐	☐
Social activity and contact with others	☐	☐	☐
Leisure / holidays	☐	☐	☐
Religious observance	☐	☐	☐
Participation / engagement	☐	☐	☐

Comments

.

Please continue on a separate sheet if necessary. Please state Q10

Q11. Which of the following **employment needs** do you think are important or relevant following a diagnosis of TIA?

	Yes	Maybe	No
Information / advice	☐	☐	☐
Training / support	☐	☐	☐
Self-management	☐	☐	☐
Empowerment / decision making	☐	☐	☐
Access to services	☐	☐	☐
Advocacy	☐	☐	☐
Aids and adaptations	☐	☐	☐
Health and safety	☐	☐	☐
IT / internet access	☐	☐	☐

Comments

Please continue on a separate sheet if necessary. Please state Q11

Q12. Which of the following **financial / legal and care** needs do you think are important or relevant following a diagnosis of TIA?

	Yes	Maybe	No
Benefits, financial advice and support	☐	☐	☐
Child care	☐	☐	☐
Power of attorney	☐	☐	☐
Residential / day care	☐	☐	☐
Care support at home	☐	☐	☐
Respite / emergency care	☐	☐	☐
Pet care	☐	☐	☐
End of life issues	☐	☐	☐
Family/supporter strain/well-being	☐	☐	☐

Comments

Please continue on a separate sheet if necessary. Please state Q12

The final questions are about **the support your relative/friend and you received from the hospital and primary health care services** after the TIA.

Q13. Is there **anything the hospital could have done differently** that might have made things easier after the TIA diagnosis was made?

Yes ☐ No ☐

If yes, please give details

Please continue on a separate sheet if necessary. Please state Q13

Q 14. Is there **anything that your GP, practice nurse or other primary care staff could have done differently** that might have made things easier after the TIA diagnosis was made?

Yes ☐ No ☐

If yes, please give details

Please continue on a separate sheet if necessary. Please state Q14

Q15. Was there **anyone or anything specifically** that made things easier after the TIA diagnosis was made?

Yes ☐ No ☐

If yes, please give details

Please continue on a separate sheet if necessary. Please state Q15

Q16. Finally, is there **anything not covered elsewhere in this questionnaire that has concerned or worried you** in relation to the person who has had a TIA?

Yes ☐ No ☐

If yes, please give details

Please continue on a separate sheet if necessary. Please state Q16

THANK YOU FOR TAKING THE TIME TO COMPLETE THIS SURVEY

C5 Interview template for Professional interviews

University of Central Lancashire

Poole Hospital NHS
NHS Foundation Trust

Interview schedule

- What professional involvement do you have with people following TIA?
- Please examine this list of needs identified by people following TIA, do you think any of these unexpected? If so which ones and why?
- Are there any needs that you would have expected to see on the list which are missing?
- In your experience, how are patients' needs assessed and identified in practice?
- Which of the listed needs are currently met either by yourself or others?
- How are those needs met?
- Of the unmet needs, can you suggest how they might be met?
- Which three needs do you feel are the priority to address?
- Is there anyone caring for, or offering services to people following TIA, that you feel I should talk to?

C6 Table showing all free text comments clustered by main theme

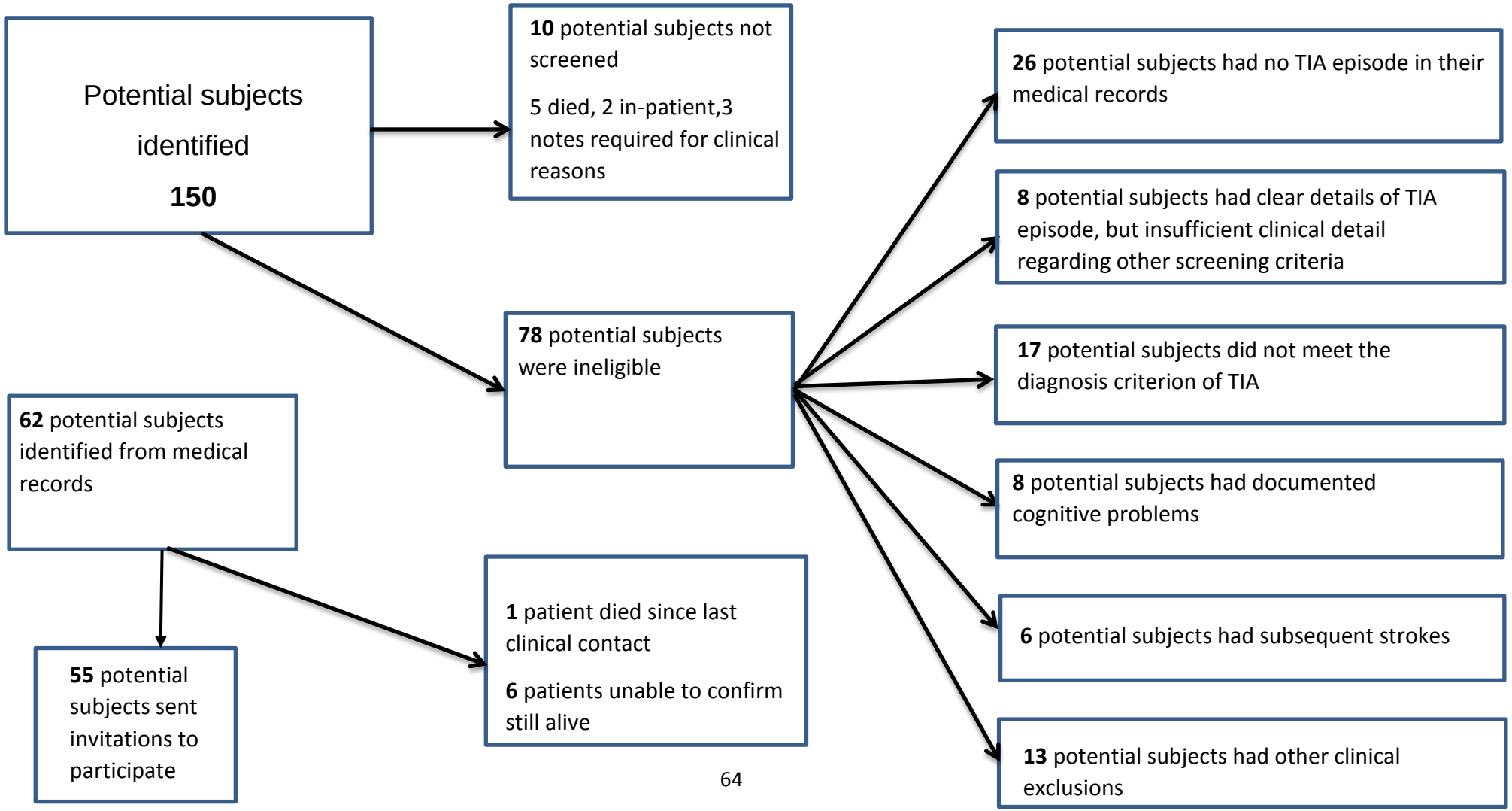
Theme	Are there any other needs that have not been covered elsewhere in this survey that would, in your opinion, be relevant / important to patients following TIA? Please specify
General comments about the survey	Most of the survey seems stroke centred not TIA and may not be as relevant to sufferer of TIA, but still relevant
	I didn't really understand questions???? All are relevant but depends on individual when assessed??
	Difficult to say as you are talking about TIA, which usually do not have too many long term effects. If you were asking about stroke then that would be different!
	I feel anything at all could be relevant following TIA depending on the individual and how the TIA has affected them, their coping strategies, social support networks and general wellbeing.
	I have answered the survey thinking that the patients have already resolved but may still have worries about certain aspects.
Clarifying definition of TIA	Many of these questions appear to relate to stroke rather than TIA which by definition should have resolved.
	Following TIA, all of these symptoms should have resolved in a 24 hr period. If the symptoms have not then all of the above will affect the individual differently depending on what they themselves place most value on
	All questions answered on the assumption that all the TIA symptoms resolved within 24 hrs otherwise they have had a stroke and the answers would be very different
	some of these are hard to answer as for a true TIA they are not relevant (the symptoms have resolved) but actually they may not have the TIA in isolation so some issues may therefore be relevant
	TIA symptoms last for less than 90 minutes on average, with full resolution or they are diagnosed with stroke. Your survey seems to be aimed at stroke patients.
	No. The questions ask for our opinion following TIA so full recovery should happen. If it is minor stroke as well then the answers may be different.
	Many of these questions seem irrelevant if it is a TIA - which means the patient has fully resolved and has no residual deficit. the questions appear more for stroke or minor stroke
	Found survey difficult to complete - TIA shouldn't leave ongoing/lasting physical or cognitive problems (otherwise should be classed as stroke) so unsure how to answer a lot of the questions.
Reiteration of survey items	I hope I have understood the questions in what you are looking for, I answered no in question 6 as a patient with a

	TIA should have no symptoms after 24 hours. Also I would educate patients about the FAST campaign and speak about risk factors and lifestyle changes, self-management is very important in TIA as often it is a warning that they are at increased risk of a stroke.
	A lot of TIA patients fear that they will go on in later life and have a "big" stroke
	Follow up re: B/P, medications any other health related issues
	Lifestyle modification - smoking cessation, exercise
	Lifestyle changes - behaviour change management.
	Education, education, education!!!
	Availability of prompt services for secondary prevention i.e. smoking cessation clinics, vascular access
	Family/carer support
	In my experience after a TIA people need lots of information and help/encouragement to change lifestyle as required.
	Also emotional support - fear and reduced confidence can be big issues after TIA
TIA specific comments	How soon after TIA are we speaking about. The answers depend on how well people cope with a diagnosis even though physically they are fully recovered they may not perceive themselves that way
	Travel Information Sympathetic Travel Insurance Companies
	Stroke nurse follow up
	What follow-up support/appointments to expect from Hospital/GP (e.g. pt's unaware of Stroke Nurse Practitioner & expect to see Dr/Consultant)
	I feel TIA patients need follow up post diagnosis by a person who is knowledgeable regarding TIA and prevention
	Knowing when or if it will happen again
	What are the risks of further TIA and stroke
	Education of family / close others who need to understand what has occurred

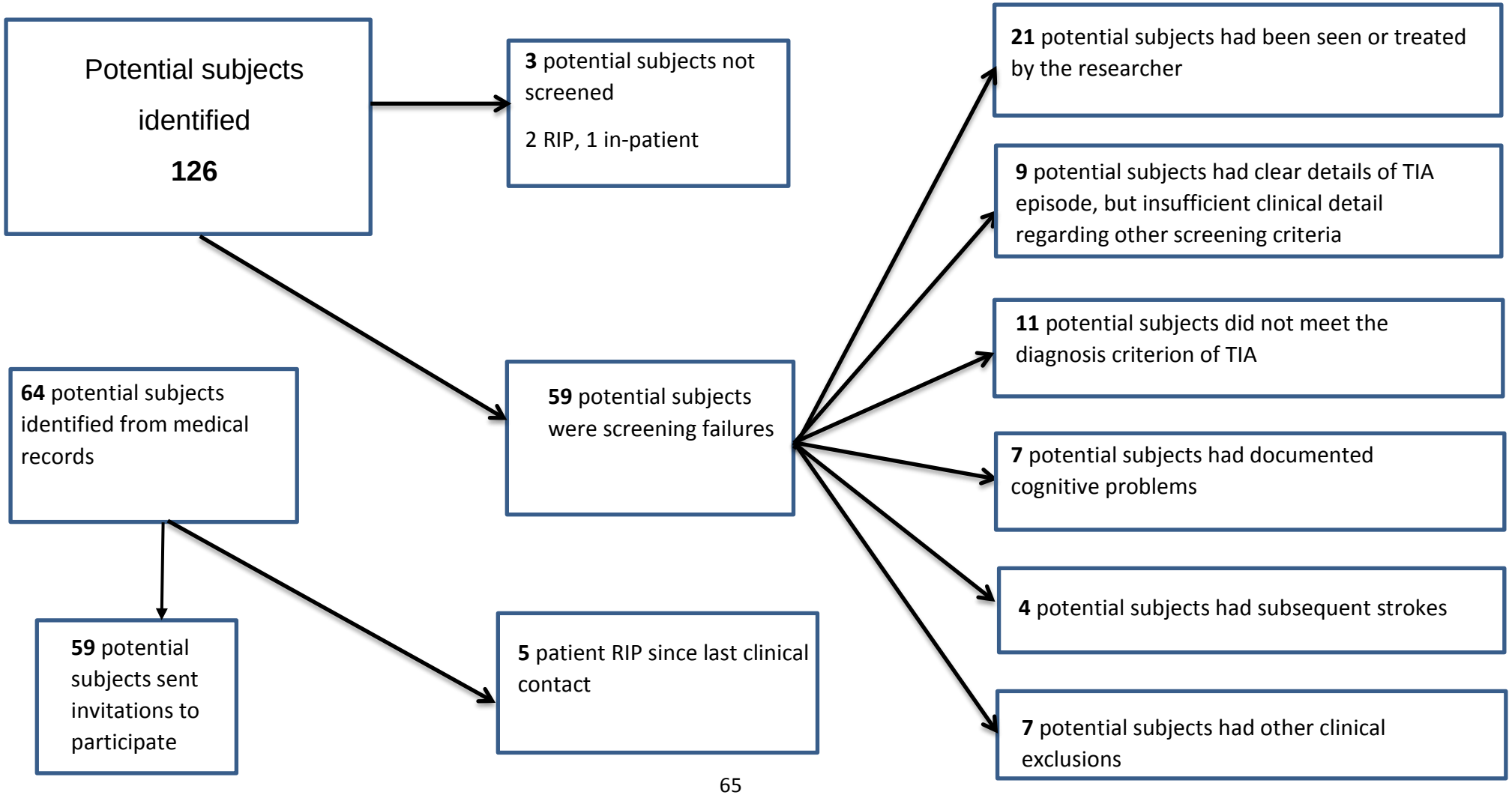
Verbatim report of comments

C7 Screening Flowcharts Northwest and Southwest

Flow Chart Showing Screening Process for Potential Participants for Focus Group



Flow Chart Showing Screening Process for Potential Participants for Semi-structured interviews



C8 Patient interview participant thumbnail pen sketches

1. This interviewee was a retired lady aged 79 years. She experienced her TIA 10 months prior to her interview. She lived with her disabled husband for whom she was the main carer. Other medical conditions included hypertension, diabetes, scoliosis and kyphosis of her spine requiring the use of a walking frame. On the day of her TIA she was sitting in the kitchen reading her newspaper when she realised she 'didn't feel quite right', and discovered she couldn't work out how to use the telephone, when trying to contact her daughter. When she was eventually able to do so, her daughter thought her mother 'didn't sound right' and arranged for a neighbour to go round whilst she and her son travelled to her mother's house. The neighbour completed the FAST test. She was seen by her GP the following day and referred to the TIA clinic at the local hospital the next day where the diagnosis was confirmed.

2. This interviewee was a 36 year old lady who was in full-time employment as a pharmacist in a community hospital. She lived alone. She had previously experienced two TIAs and a completed stroke. She had suffered with depression since her stroke in 2007, but had no other past medical history of note. She was a non-smoker. She was not overweight and enjoyed walking and trekking. This interview was established to explore the experiences of her most recent TIA, which occurred seven months previously when she had a viral infection, which lead to an episode of dizziness, poor co-ordination and word-finding problems that lasted 10-15 minutes. The symptoms came on while she was at work and she was encouraged to see the Out Of Hours doctor based at the community hospital where she worked. He made a diagnosis of TIA and sent her to the main hospital. She was signed off work for one month.

3. The next interviewee was a 72 year old man who lived with his wife in a retirement flat, and was a former engineer. He had his TIA two months prior to his interview. Relevant medical history included a myocardial infarction seven years ago, hypertension and high cholesterol. He had, what he considered, a 'good' diet, and walked and swam regularly following his myocardial infarction.

On the day of his TIA he was in the sitting room during the evening when his wife and son noticed his mouth had drooped and his speech was slurred. His wife called an ambulance, and by the time the paramedics arrived he 'felt a fraud', because his symptoms had disappeared. He was taken to the Emergency Department (ED) that evening where he was told he had probably had a TIA. His wife was also given information in ED. He was transferred to a ward after 02:00 the following morning and later in the morning he felt completely back to normal. He was discharged later that day (Saturday) and was seen in clinic on Monday, when further investigations were performed and a final diagnosis of TIA was made.

4. This interviewee was a 59 year old man who lived with his wife in a house in the South West of England. He was a banker who was going through the process of redundancy at the time of his TIA. It was four months since his symptom onset and three months since he felt he had received a TIA diagnosis. He had previously been a fit and well man, who was quite physically active and cycled to work daily at the time of the event. His TIA symptoms were somewhat atypical in that initially, he noticed cognitive problems, such as difficulty operating equipment or providing well known phone numbers. He described feeling unwell and 'spaced out' at work one morning. His colleagues noticed he was not 'himself' and suggested he went home, which he did. His wife persuaded him to visit his GP. Over the course of the following month he received a range of investigations and eventually was told he had had a TIA.

5. This lady was a 70 year old retired teacher from the South West of England. She had her TIA six weeks prior to her interview. She had a history of paroxysmal atrial fibrillation and had previously been on warfarin, which she reported was stopped by her GP as unnecessary. Recently, she had noticed an increase in palpitations and a new GP had planned to start warfarin at the time she had her TIA. Her husband had a TIA himself four years ago. On the day of her TIA she had been out in the garden hanging out some washing. When she walked back into the kitchen, her husband noticed her face and arm weakness and said 'tell me you are joking', which she did not understand at the time, as she was unaware of any problem. He sat her down and

performed the FAST test and immediately called an ambulance. She was admitted to hospital overnight and when she woke the next morning she felt entirely back to normal. She was told, before discharge that day, that her diagnosis was TIA. She was rather tearful during her interview, but wished to continue.

6. This interviewee was an 88 year old man who had his TIA three months previously. His wife has been in hospital for six weeks at the time of the interview. He was a retired engineer, who was usually fit and active and played bowls 2-3 times each week. He had a serious head injury in his forties and he had a stroke in his seventies, from which he recovered with only minor residual problems of sensory impairment in his left arm and leg. On the day of his TIA he was bowling with a friend, when he noticed his left leg was not working properly. He was still able to walk, so he walked about for a while, hoping to 'walk it off'. After about half an hour he went and had a cup of tea, at which point he felt he had recovered, nevertheless, he mentioned it to his GP the following day and was referred to the TIA clinic, where he received his TIA diagnosis.

7. This lady was an 82 year old widow. She had her most recent TIA six months ago. She has atrial fibrillation and has been treated with ablation and has had a demand pacemaker fitted. She also has a tissue valve replacement to which she attributes the atrial fibrillation. She recounts having had two TIAs, one in the Coronary Care Unit following a cardiac admission and one that prompted her invitation to participate in this research. Her care was split between the local NHS provider and private hospitals. On the day of her TIA she was sitting in her living room alone, when she noticed pins and needles in the right side of her face and her right arm. When she tried to speak to herself, her speech was slurred. The symptoms lasted about 90 minutes, but she went to bed and contacted her GP the following day after discussing the episode with her daughter. Her diagnosis was confirmed in TIA clinic.

8. This interviewee was a 87 year old lady, who was living with her partner. She had her most recent TIA two months ago. She had diabetes and has previously had difficulties controlling her blood glucose levels, but at the time

of the interview her diabetes was under control with an HbA1c of 5.8. She stated she had a number of TIAs, although her descriptions of her symptoms were atypical. On the day of her most recent TIA she was in the car with her daughter. She felt altered sensation in both legs and when her daughter stopped the car she could not stand or speak properly. Her GP referred her to TIA clinic where she was diagnosed as having had a TIA.

9. This interviewee was an 83 year old man who was a retired banker. He had his most recent TIA five months ago. He has had a total of three TIAs, the first approximately 15 years ago. He was diabetic and had some episodes of symptomatic hypoglycaemia in the past. He enjoyed travelling and was very active for his age. On the day of his most recent TIA he was having breakfast when he realised he was unable to speak. He attracted the attention of his partner, who had been present during previous episodes, so realised what was happening and phoned for an ambulance immediately. The aphasia lasted about five minutes. He was taken to hospital where he was seen in the ED, then transferred directly to the TIA clinic, where he was seen quickly. He was seen and investigated with CT and carotid imaging. He was sent to cardiology for an echocardiogram, but during the investigation he developed a second episode of aphasia and was rushed back to ED for consideration of thrombolytic treatment. He recovered again quite quickly and was taken back to TIA clinic.

10. This interviewee was an 86 year old man. He had one, possibly two, TIAs approximately four months ago. He was semi-retired, having built up his own construction company, which had been taken over by his son. However, he still involved himself in some business activity. He was a keen sailor and since his recent TIA and other health issues had not been out on a boat, which he felt was a significant loss to his quality of life. He felt that his problems started when he had an episode of transient global amnesia. He had been fit and well until then. On the day he experienced, what was subsequently thought to be, his first of two TIAs, he was visited by a friend. During the visit he became aware his speech was not making sense, but he was unable to explain this to his friend. He was told at the time it was a TIA. The second episode occurred whilst sitting chatting with his wife. She observed a right facial weakness and

slurred speech. She phoned for an ambulance and her husband was taken to the local hospital. The symptoms were transient and he was seen in TIA clinic the following day, where a TIA diagnosis was given.

11. The final participant was an active 80 year old, who had her TIA approximately four months prior to the interview. She was a retired infant school head teacher. She lived with her husband. She enjoyed gardening and shopping, was active in the University of the Third Age and did various crafts and activities. She had been fit and well since her TIA. On the day of her TIA she woke up as usual about half past seven, but when she attempted to get out of bed, she found her right leg would not move and her right arm was not working quite properly either. Her husband recognised immediately that it looked like a stroke and called an ambulance. By the time she arrived on the stroke ward, use of her leg was returning. She was kept in hospital for two nights because she came in over a weekend and 'they wanted to do more tests'. Her symptoms had completely resolved within 24 hours.

C9 Patient focus group participant thumbnail pen sketches

Participant **A**. A 65 year old retired social worker who lived with her husband. She was hoovering when she developed a sudden onset of right face, arm, and leg weakness. She was also unable to speak. Her husband called an ambulance. Her symptoms started to resolve after a few minutes, but the weakness recurred in hospital. Once the symptoms fully resolved, later the same day, she was sent home.

Participant **B**. A 76 year old semi-retired farmer's wife, who was still involved in the running of the dairy. She had experienced four TIAs over a period of three years. Each event occurred at night when she was asleep. She woke on each occasion to find left facial weakness and altered sensation, which resolved quickly. She reported the hospital could not find any reason for these events.

Participant **C**. A 69 year old lady who experienced 'tunnel vision' to the right and felt unsteady. Symptoms lasted approximately ten minutes and resolved completely, at which point she dismissed the event. The following day she attended her GP surgery for a routine blood test, but did not report the event. Later the same day she returned to the GP surgery for a blood pressure check, which showed her BP to be elevated, at which point she mentioned her visual problems and was referred into TIA clinic. Participant one normally enjoyed good health and lived alone.

Participant **D**. An 83 year old man, who experienced visual loss in one eye on two occasions on a Saturday approximately seven weeks prior to the focus group. He had previously received radiotherapy to that eye following a tumour. He assumed the visual loss was due to the tumour recurring. He attended the GP surgery on Monday and was referred to the Eye Infirmary, where a diagnosis of a TIA was made and he was referred to the TIA clinic. He lived with his wife.

Participant **E**. A 63 year old lady who experienced partial loss of vision in one eye for 10 seconds, about ten weeks prior to the focus group. She phoned her optician the day after her visual loss, and he recommended she speak to her

GP, who immediately referred her to TIA clinic. She was found to have a critical carotid stenosis and received vascular surgery within one week of the initial event. She reports feeling 'a fraud' because her symptoms were so trivial. This lady lived with her husband and they enjoyed an active life.

Participant **F**. A 91 year old lady who had several TIAs over a period of 6 years. Her most recent event was two months ago. Each occurrence involved her speech and right arm. This lady lived next door to her daughter, but was usually independent for personal care, although her daughter cooked and cleaned for her. Her daughter encouraged her to seek medical advice following the event.

Participant **G**. A 72 year old lady who had several hours duration of loss of speech and right arm weakness about five months prior to the focus group. She was known to have atrial fibrillation and was in the process of commencing warfarin when she had her TIA. She lived with her husband, who recognised her symptoms and called for help.

Participant **H**. A 58 year old man who experienced some left arm weakness, slurred speech and unsteadiness that lasted for five to ten minutes. He had dismissed his symptoms when they resolved and so did not seek help for several days until he was advised by a friend to contact his GP. This occurred about four months prior to the focus group. Participant H lived alone.

Participant **I**. An 87 year old lady who woke one morning about nine weeks prior to the focus group and noticed her left arm and leg felt heavy. She tried to get out of bed, fell to the floor, and could not get up. She lived with her husband who had advanced dementia. She called 999 and was taken to hospital. Participant I was already improving as the paramedics arrived. However at the focus group it became apparent that, although she had been told she had a TIA, and that was the diagnosis in her medical records, this lady had residual arm weakness with impaired function.

Participant **J**. A 64 year old retired nurse who had a 15 minute period of dysphasia whilst out with friends. She recognised what was happening, but since it resolved relatively quickly she chose not to seek help until after the weekend. She had extensive comorbidity, renal disease and inclusion body

myositis which limited her mobility. Participant J lived alone and had an active social life.

C10 Table Showing the TIA only concepts and supporting quotes.

Issues	Supporting quotes to illustrate need
Denial	"*Oh yes, coz I didn't want to go the next day. I said 'I'm OK, I don't need to go anywhere'. I thought I was wasting their time, you know…"* ***1*** *"I feel a bit of a fraud really, why have I got you out?"* ***3*** *(to paramedics)* "*there's been no physical evidence that I've had a TIA, which is great, I was thinking, coz you do wonder what the hell is going on, but there's been no physical evidence other than the behaviour on the day…*" **4**.
Avoidance of delay	"*the number one concern really was the passage of time having seen the doctor before being seen at the hospital…I can remember the final diagnosis meeting I had with (names doctor) in the hospital and she said I couldn't drive within a month. I said 'A month is up tomorrow'…"* ***4*** *(negative)* "*fortunately he knows, he's seen it before, and well, he immediately calls an ambulance, and we make our way up to the hospital, which only takes five or ten minutes…"* ***9*** *(positive)*
Encouragement to seek help	"*one of my colleagues, with more common sense than me at the time, said 'I don't think you're right…'* **4** "*Well my daughter, my eldest daughter wanted to take me straight to the hospital and I said no, I don't want to go, so she got on to the doctor, my doctor, and got me an appointment into the clinic…"* ***8***
Validation of the experience	"*they tried to see me move my arms and I seemed to be alright then…I wondered what came over me*…" **1**
Over protective	"*I'm told with no uncertain terms what I can do and don't do by my husband…*" **11** views "*I used to phone or text her and we were texting all the time, coz I was worried about leaving her on her own, because of what happened in the first place...*" Husband of participant **5**
Positive attitude	"*it's important to try to get back to normal as soon as possible, with a view that everything was positive, and I think if you've got positive people around you, that's always helpful…*" **3**
Self monitoring / hypervigilance	"*I sometimes think 'are my arms alright, are my legs alright', so I check them and then I rub my neck and head…"*. **5**
Acceptance	"*It's no good worrying, you've just got to get on with it, you know*…" **11**

C11 Table showing free text responses to the supporters' survey questions

	Free text responses
Is there anything the **hospital** could have done differently that might have made things easier after the TIA diagnosis was made?	• On reflection I feel that if we had presented through A&E the diagnostic process would have been more immediate and therefore more relevant. However once the tests were finally carried out, then the hospital staff was able to supply support. Perhaps the GP referral could have been more speeded up – although minor symptoms were evident following the incident it seemed to me that an immediate follow up would have been more appropriate. • It would have been nice if further contact from other services e.g. stroke association, nurse lead, focus groups or other services had been highlighted. It appears that if you have a TIA you usually recover very quickly (within a few hours) and are then quickly discharged. • More information on how much rest is required following TIA as opposed to encouragement to return to normal activity as much as possible
Is there anything that your **GP, practice nurse or other primary care staff** could have done differently that might have made things easier after the TIA diagnosis was made?	• As already stated the only different action that could be taken in this case was to be referred more speedily • Arranged to see the person who suffered the TIA and explained what may happen or prescriptions that may be taken to prevent further TIAs or even stroke. I also think there is a lot of confusion around a TIA or stroke and even some consultants may confuse patients when talking to their patient after a hospital admission. • The care was exemplary at (names hospital) • It would have been helpful to have been given information about stroke groups in the area
Was there **anyone or anything specifically** that made things easier after the TIA diagnosis was made?	• The hospital procedure turned out to be very reassuring, so there was nothing in particular they could have done to enhance the service. • Family support and encouragement • Discussions with the stroke clinic at (names hospital)
is there anything **not covered elsewhere** in this questionnaire that has concerned or worried you in	• Indeed most concerns & worries are set out in this survey. We have been lucky to get back to almost full recovery. However my major concern is about any side effects that seem to go hand in hand with the prescribed preventative medication, considering that they will be planned as a long

relation to the person who has had a TIA?	term prospect. We have been lucky that it has turned out to be a relatively low attack and whereas we don't want further attacks to be upon us, we also do not want personality change / lack of libido & other minor physical changes – as it seems to me that the whole person can change as a result of the attack itself & or the medication!? • Depending on the hospital a TIA / potential stroke is taken has a substantial impact on the type of treatment you receive of the follow-up you are entitled to. Also this may lead to further TIAs or even a proper stroke. • Has the aneurysm in (names person supported)'s knee had or been a causal effect of the TIA

C12 Professional participant thumbnail pen sketches

Participant (a). Stroke Consultant Physician who sees people with TIA either as new patients in clinic, when a diagnosis is made, on the Acute Stroke Unit or at follow-up clinic.

Participant (b). Community Stroke Co-ordinator. Her main role is to complete the six month reviews following stroke. She has contact with people following TIA when they are referred to her for community support.

Participant (c). GP, who is also the commissioning lead for Stroke Services with a Clinical Care Group based in the South West of England. His responses were based on a mixture of his clinical experience of people following TIA and his views as a commissioner of services.

Participant (d). Stroke Nurse Practitioner who sees patients following TIA as new patients in clinic where a diagnosis is made. She also sees people in follow-up clinics and in the Emergency Department.

Participant (e). TIA Nurse Specialist, whose main role is to see people at follow-up and ensure they understand what has happened, promote lifestyle change, and answer questions.

Participant (f). Trainee Consultant Practitioner, who is a therapist by background. She is currently in an acute placement within a stroke service in the South West of England. Her experience with people following TIA is mainly in observing a wide range of clinicians providing acute and follow-up TIA services.

Participant (g). GP in the South West of England. His role in relation to people with TIA is the initial recognition of symptoms and potential diagnosis, and forward referral for specialist assessment. Most GPs will see 3-4 new TIAs per year, but will have more patients on their books who have previously had a TIA.

Participant (h). Emergency Department Consultant. The majority of people seen with TIA in the ED are initially brought in by ambulance as FAST positive for consideration for thrombolysis. If their symptoms are rapidly resolving, they

are monitored very closely, and if complete resolution occurs, they are usually referred to the TIA clinic for specialist assessment.

Participant (i). Consultant Neurologist, with a special interest in rehabilitation. Participates in delivering acute TIA clinic services. Sees people in clinic and makes a diagnosis. He rarely offers follow-up appointments, leaving provision of these to the nursing team.

Participant (j). Research Physiotherapist. Recently completed some research with people following TIA and gained insight into their experiences as part of the research conducted.

Participant (k). GP Practice Nurse from the Home Counties. She expressed an interest in participating in research previously at a regional conference. She provides clinics for the management of long-term conditions, and within that remit, has stroke / TIA clinics which monitor and support patients and meet Quality Outcome Framework (QOF) requirements for the GP practice.

C13 High priority needs identified during professional interviews.

Participant	Needs
1 – Stroke Consultant	Risk reduction Keeping Healthy Psychological support
2 – Community Stroke Co-ordinator	Reassurance Lifestyle advice Confidence Secondary prevention
3 – Commissioner of Services and GP	Psychological support Lifestyle advice Seeing TIA as part of vascular disease
4 – Stroke Nurse Practitioner	Health promotion (secondary prevention) Psychological support Sustaining change
5 – TIA Nurse Specialist	Risk reduction Validation of the experience Help seeking Advice and support
6 – Trainee Consultant Practitioner	Secondary prevention (lifestyle and medication) Empowerment Psychological support
7 – GP	Information and advice Psychological support Secondary prevention (lifestyle and medication)
8 – Emergency Department Consultant	Secondary prevention Healthy lifestyle Family / supporter strain
9 – Consultant Neurologist with a special interest in Rehabilitation	Restoring physical fitness Self-image Returning to everyday life
10 – Research Physiotherapist	Emotional support Assessing willingness to change Secondary prevention (lifestyle and medication)
11 – GP Practice Nurse	Secondary prevention (lifestyle) Medication Quality of life

Appendix D

D1 Facilitators briefing papers

Group A

Facilitator: C. Dickson

ED consultant

Stroke Nurse Practitioner

Patient

Patient

Group B

Facilitator: B Clark

Stroke Consultant

Research Therapist

Patient

Carer

Group Lead: Laura Gleave

Supervisor: Jo Gibson

Scribe: Debbie Webb

Agenda

13:30	Lunch and signing of consent forms	
14:00	Welcome and introduction	LG
14:20	Group work. Identifying needs	Facilitated CD & BC
15:00	Feedback	CD & BC
15:20	Coffee	
15:30	Presentation of current model of needs	LG
15:45	Group work – combining ideas & agreeing needs	
16:15	Suggestions for how best to meet needs	
16:30	Close	

Facilitators questions

What needs do you think fit into each time slot?

Do some needs span more than one time slot?

What are the issues / problems / difficulties?

How might needs be met?

Who could / should meet the needs?

Onset	Diagnosis	Early (0-28 days)	Later (after 28 days)

D2 Full set of study documents

Invitation in clinic

Letter of invitation

Dear ……..,

You have been given the diagnosis of mini-stroke, or TIA (Transient Ischaemic Attack).

At Poole Hospital we are conducting some research supported by University of Central Lancashire looking at what people feel they need after this diagnosis.

I wonder whether you would be interested in participating in this research? You are offered the opportunity to participate in a meeting and give your views on a model (description) of TIA needs developed based on previous research in this area. We need people to help us refine the model by discussing it at a meeting and sharing their thoughts and views.

If you feel someone helped to support you either practically, emotionally or physically during or after your TIA, we would be interested in having them join you at the group. If you are considering participating, would you please ask them whether they will join you? Please show them this letter and the enclosed information sheet (lilac paper).

If you attend a meeting, there would be others who have also been given the same diagnosis, people who have offered support to those who have had a TIA and professionals who provide support or services to people who have had a TIA. There will be a maximum of ten people at the meeting.

If you think you might be interested, would you please read the enclosed information sheet (yellow paper). Once you have read the information provided, if you have any questions please contact Laura Gleave, the researcher, who

would be happy to answer your questions (07583342448), she will phone you back to avoid you having the cost of the telephone call. Alternatively you can contact her by email or complete the response slip attached to the information sheet and send it back in the pre-paid envelope.

The group will be run in early November 2014, at Poole Hospital.

There is absolutely no obligation to participate, and your future treatment will not be affected in any way if you choose not to participate. The doctor you have seen today is only involved in making contact with you and inviting you to consider participating, they will not be at any of the meetings and will not have access to any of the information gathered.

For practical reasons the researchers cannot include anyone with severe hearing loss, so please be aware of this. If you, or your 'supporter' have any communication problems, please discuss them with the researcher. Every reasonable effort will be made to include you, but a minimum level of communication will be necessary to participate in a group discussion. If you use reading glasses, please remember to take them with you if you participate.

It is also possible that you will not be selected to attend a meeting, even if you have stated your willingness to participate. If this happens, it is because they already have sufficient participants, but we are grateful for your interest.

Thank you for your consideration,

Dr S Ragab

Consultant Stroke Physician

Invitation by post

University of Central Lancashire

Poole Hospital NHS
NHS Foundation Trust

Letter of invitation

Dear ……..,

You have been given the diagnosis of mini-stroke, or TIA (Transient Ischaemic Attack).

At Poole Hospital we are conducting some research supported by University of Central Lancashire looking at what people feel they need after this diagnosis.

I wonder whether you would be interested in participating in this research? You are offered the opportunity to participate in a meeting and give your views on a model (description) of TIA needs developed based on previous research in this area. We need people to help us refine the model by discussing it at a meeting and sharing their thoughts and views.

If you feel someone helped to support you either practically, emotionally or physically during or after your TIA, we would be interested in having them join you at the group. If you are considering participating, would you please ask them whether they will join you? Please show them this letter and the enclosed information sheet (lilac paper).

If you attend a meeting, there will be others who have also been given the same diagnosis, people who have offered support to those who have had a TIA and professionals who provide support or services to people who have had a TIA. There will be a maximum of ten people at the meeting.

If you think you might be interested, would you please read the enclosed information sheet (yellow paper). Once you have read the information provided, if you have any questions please contact Laura Gleave, the researcher, who would be happy to answer your questions (07583342448), she will phone you back to avoid you having the cost of the telephone call. Alternatively, you can

contact her by email or complete the response slip attached to the information sheet, and send it back in the pre-paid envelope.

The group will be run in early November 2014, at Poole Hospital.

There is absolutely no obligation to participate, and your future treatment will not be affected in any way if you choose not to. Your name has been passed to me by the clinician who saw you in clinic, however, they will not be at any of the meetings and will not have access to any of the information gathered.

For practical reasons the researchers cannot include anyone with severe hearing loss, so please be aware of this. If you have any communication problems, please discuss them with the researcher. Every reasonable effort will be made to include you, but a minimum level of communication will be necessary to participate in a group discussion. If you use reading glasses, please remember to take them with you if you participate.

It is also possible that you will not be selected to attend a meeting, even if you have stated your willingness to participate. If this happens, it is because they already have sufficient participants, but we are grateful for your interest.

Thank you for your consideration,

Dr S Ragab

Consultant Stroke Physician

Date

Dear,

I hope you don't mind me contacting you again. My name is Laura Gleave. I am currently undertaking some post graduate research looking at the needs of people following TIA.

By definition a TIA is '*a sudden, focal neurological deficit that lasts for less than 24 hours, is of presumed vascular origin, and which is confined to an area of the brain or eye perfused by a specific artery*.' There must be complete recovery within 24 hours, with no residual deficit (WHO 1989). For this reason TIAs would not be expected to give rise to persistent symptoms, but nonetheless, some people who have experienced a TIA do seem to have difficulties or problems after the event.

There are some studies that have looked at the experiences of patients after stroke. However, there is little research published about the experience of, impact on, and meaning of having a TIA for patients. This gap in knowledge may be addressed by identifying patients' perceived needs following TIA and adding to the evidence base upon which service provision could be built.

You suggested at interview that you might be interested in participating in an expert panel. Can you help me, please?

I am putting together an expert panel comprising patients, supporters and professionals and would value your input. I am planning a focus group using the expert panel to review a previously developed model of TIA needs, with a view to validating and refining the model. Discussion will focus on which needs are associated with TIA, categorisation of needs, and how needs can be identified and met.

The meeting will be held on 7th November 2014, and conducted in the day room on the Stroke Rehab ward at Poole Hospital.

The meeting will last no longer than 3 hours, but is likely to last less than that. It will be audio recorded and subsequently transcribed and anonymised. Quotes may be used for reporting purposes but there would be no way that any quotes

could be traced back to you as an individual. For more detail, please see the attached information sheet.

If you are interested in helping me with my research, please contact me so I can answer any questions you might have. It is possible that you will not be selected to attend a meeting even if you have stated your willingness to participate. If this happens it is because we already have sufficient participants, but I am grateful for your interest.

I can be contacted at work on 01202 263039, out of hours mob. 07583 342448,

email LGleave1@uclan.ac.uk

Thank you for taking the time to read this invitation. I look forward to hearing from you in due course.

Yours sincerely,

Laura Gleave

Stroke Nurse Practitioner, Poole Hospital NHS Foundation Trust
Research Student, University of Central Lancashire

What are patient needs after Transient Ischaemic Attack?

Refinement of a previously developed model of needs following TIA using focus group methods with an expert panel.

Please keep for future reference.

Chief Investigator / Researcher: Laura Gleave.

Supervisor: Dr Jo Gibson.

What is the purpose of the study?

The purpose of the study is to explore patients' perceived needs after a **mini-stroke** or TIA (Transient Ischaemic Attack). This study is being undertaken entirely independently from your hospital doctors and GP, as part of a postgraduate research degree based at Poole Hospital and supported by the University of Central Lancashire.

To date there has been no comprehensive review of patient needs following TIA. This study is part of a programme of work that aims to fully explore TIA patients' needs so that they can be identified and assessed. By fully understanding patients' needs after TIA, it might be possible to propose strategies to meet these identified needs.

In this, the final phase of the research, we will present a model (description) of what TIA needs appear to be and will ask you to consider categorisation of needs and how best to meet those needs.

We are very keen for you to participate in our expert panel, to help us understand TIA from your experience as a patient. As someone who has experienced a TIA, you have

expertise which the professionals and research team lack. We would really appreciate your participation.

If there is someone who you feel offered you particular help and support either during or after your TIA, we would be very keen to hear from them as well (We call these people supporters). There is a separate information sheet for them (lilac paper).

Why have I been invited?

You have been given the diagnosis of TIA, since 1st May 2014 and have been selected to be invited to participate in this research.

What will I have to do?

At the meeting you will meet with others who have also had a TIA or been involved in the care of people following TIA. As a group, you will be asked to consider a model of needs identified by people following TIA. The model has been developed based on information gathered over the course of a number of research projects. You will be asked your views on the model presented. By talking and listening to others and sharing your own experiences, we aim to refine and validate the proposed model of needs following TIA. You will also be asked about the importance of various needs and possible ways in which those needs could be met. You do not have to share anything you do not feel comfortable with.

The expert panel meeting will be audio recorded. After the group finishes, a written record of the recording will be made, and the audio recording destroyed as soon as possible.

Do I have to take part?

It is up to you to decide. You will be asked to read this information sheet and decide whether you would like to take part. If you are willing to participate, we will ask you to sign a consent form before you participate, to show you have agreed to take part. You are free to withdraw at any time, without giving a reason. This would not affect the standard of care you receive. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

What will happen to me if I take part?

If you agree to take part, you may be invited to attend a group meeting to discuss your experiences and views with others who have had a TIA, their supporters or healthcare professionals who care for people following TIA. The meeting will last no more than three hours in total.

Light refreshments will be provided.

Expenses and payments

You will be offered reimbursement for reasonable travel and parking costs incurred in relation to the expert panel meeting, to a maximum of £20.

What are the possible disadvantages and risks of taking part?

Some people may find talking about their TIA experiences, or listening to others' experiences upsetting. It is entirely up to you what experiences you share with the group. As part of the 'ground rules' of the expert panel meeting, the discussion should remain confidential within the group, and not be discussed with others later, however due to the nature of the meeting, complete anonymity cannot be guaranteed.

What are the possible benefits of taking part?

We cannot promise the study will help you, but the information we obtain from this study will help improve our understanding of the experiences of people following TIA.

What happens when the research study stops?

Your involvement ends. There will be no further contact relating to the research. We will look very carefully at all that has been discussed, to identify patterns. All data will be held anonymously and stored on the hospital Mainframe computer and on the Mainframe computer at the University of Central Lancashire, in a password protected file. Your confidentiality will be maintained by storing identifiable data separate from the written record of the group discussion.

What if there is a problem?

Any complaint about the way you have been dealt with during the study or any possible harm you might suffer will be addressed.

What will happen if I do not want to carry on with the study?

You can choose to stop participating at any time during the study. It will not affect your medical care.

What if there is a problem?

Complaints - If you have a concern about any aspect of this study, you should ask to speak to the researcher who will do their best to answer your questions (07583342448). If you remain unhappy and wish to complain formally, you can do this through PALS at Poole Hospital NHS Foundation Trust (Tel. 01202 448499), details can be obtained from the hospital, or contact Dr Nigel Harrison Dean of the School of Health, at the University of Central Lancashire (Tel. 01772 893701).

Harm, NHS based research - In the event that something does go wrong and you are harmed during the research and this is due to someone's negligence then you may have grounds for a legal action for compensation but you may have to pay your legal costs. The normal National Health Service complaints mechanisms will still be available to you (if appropriate).

Will my taking part in this study be kept confidential?

As previously stated, it is not possible to guarantee complete confidentiality since there will be other participants in the group, however all participants will be asked to treat the group discussion as confidential to the group members and not talk about the meeting with others after the event.

All information which is collected about you during the course of the research will be kept strictly confidential. No quotes of other data used or published will be made public in a way that could allow you to be identified.

Involvement of the General Practitioner/Family doctor (GP)

It is standard practice to inform a patient's GP of their participation in a research study. However, it is your decision whether you would like your GP informed of your participation in this study. There is no medical intervention, so it would be unlikely for participation to have a direct effect on your health care. Neither your GP, or any other person involved in your care will be informed of anything discussed in the group.

What will happen to the results of the research study?

All data will be stored with no personal identifiers (just a participant number) in secure electronic storage at the University of Central Lancashire and at Poole Hospital NHS Trust. Any paper based information generated during the group will be scanned and saved electronically. Electronic data will be password protected and stored on the University's mainframe computer. Access to any data is restricted to the research team only and no information that could identify you will be made public. Any publications or reports arising from this study will include only anonymised information. Audio recordings will be written up and original recordings destroyed. We may use the anonymised data and the report in other related research projects. It will not be possible for any participant to be identified by this anonymised data.

Who is organising and funding the research?

The study is to be undertaken as part of a postgraduate research degree and has no external funding. The University of Central Lancashire is the institution hosting the researcher.

Who has reviewed the study?

This study has been internally reviewed by the research team at the School of Health, and the Faculty of Health Ethics Committee at the University of Central Lancashire, and has also been reviewed by East of England - Norfolk NHS Ethics Committee to ensure that the very highest standards of planning and conduct are applied to this project. All associated documents such as this information sheet and letter of invitation have also been reviewed.

If you have any further questions and would like to discuss the research further, please contact Laura Gleave on 07583342448. She will then call you back.

You can also contact her by email at LGleave1@uclan.ac.uk,

or by post at:

Laura Gleave,
C/o. Rockley Ward
Poole Hospital,
Longfleet Road
Poole,
Dorset.
BH15 2JB

Thank you for taking the time to read through this information and for considering this request.

If you have decided you would like to participate, please fill out the slip attached and return it in the pre-paid envelope.

✂

I ……..
(Name)

would / would not be interested in participating in a expert panel discussion about needs following a diagnosis of TIA, or mini-stroke.

I would prefer to be contacted by:

Phone ☐ Number ……..

E-mail ☐ Address ……..

Post ☐ Address ……..

……

……

Signed …….. Date ……

What are patient needs after Transient Ischaemic Attack?

Refinement of a previously developed model of needs following TIA using focus group methods with an expert panel.

Please keep for future reference.

Chief Investigator / Researcher: Laura Gleave.

Supervisor: Dr Jo Gibson.

What is the purpose of the study?

The purpose of the study is to explore patients' perceived needs after a **mini-stroke** or TIA (Transient Ischaemic Attack). This study is being undertaken entirely independently from your hospital doctors and GP, as part of a postgraduate research degree based at Poole Hospital and supported by the University of Central Lancashire.

To date there has been no comprehensive review of patient needs following TIA. This study is part of a programme of work that aims to fully explore TIA patients' needs so that they can be identified and assessed. By fully understanding patients' needs after TIA, it might be possible to propose strategies to meet these identified needs.

In this, the final phase of the research, we will present a model (description) of what TIA needs appear to be and will ask you to consider categorisation of needs and how best to meet those needs.

Why have I been invited?

You have been identified as someone who supported a person who has experienced a TIA. The support might have been physical, emotional or practical. The person with

the TIA has been invited to participate in some research at Poole Hospital, supported by the University of Central Lancashire. As part of that invitation, they were given this information sheet to pass to someone they felt played a significant role in offering them support. In earlier research it has become apparent that supporters may have a different perspective and different experience of TIA to those of the person who experienced it. For that reason we are very keen for you to participate in our expert panel, to help us understand TIA from perspective of the supporter.

What will I have to do?

At the meeting you will meet with others who have also had a TIA or been involved in the care of people following TIA. As a group, you will be asked to consider a model of needs identified by people following TIA. The model has been developed based on information gathered over the course of a number of research projects. You will be asked your views on the model presented. By talking and listening to others and sharing your own experiences, we aim to refine and validate the proposed model of needs following TIA. You will also be asked about the importance of various needs and possible ways in which those needs could be met. You do not have to share anything you do not feel comfortable with.

The expert panel meeting will be audio recorded. After the group finishes, a written record of the recording will be made, and the audio recording destroyed as soon as possible.

Do I have to take part?

It is up to you to decide. You will be asked to read this information sheet and decide whether you would like to take part. If you are willing to participate, we will ask you to sign a consent form before you participate, to show you have agreed to take part. You are free to withdraw at any time, without giving a reason. This would not affect the standard of care you or the person with TIA receive. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

What will happen to me if I take part?

If you agree to take part, you may be invited to attend a meeting to discuss your experiences and views with others who have had a TIA, their supporters or healthcare

professionals who care for people following TIA. The meeting will last no more than three hours in total.

Light refreshments will be provided.

Expenses and payments

You will be offered reimbursement for reasonable travel and parking costs incurred in relation to the expert panel meeting, to a maximum of £20.

What are the possible disadvantages and risks of taking part?

Some people may find talking about their TIA experiences, or listening to others' experiences upsetting. It is entirely up to you what experiences you share with the group. As part of the 'ground rules' of the expert panel meeting, the discussion should remain confidential within the group, and not be discussed with others later, however due to the nature of the meeting, complete anonymity cannot be guaranteed.

What are the possible benefits of taking part?

We cannot promise the study will help you, but the information we obtain from this study will help improve our understanding of the experiences of people following TIA.

What happens when the research study stops?

Your involvement ends. There will be no further contact relating to the research. We will look very carefully at all that has been discussed, to identify patterns. All data will be held anonymously and stored on the hospital Mainframe computer and on the Mainframe computer at the University of Central Lancashire, in a password protected file. Your confidentiality will be maintained by storing identifiable data separate from the written record of the group discussion.

What will happen if I do not want to carry on with the study?

You can choose to stop participating at any time during the study. It will not affect your medical care or the care of the person who had a TIA.

What if there is a problem?

Complaints - If you have a concern about any aspect of this study, you should ask to speak to the researcher who will do their best to answer your questions (07583342448). If you remain unhappy and wish to complain formally, you can do this through PALS at Poole Hospital NHS Foundation Trust (Tel. 01202 448499), details can be obtained from the hospital, or contact Dr Nigel Harrison Dean of the School of Health, at the University of Central Lancashire (Tel. 01772 893701).

Harm, NHS based research - In the event that something does go wrong and you are harmed during the research and this is due to someone's negligence then you may have grounds for a legal action for compensation but you may have to pay your legal costs. The normal National Health Service complaints mechanisms will still be available to you (if appropriate).

Will my taking part in this study be kept confidential?

As previously stated, it is not possible to guarantee complete confidentiality since there will be other participants in the group, however all participants will be asked to treat the group discussion as confidential to the group members and not talk about the meeting with others after the event.

All information which is collected about you during the course of the research will be kept strictly confidential. No quotes of other data used or published will be made public in a way that could allow you to be identified.

What will happen to the results of the research study?

All data will be stored with no personal identifiers (just a participant number) in secure electronic storage at the University of Central Lancashire and at Poole Hospital NHS Trust. Any paper based information generated during the group will be scanned and saved electronically. Electronic data will be password protected and stored on the University's mainframe computer. Access to any data is restricted to the research team only and no information that could identify you will be made public. Any publications or reports arising from this study will include only anonymised information. Audio recordings will be written up and original recordings destroyed. We may use the anonymised data and the report in other related research projects. It will not be possible for any participant to be identified by this anonymised data.

Who is organising and funding the research?
The study is to be undertaken as part of a postgraduate research degree and has no external funding. The University of Central Lancashire is the institution hosting the researcher.

Who has reviewed the study?
This study has been internally reviewed by the research team at the School of Health, and the Faculty of Health Ethics Committee at the University of Central Lancashire, and has also been reviewed by East of England - Norfolk NHS Ethics Committee to ensure that the very highest standards of planning and conduct are applied to this project. All associated documents such as this information sheet and letter of invitation have also been reviewed.

If you have any further questions and would like to discuss the research further, please contact Laura Gleave on 07583342448. She will then call you back.

You can also contact her by email at LGleave1@uclan.ac.uk,

or by post at:

Laura Gleave,
C/o. Rockley Ward
Poole Hospital,
Longfleet Road
Poole,
Dorset.
BH15 2JB

Thank you for taking the time to read through this information and for considering this request.

If you have decided you would like to participate, please fill out the slip attached and return it in the pre-paid envelope.

✂

I ……..
(Name)

would / would not be interested in participating in a expert panel discussion about needs following a diagnosis of TIA, or mini-stroke.

I would prefer to be contacted by:

Phone ☐ Number ……..

E-mail ☐ Address ……..

Post ☐ Address ……..

……

……

Signed …….. Date ……

What are patient needs after Transient Ischaemic Attack?

Refinement of a previously developed model of needs following TIA using focus group methods with an expert panel.

Please keep for future reference.

Chief Investigator / Researcher: Laura Gleave.

Supervisor: Dr Jo Gibson.

What is the purpose of the study?

To date there has been no comprehensive review of patient needs following TIA. This study is part of a programme of work that aims to fully explore TIA patients' needs so that they can be identified and assessed. By fully understanding patients' needs after TIA, it might be possible to propose strategies to meet these identified needs.

Earlier elements of this research programme have suggested a range of needs identified by patients and professionals. Interestingly the two groups of needs, whilst having many similarities, also have considerable differences. A model of needs following TIA has been developed and will be presented in this phase of the research for consideration, refinement and validation. Needs will be categorised and the ways in which needs might be identified and met, by health and social care staff and by patients and supporters will be considered.

Why have I been invited?

You have been identified as someone who cares for or supports people following TIA. You may have been recommended to be contacted by a work colleague, who feels you may have insight or information that would be relevant to the research. Please don't worry if you feel that you do not have a major role in TIA after-care, there may be a specific element to your role that has prompted contact.

What will happen if I take part?

You will join us at a venue in Poole Hospital where you will be asked to complete a written consent form then participate in a group discussion based on a proposed model

of needs following TIA. You will be invited to participate in a group comprising patients, supporters and professionals – the expert panel. The meeting will last no more than 3 hours, but is likely to finish before that. Light refreshments will be provided.

Expenses and payments?

You will be offered reimbursement for reasonable travel and parking costs to a maximum of £20.

What will I have to do?

The group will consider the model presented and discuss how well it fits with the experiences of the group. The group will be asked for suggestions about how to refine the model. Needs will be categorised and consideration will be given to how needs can be identified and met

.

The group will be audio recorded. After the meeting, a written record of the recording will be made, and the audio recording destroyed as soon as possible. The meeting will last no more than three hours

What happens when the research study stops?

Your involvement ends. There will be no further contact relating to the research. We will look very carefully at all that has been discussed, to identify patterns. All data will be held anonymously and stored on the Mainframe computer at the University of Central Lancashire and in the Poole hospital mainframe computer, in a password protected file. Your confidentiality will be maintained by storing identifiable data separate from the written record of the interview.

Will my taking part in the study be kept confidential?

Yes. We will follow ethical and legal practice and all information about you will be handled in confidence.

All information which is collected about you during the course of the research will be kept strictly confidential, and any information about you that is used or published, will have your name and address removed so that you cannot be recognised

What will happen to the results of the research study?
All data will be stored with no personal identifiers (just a participant number) in secure electronic storage at the University of Central Lancashire and at Poole Hospital NHS Trust. Any paper based information generated during the group will be scanned and saved electronically. Electronic data will be password protected and stored on the University's mainframe computer. Access to any data is restricted to the research team only and no information that could identify you will be made public. Any publications or reports arising from this study will include only anonymised information. Audio recordings will be written up and original recordings destroyed. We may use the anonymised data and the report in other related research projects. It will not be possible for any participant to be identified by this anonymised data. Anonymised direct quotes may be used may be used in the write up of the study.

Who is organising and funding the research?
The study is to be undertaken as part of a postgraduate research degree and has no external funding. The University of Central Lancashire is the institution hosting the researcher.

Who has reviewed the study?
This study has been internally reviewed by the research team at the School of Health, and the Faculty of Health Ethics Committee at the University of Central Lancashire, and has also been reviewed by East of England - Norfolk NHS Ethics Committee to ensure that the very highest standards of planning and conduct are applied to this project. All associated documents such as this information sheet and letter of invitation have also been reviewed.

Why might I not be selected for the research?

Depending on the level of responses, it is possible that we will reach the numbers needed to answer our questions without asking you to participate. If you are not needed, I would like to take the opportunity to thank you for your interest.

Complaints - If you have a concern about any aspect of this study, you should ask to speak to the researcher who will do their best to answer your questions (07970794788). If you remain unhappy and wish to complain formally, you can contact Nigel Harrison, Dean of the School of Health, at the University of Central Lancashire (Tel. 01772 893701).

If you have any further questions and would like to discuss the research further, please contact Laura Gleave on 07583342448. I will then call you back.

You can also make contact by email at LGleave1@uclan.ac.uk,

or by post at:

Laura Gleave,
C/o. RANVC / Rockley Ward
Poole Hospital,
Longfleet Road
Poole,
Dorset.
BH15 2JB

Thank you for taking the time to read through this information and for considering this request.

If you have decided you would like to participate, please contact the researcher on 07583342448 or 01202 263039 or via email.

University of Central Lancashire

Poole Hospital NHS
NHS Foundation Trust

Letter of confirmation

Dear,

Thank you for agreeing to participate in research looking at peoples' needs and experiences following a TIA or 'mini-stroke'.

We have now finalised the arrangements for the meetings. I would like to confirm your place on the expert panel being held between 1:30pm and 4:30pm on 7th November 2014.

The meeting will be held in the day room of the stroke rehabilitation ward (Brownsea ward) on Level 4 of the Philip Arnold Unit. Please report to the TIA clinic receptionist, Debbie on arrival.

When you arrive you will be offered lunch. Please inform me of any dietary requirements you may have. The first half an hour will be taken up with paperwork and lunch, then the meeting itself will start. Even if the meeting starts late it will finish on time.

During the meeting you will be asked to use your experiences and views about needs following a TIA. You will be given some material to discuss as a group, and some tasks to complete. I will then present the model of TIA needs that is based on the research findings so far. We will then look at creating a refined model which takes account of your views and experiences.

Parking will be available free of charge in the main multistory car park.

If you have any further questions or need to contact me for any other reason, I can be contacted on 07970794788 or 01202 263039. Please be aware I will be away from 1st

to 31st October inclusive, but can be contacted by email at LGleave1@uclan.ac.uk during this time.

I look forward to meeting you on 7th November,

Kind regards,

Laura Gleave

Stroke Nurse Practitioner, Poole Hospital NHS Trust

Research Student, University of Central Lancashire

CONSENT FORM (Poole only)

Study Number:

Patient Identification Number for this trial:

Title of Project: **What are patient needs after Transient Ischaemic Attack?**

Refinement of a previously developed model of needs following TIA using focus group methods with an expert panel.

Name of Researcher: Laura Gleave.

Please initial boxes

1. I confirm that I have read and understand the information sheet dated 19th June 2014 (version 3) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being effected. ☐

4. I agree to my GP being informed of my participation in the study. ☐

5. I understand that group will be audio-recorded and transcribed. ☐

6. I understand that anonymised direct quotes may be used in the write up of the research. ☐

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

Name of Patient	Date	Signature
Name of researcher taking consent	Date	Signature

When completed, 1 for patient; 1 for researcher site file

University of Central Lancashire

Poole Hospital NHS
NHS Foundation Trust

CONSENT FORM

Study Number:

Supporter Identification Number for this trial:

Title of Project: **What are patient needs after Transient Ischaemic Attack?**

Refinement of a previously developed model of needs following TIA using focus group methods with an expert panel.

Name of Researcher: Laura Gleave.

Please initial boxes

1. I confirm that I have read and understand the information sheet dated 19th June 2014 (version 3) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐

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

3. I understand that interview will be audio-recorded and transcribed. ☐

4. I understand that anonymised direct quotes may be used in the write up of the research. ☐

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

_____	_____	_____
Name of Supporter	Date	Signature

_____	_____	_____
Name of researcher taking consent	Date	Signature

When completed, 1 for patient; 1 for researcher site file

CONSENT FORM

Study Number:

Professional Identification Number for this trial:

Title of Project: **What are patient needs after Transient Ischaemic Attack?**

Refinement of a previously developed model of needs following TIA using focus group methods with an expert panel.

Name of Researcher: Laura Gleave.

Please initial boxes

1. I confirm that I have read and understand the information sheet dated 19th June 2014 (version 3) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐

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

3. I understand that interview will be audio-recorded and transcribed. ☐

4. I understand that anonymised direct quotes may be used in the write up of the research. ☐

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

_____	_____	_____
Name of Professional	Date	Signature

_____	_____	_____
Name of researcher taking consent	Date	Signature

When completed, 1 for patient; 1 for researcher site file

D3 Expert panel participant thumbnail sketches

Participant (i). Emergency Department Consultant. Many people seen with TIA in the Emergency Department are initially brought in by ambulance as FAST positive, for consideration for thrombolysis. If their symptoms are rapidly resolving, they are monitored very closely and if complete resolution occurs, they would usually be referred to the TIA clinic, for specialist assessment.

Participant (ii). Stroke Nurse Practitioner who sees patients following TIA as new patients in clinic, where a diagnosis is made. She also sees people in follow-up clinics, and in the Emergency Department.

Participant (iii). A 46 year old lady who was given a TIA diagnosis 7 weeks previously. She had an episode of numbness and 'pins 'n' needles' in her left side, which lasted for several hours. She lives alone and works full time as an employee of the Stroke Association, working in the community with TIA and stroke survivors. She called an ambulance and was taken to the Emergency Department.

Participant (iv). A 76 year old lady, who had her TIA 11 weeks ago. Her initial symptom was left leg weakness and an 'inability to walk straight' in the high street. This lasted about 30 minutes. She was observed by a shop keeper who came to her assistance, sat her down and suggested she should see a doctor. This was over a weekend, so she waited and saw her doctor on Monday. She lives with her husband who has previously had a stroke.

Participant (v). Stroke Consultant Physician who sees people with TIA either as new patients in clinic, when a diagnosis is made, on the Acute Stroke Unit or at follow-up clinic.

Participant (vi). Research Physiotherapist. Recently completed some research with people following TIA and gained insight into their experiences as part of the research conducted.

Participant (vii). An 86 year old man who had a TIA 9 weeks ago. His symptoms were difficulty standing up and weakness / numbness across the left side of his body, which lasted about five to ten minutes. He considers himself to be generally fit and well. He is a retired chef and usually does all the cooking at

home and feels he normally has a good diet, and takes plenty of exercise. He was surprised and disappointed to have a TIA.

Participant (viii). Wife of participant 7, considers herself to be in good health.