AN IN-DEPTH EXPLORATION
OF AN APHASIA CARE PATHWAY

by

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This thesis is submitted in partial fulfilment of the requirements for
the award of the Degree of Professional Doctorate in Health Sciences

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School of Health Sciences and Social Work

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# Contents

Table of contents .................................................................................................................. ii

List of tables ........................................................................................................................... viii

List of figures .......................................................................................................................... ix

List of appendices .................................................................................................................. x

List of abbreviations .............................................................................................................. xii

Acknowledgements and dedications .................................................................................... xiii

Dissemination ........................................................................................................................ xiv

Declaration ............................................................................................................................. xv

Abstract ............................................................................................................................... xvi

Chapter 1: INTRODUCTION ................................................................................................. 1

1.1 Background to the research ......................................................................................... 1

1.2 Stroke: an overview ..................................................................................................... 2

1.3 Aphasia: an overview ................................................................................................. 2

1.3.1 Incidence and prevalence of aphasia .................................................................... 3

1.3.2 Aphasia and stroke: an overview ......................................................................... 3

1.4 Outline of the Thesis ..................................................................................................... 4

Chapter 2: LITERATURE REVIEW ...................................................................................... 6

2.1 The context of aphasia within stroke and its recovery ............................................ 6

2.1.1 Living with aphasia .............................................................................................. 6

2.1.2 The impact of aphasia on family members and carers ...................................... 8

2.1.3 Impact of aphasia on the rehabilitation process ................................................ 9

2.2 The role of Health Care Professionals with people with aphasia .......................... 11

2.2.1 The role of SLT with PWA ............................................................................... 12

2.3 Information needs about aphasia ............................................................................... 14
3.3.1 Sampling........................................................................................................................................45
3.3.2 Role of gatekeepers in the recruitment process .............................................................................47
3.3.3 Sample for the aphasia care pathway study ....................................................................................48
3.3.4 Sample size in qualitative research ................................................................................................48
3.3.5 Sample 1: People with aphasia ......................................................................................................49
3.3.6 Sample 2: Carers of PWA ..............................................................................................................50
3.3.7 Sample 3: HCPs ..............................................................................................................................51
3.3.8 Participant consultation before recruitment ....................................................................................52
3.4 Data collection ....................................................................................................................................53
  3.4.1 Focus groups ..................................................................................................................................53
  3.4.2 Interviews ......................................................................................................................................58
3.5 Data analysis in qualitative research .................................................................................................61
  3.5.1 Introduction to the thematic framework analysis ...........................................................................61
  3.5.2 Managing the data ........................................................................................................................62
  3.5.3 Identifying concepts and themes ...................................................................................................63
  3.5.4 Validity of data ...............................................................................................................................64
  3.5.5 Positionality ....................................................................................................................................65
  3.5.6 Rigour and reflexivity .....................................................................................................................65
3.6 Analysis of the qualitative data in the aphasia care pathway study ....................................................66
  3.6.1 Familiarisation ...............................................................................................................................66
  3.6.2 Identifying themes and codes .......................................................................................................67
  3.6.3 Validation of the data .....................................................................................................................68
  3.6.4 Summary of the qualitative data analysis ......................................................................................70
3.7 Results from the qualitative data analysis ..........................................................................................71
  3.7.1 Interpreting the data .....................................................................................................................74
  3.7.2 Summary of themes .......................................................................................................................74
3.7.3 Theme 1: characteristics of care pathways in the NHS .............................................76
3.7.4 Theme 2: Characteristics and value of an aphasia care pathway ..............................79
3.7.5 Theme 3: Provision of aphasia related information .................................................84
3.7.6 Theme 4: Psychosocial factors influencing response to the aphasia care pathway .................................................................87
3.8 Discussion and recommendations ........................................................................90
3.8.1 Methodological strengths and limitations .........................................................92
3.8.2 Implications for practice .....................................................................................94
3.9 Summary ................................................................................................................94

Chapter 4 MIXED METHODS DESIGN – the quantitative study ........................................95

4.1 Introduction to quantitative research design ................................................................95
4.1.1 Background to the quantitative study .....................................................................96
4.1.2 Aims and objectives of the study ............................................................................96
4.2 Method .....................................................................................................................96
4.2.1 Study design ..........................................................................................................96
4.2.2 Design of the survey .............................................................................................98
4.2.3 Piloting the survey ................................................................................................101
4.2.4 Data collection ........................................................................................................103
4.2.5 Sampling ................................................................................................................104
4.2.6 Distribution of the survey .....................................................................................105
4.3 Analysis of the survey data .......................................................................................105
4.3.1 Descriptive statistics ............................................................................................105
4.4 Survey findings ........................................................................................................106
4.4.1 Results of the descriptive analysis .......................................................................107
4.4.2 Results of the qualitatively analysed questions .....................................................110
4.5 Summary of survey findings ....................................................................................112
6.6.1 My personal journey.................................................................148

Chapter 7 CONCLUSION ........................................................................150

REFERENCES .........................................................................................152
<table>
<thead>
<tr>
<th>Table</th>
<th>Title</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.1</td>
<td>Incidence and prevalence of stroke and aphasia</td>
<td>3</td>
</tr>
<tr>
<td>2.1</td>
<td>Literature review inclusion and exclusion criteria</td>
<td>18</td>
</tr>
<tr>
<td>2.2</td>
<td>Electronic data bases searched</td>
<td>19</td>
</tr>
<tr>
<td>2.3</td>
<td>Journals searched manually</td>
<td>19</td>
</tr>
<tr>
<td>2.4</td>
<td>MeSH headings</td>
<td>20</td>
</tr>
<tr>
<td>3.1</td>
<td>Summary of recruitment process</td>
<td>51</td>
</tr>
<tr>
<td>3.2</td>
<td>Stages of focus groups</td>
<td>56</td>
</tr>
<tr>
<td>3.3</td>
<td>Stages of thematic framework analysis</td>
<td>62</td>
</tr>
<tr>
<td>3.4</td>
<td>Peer validation process</td>
<td>69</td>
</tr>
<tr>
<td>3.5</td>
<td>Themes from participations validation process</td>
<td>70</td>
</tr>
<tr>
<td>3.6</td>
<td>Characteristics of PWA who attended a focus group</td>
<td>72</td>
</tr>
<tr>
<td>3.7</td>
<td>Characteristics of carers interviewed</td>
<td>72</td>
</tr>
<tr>
<td>3.8</td>
<td>Characteristics of HCPS interviewed</td>
<td>73</td>
</tr>
<tr>
<td>3.9</td>
<td>Themes for focus groups and interviews</td>
<td>73</td>
</tr>
<tr>
<td>3.10</td>
<td>Main themes with examples of contributory codes</td>
<td>74</td>
</tr>
<tr>
<td>4.1</td>
<td>Stages of survey design</td>
<td>101</td>
</tr>
<tr>
<td>4.2</td>
<td>Coding instructions</td>
<td>106</td>
</tr>
</tbody>
</table>
List of figures

3.1 Sequential embedded exploratory design model..................................................38

3.2 Summary of qualitative data analysis.....................................................................71

4.1 Number of SLTs using an aphasia care pathway.....................................................107

4.2 Number of SLTs agreeing to statement regarding an accessible version of an aphasia care pathway..................................................................................................................108

4.3 Number of years working with PWA......................................................................109

4.4 Primary care setting of respondents.......................................................................109

4.5 Agenda for change banding of survey respondents.................................................110

5.1 Flowchart summarising mixed methods research design ......................................121

5.2 Sequential data analysis design.............................................................................123
**List of Appendices**

<table>
<thead>
<tr>
<th>Appendix</th>
<th>Description</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Appendix 1:</td>
<td>Solent NHS trust Aphasia care pathway</td>
<td>165</td>
</tr>
<tr>
<td>Appendix 2:</td>
<td>Table of evidence</td>
<td>166</td>
</tr>
<tr>
<td>Appendix 3:</td>
<td>Letter of approval from Berkshire B NHS Research &amp; Ethics Committee</td>
<td>169</td>
</tr>
<tr>
<td>Appendix 4:</td>
<td>Study information sheet for PWA</td>
<td>171</td>
</tr>
<tr>
<td>Appendix 5:</td>
<td>Study information sheet for carers</td>
<td>176</td>
</tr>
<tr>
<td>Appendix 6:</td>
<td>Study information sheet for HCPs</td>
<td>180</td>
</tr>
<tr>
<td>Appendix 7:</td>
<td>Consent form for PWA entering the study</td>
<td>184</td>
</tr>
<tr>
<td>Appendix 8:</td>
<td>Referral form for SLTs to use to refer carers</td>
<td>186</td>
</tr>
<tr>
<td>Appendix 9:</td>
<td>Referral form for HCPs into the study</td>
<td>187</td>
</tr>
<tr>
<td>Appendix 10:</td>
<td>Consent form for carers and HCPs entering the study</td>
<td>188</td>
</tr>
<tr>
<td>Appendix 11:</td>
<td>Focus groups guide</td>
<td>189</td>
</tr>
<tr>
<td>Appendix 12:</td>
<td>Copy of letter inviting PWA to attend a focus group</td>
<td>190</td>
</tr>
<tr>
<td>Appendix 13:</td>
<td>Interview topic guide for use with carers</td>
<td>192</td>
</tr>
<tr>
<td>Appendix 14:</td>
<td>Interview topic guide for use with HCPs</td>
<td>193</td>
</tr>
<tr>
<td>Appendix 15:</td>
<td>Framework of index of labels</td>
<td>194</td>
</tr>
<tr>
<td>Appendix 16:</td>
<td>Examples from interview and focus group transcripts with initial labels identified</td>
<td>196</td>
</tr>
<tr>
<td>Appendix 17:</td>
<td>Initial themes and sub themes from focus groups and interview analysis</td>
<td>204</td>
</tr>
<tr>
<td>Appendix 18:</td>
<td>Emerging themes from peer validation</td>
<td>206</td>
</tr>
<tr>
<td>Appendix 19:</td>
<td>Copy of letter published in SLT Bulletin March 2015</td>
<td>207</td>
</tr>
</tbody>
</table>
Appendix 20: Copy of the survey pilot .................................................................208
Appendix 21: Copy of the final version of the survey ................................210
Appendix 22: Summary of descriptive statistics .......................................213
<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Full Form</th>
</tr>
</thead>
<tbody>
<tr>
<td>BOS</td>
<td>Bristol On Line survey</td>
</tr>
<tr>
<td>COPD</td>
<td>Chronic obstructive pulmonary disease</td>
</tr>
<tr>
<td>CPD</td>
<td>Continual professional development</td>
</tr>
<tr>
<td>CSS</td>
<td>Communication support service</td>
</tr>
<tr>
<td>CVA</td>
<td>Cerebro vascular accident</td>
</tr>
<tr>
<td>ESCR</td>
<td>Economic and Social Research Council</td>
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<tr>
<td>HCPs</td>
<td>Health care professionals</td>
</tr>
<tr>
<td>HCPC</td>
<td>Health and Care Professions Council</td>
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<td>ICPs</td>
<td>Integrated care pathways</td>
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<td>L</td>
<td>Left</td>
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<tr>
<td>NHS</td>
<td>National Health Service</td>
</tr>
<tr>
<td>NICE</td>
<td>National Institute of Clinical Excellence</td>
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<tr>
<td>OT</td>
<td>Occupational Therapist</td>
</tr>
<tr>
<td>PPI</td>
<td>Public and patient involvement</td>
</tr>
<tr>
<td>PT</td>
<td>Physiotherapist</td>
</tr>
<tr>
<td>PWA</td>
<td>People with aphasia</td>
</tr>
<tr>
<td>R</td>
<td>Right</td>
</tr>
<tr>
<td>RCP</td>
<td>Royal College of Physicians</td>
</tr>
<tr>
<td>RCSLT</td>
<td>Royal College of Speech and Language Therapists</td>
</tr>
<tr>
<td>RCT</td>
<td>Randomised controlled trial</td>
</tr>
<tr>
<td>SLT</td>
<td>Speech and Language Therapist</td>
</tr>
<tr>
<td>SSNAP</td>
<td>Sentinel stroke national audit programme</td>
</tr>
</tbody>
</table>
Acknowledgements and dedications

First and foremost I would like to thank the PWA, their families and carers who have contributed to the findings reported in this study and more widely those who I have had the privilege of working with and who have inspired me to explore the aphasia care pathways, to improve the service they receive. Aphasia is a dramatic, devastating life changing condition; I have nothing but respect for those who have to learn to live with the consequences of it. I dedicate this work to them.

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Dissemination

Publication arising from this piece of research


Invited presentations


Poster Presentation

Solent NHS Trust AHP Conference November 2016
Declaration

Whilst registered as a candidate for the above degree, I Lynn Dangerfield, have not been registered for any other research award. The results and conclusions embodied in this thesis are the work of the named candidate and have not been submitted for any other academic award.

Signed: .......Lynn Dangerfield......... Date: ........23/02/18....................

Word Count = 50,579 excluding references and appendices
Abstract

An in-depth exploration of an aphasia care pathway

Introduction: Clinical or care pathways are increasingly being employed in health care settings, as a structured plan of care, to share with clients and their families and to implement clinical guidelines. Studies have explored the value of generic care pathways, yet there is limited evidence for the use of an aphasia care pathway. This research aimed to review and contribute to the theory and evidence-base for an aphasia care pathway, from a range of the key stakeholders including people with aphasia (PWA) carers and health care professionals (HCPs) including Speech and Language Therapists (SLTs). The aim was to illuminate their experiences and to measure the extent to which practising SLTs referred to an aphasia care pathway in their clinical practice, in order to address the research “Is there a need for an aphasia specific care pathway”?

Methods and procedures: Qualitative research techniques were used initially, PWA participated in focus groups and carers and HCPs in interviews, all were purposively selected. Focus groups and interviews were transcribed verbatim and the data analysed using the thematic based framework. A survey was distributed to SLTs working with PWA, to collect quantitative data. A sequential mixed methods analysis identified similarities and differences in the data sets which were then synthesised.

Outcomes and results: Thematic framework analysis illuminated four themes: experiences of care pathways within the NHS, characteristics and value of an aphasia care pathway, provision of aphasia related information and psychosocial factors that influence response to an aphasia care pathway. Descriptive statistics identified 42% of SLTs used an aphasia care pathway. 88% of all respondents agreed that an accessible version of an aphasia care pathway should be developed.

Conclusions and implications: This study highlights that, whilst the key stakeholders had awareness of an aphasia care pathway, modifications are required, including a description of the core elements of an aphasia care pathway, clear timescales for interventions, the provision of information in a timelier manner. In addition, the need for the key stages of a care pathway to be provided by a registered SLT and for an accessible representation of an aphasia care pathway to be available, were identified as priorities.
Chapter 1: INTRODUCTION

1.1 Background to the research

It is estimated that one third of people who have a stroke will have aphasia, affecting the ability to use language in all its modalities, understanding or processing what is being said and being able to express oneself effectively (Hilari & Botting, 2011). Consequently, aphasia can have a profound effect on many aspects of a person’s life, impacting upon daily activities, emotional well-being, relationships and overall quality of life.

Speech and Language Therapists (SLTs) have primary responsibility for the assessment, diagnosis and management of aphasia resulting from a stroke, with the aim of maximising an individual’s ability to be able to communicate. They also have a key role in educating and training others involved in the care of a person with aphasia, including family members and other health care professionals (Brady, Kelly, Godwin, Enderby & Campbell 2016).

Clinical care pathways have been developed within the National Health Service (NHS) for a number of years (Claridge, Parker & Cook 2005) and the introduction of the Health and Social Care Bill (2013) has resulted in them becoming firmly established as part of the delivery of effective health care.

Within the NHS there are established and extensively used care pathways, for example for diabetes, chronic obstructive pulmonary disease (COPD) and stroke care pathways. Whilst SLTs are required to produce care pathways, within the framework for integrated evidence based care for patients, this has proved challenging. A care pathway for aphasia was introduced within Solent NHS Trust in 2012, (appendix 1), however its application has been restricted by an insufficient evidence base. This was a key driver behind this programme of research. A comprehensive literature review has been conducted by the author, but did not source a specific article relating to aphasia care pathways. The programme of research described in this thesis therefore aims to explore an aphasia care pathway from the perspectives of the main stakeholders, in order to contribute to the evidence base. A mixed methods approach has been taken, combining the strengths of qualitative methods to enhance the subsequent quantitative stages of data collection and
analysis. Consequently, the thesis presented here is organised according to the overall design and progression of the research.

1.2 Stroke: an overview

Stroke is a clinical syndrome, caused by either a bleed or a blockage to blood supply within the cerebral hemisphere, cerebellum or brain stem, characterised by rapidly developing signs of disturbance of cerebral functions, lasting more than 24 hours or leading to death (Royal College of Physicians, RCP, and Stroke Guidelines 2016). It is accepted that 85% of strokes are due to cerebral infarction, 10% due to primary haemorrhage and 5% due to subarachnoid haemorrhage. The risk of recurrent stroke is 26% within 5 years of a first stroke and 39% by 10 years (Mohan, Wolfe, Rudd & Heuschmann, 2011).

Annually 17 million people worldwide suffer a stroke, of these 5 million will not survive and another 5 million are left permanently disabled (Clarke & Forster, 2015). Each year, 130,000 people suffer a stroke in England and Wales and at any time, 250,000 people in the UK live with severe disability following a stroke. It affects between 174 and 216 people per 100,000 of the population in the UK each year and accounts for 11% of all deaths in England and Wales (Code & Petheram 2011). Stroke is an age related condition, although people of any age can be effected, approximately 25% of strokes in the UK occur in people below the age of 65, it is estimated that 13 in 100,000 children suffer a stroke (Clarke & Forster 2015).

1.3 Aphasia: an overview

Aphasia is the term used to describe a language disorder that results from damage to those areas of the brain that are responsible for language and is the most commonly occurring stroke related communication difficulty. For the majority of people the left hemisphere of the brain is dominant, controlling most aspects of language processing. Any damage to this area from head injury, disease, infarction or a bleed can affect language functions, verbal, written and gestural (Hilari & Botting, 2011).

Aphasia can affect up to 40% patients suffering a first stroke (Code & Petheram 2011). A person with aphasia often finds that their ability to understand, speak, read or write is affected, whilst cognitive functioning is likely to remain intact for a single hemisphere or
first stroke. They may have problems in answering the telephone, watching television or
listening to the radio. Everyday tasks and conversations can become difficult, this often
leads to frustration, social isolation and a breakdown in close relationships (Parr 2007).

1.3.1 Incidence and prevalence of aphasia

The incidence of aphasia refers to the number of new cases identified in a specified time
period, the prevalence of aphasia refers to the number of people who are living with
aphasia in a given time period. The incidence and prevalence of stroke and aphasia are
summarised in table 1.1

Table 1.1 Incidence and prevalence of stroke and aphasia

<table>
<thead>
<tr>
<th>Incidence of stroke and aphasia</th>
<th>Prevalence of stroke and aphasia</th>
</tr>
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<tbody>
<tr>
<td>152,000 people in the UK suffer a stroke each year (Stroke Association 2015)</td>
<td>1: 15 per thousand population will suffer a stroke (Stroke Association 2015)</td>
</tr>
<tr>
<td>250,000 people in the UK have aphasia (Stroke Association 2015)</td>
<td>40% patients suffering a first stroke have a diagnosis of aphasia (Code &amp; Petheram 2011).</td>
</tr>
<tr>
<td>Number of PWA within the local health economy = 400</td>
<td>30% PWA have long term communication difficulties (Code &amp; Petheram 2011)</td>
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1.3.2 Aphasia and stroke: an overview

Aphasia has a significant impact upon the stroke multi-disciplinary team as the
communication difficulty will influence response to nursing, medical and rehabilitation
processes. National drivers, most notably the Royal College of Physicians (RCP) National
Clinical Guidelines for Stroke 5th edition (2016) and the NICE Stroke guidelines (2014) all
emphasise the importance of a unified, multidisciplinary response to stroke, continuing
from prevention, through acute care and rehabilitation, into community and long term
care.

SLTs should provide the multi-disciplinary stroke team with communication strategies
that are tailored to enhance communication with PWA. Providing communication
training to health care providers is likely to improve the ability of people with aphasia to
understand information and participate in health care decision-making; appropriate
communication strategies need to be identified in order to support the patient and his or her health care providers (O’Halloran, Grohn & Worrall 2012).

1.4 Outline of the Thesis

This introductory chapter has provided a background to the study and an overview of stroke and aphasia, identifying the impact of an acute and rapid change in an individual’s ability to communicate as the result of a stroke.

Chapter 2 provides a comprehensive review of the literature underpinning the work described in this thesis. The first section presents a background to the programme of study, highlighting the impact of aphasia on the individual, family members and the way rehabilitation is provided. This is followed by a description of the methods used to search and evaluate the evidence. Clinical care pathways are then described and evaluated, before specifically exploring aphasia care pathways. This literature review concludes with the argument that development of aphasia care pathways, to improve the experiences of those required to participate within it, is necessary. An overview of the mixed method approach is provided, illustrating why it is an appropriate method to use for this study. The aims and objectives of the study are addressed in the final section of chapter 2.

The study aimed to explore and illuminate, through a mixed methodology, the experiences and use of an aphasia care pathway from the perspective of the service user receiving the pathway and health care professionals delivering care.

Chapter 3 presents the first phase of the study, a qualitative exploration of experiences of PWA, carers and HCPs in relation to an aphasia care pathway. The principles of qualitative research are discussed, including sampling procedures, data collection and analysis. Focus group activities with PWA and interviews with carers and HCPS were conducted and analysed in order to describe quality of life from their own perspective. Relevant quotes from participants are included. The main themes identified following thematic framework analysis are explored.

Chapter 4 describes the rationale used for the quantitative arm of the study, a survey of practising SLTs. The development and distribution of the measurement tool is explained and the analysis of the results, using descriptive statistics and a thematic framework, presented.
A synthesis of the qualitative and quantitative findings using a mixed methods framework is given in Chapter 5. This includes an overview of mixed methods analysis.

Chapter 6 summarises the research findings, implications and methodological limitations. A reflection of the Professional Doctorate journey is provided.

Chapter seven provides the conclusion for the programme of research. It addresses the aims or research questions contained within the programme of research and the implications of the programme’s findings. This chapter also includes the primary recommendations for future research.

The following chapter presents findings of a systematic literature review designed to identify the evidence of the role and use of care pathways within the NHS, with a specific focus upon aphasia care pathways and the mixed methodology approach applied in this study.
Chapter 2: LITERATURE REVIEW

This chapter will critically examine the evidence for the role and use of care pathways within stroke and aphasia.

This review of literature begins with a background to the programme of study, discussing aphasia, its impact for the individual, family members and the rehabilitation journey. This is followed by details of the systematic review of the literature and a critical evaluation of the evidence found, designed to identify the evidence base for the use of care pathways within stroke care and specifically within aphasia. The research aims and objectives are presented at the end of this chapter.

The chapter is divided in six sections:

- A background to the study
- The search strategy
- Results of the literature review. The following topics will be addressed, an overview of stroke and aphasia, the impact of aphasia, the role of the Speech and Language Therapist with aphasia, the role of the multi-disciplinary team and aphasia within the context of stroke provision
- The implications of the review for clinical practice
- The aims and objectives of the aphasia care pathway study
- Mixed methods

2.1 The context of aphasia within stroke and its recovery

2.1.1 Living with aphasia

Aphasia is an acute onset of communication impairment, most frequently following a stroke, which will result in a hospital admission. The acute hospital journey for PWA is fast paced and focused on discharge and transfer to a rehabilitation environment (Hersh 2016). This can often be at the expense of the window of opportunity to capitalise on neural recovery, however the detail of early aphasia recovery remain unclear (Foster, Worrall, Rose and O’Halloran 2016). Furthermore, dysphagia (swallowing difficulties) is considered to be the primary caseload for the majority of SLTs working within acute
stroke care, limiting the availability of clinical resource to focus upon aphasia interventions (Rose, Ferguson & Power 2013).

The effects of aphasia for both individuals and their family members can be significant and long-lasting, with most cases of aphasia persisting for the remainder of an individual’s life (Brown, Worrall, Davidson & Howe, 2012). The full impact of the stroke may not become apparent until some weeks or months post onset, when the individual and their family and or carers attempts to get on with his or her life (Hilari & Botting 2011).

The concept of living successfully with aphasia emerged as an alternative to more traditional deficit models in aphasiology, encouraging a focus on positive rather than negative outcomes (Parr, 2007). Studies exploring the concept of living with aphasia have advanced the understanding of a positive approach to the condition, one of adaption and acceptance. Living with aphasia has been defined as:

“a need to do things in order to be actively engaged in rehabilitation: increase independence and have a purpose in life: the importance of social support: the value of rehabilitation: a need to adapt and make adjustments: and having a positive outlook”. (Grohn, Worrall, Simmons-Mackie & Brown, 2012 p 390)

Despite this positive definition, living with aphasia after a stroke can be a lifelong challenge, during which people with the condition and their families continue to seek and find ways to compensate for, or adapt to, persisting neurological deficits and the impact this has upon their abilities to communicate in daily life, as emphasized by Grohn, et al. (2012). A qualitative study, PWA were interviewed at four time points, three, six, nine and twelve months post stroke and asked to rate how successfully they felt they were living with aphasia, suggest what would increase their quality of life and any barriers they had encountered. Themes included participation in meaningful activities, support by family, friends and other people with aphasia. Conclusions of the study were to emphasise the importance of continual evaluation of the changing needs of PWA and their families over time. It is imperative, the authors claim, that these issues are factored into the rehabilitation process and on-going support and information given.

Aphasia can also create vulnerability within the individual, their ability to control their own environment and actively engage in decision making, for example regarding accommodation, financial arrangements and legal matters may be compromised, due to
their language impairment (Ferguson, Duffield & Worrall 2010). This may be disempowering by being misidentified as unable to make their own decisions. The Mental Capacity Act (2005) provides a framework in which to decide whether a person has the capacity to make an informed decision and is underpinned by a set of five key principles:

1. A presumption of capacity, stating that every adult has the right to make his or her own decisions and must be assumed to have capacity to do so unless it is proved otherwise.

2. The right for individuals to be supported to make their own decisions, individuals must be given all appropriate help before anyone concludes that they cannot make their own decisions.

3. Individuals must retain the right to make what might be seen as eccentric or unwise decisions.

4. Best interests, anything done for, or on behalf of people, without capacity must be in their best interests.

5. Least restrictive intervention, anything done for or on behalf of people without capacity should be the least restrictive of their basic rights and freedoms.

PWA are at risk when their decision making capacity is queried and there is a need for the development of guidelines for practice in this area (Ferguson et al. 2010).

2.1.2 The impact of aphasia on family members and carers

As a chronic disability, aphasia has a significant impact not only upon the affected individual but also on those closely related to them (Worrall, Sheratt, Rogers, Howe, Hersh, Ferguson & Davidson 2011). For this reason it is essential that the opinions of carers or significant others are sought in research exploring the impact of an acquired communication disability. Aphasia is an experience which is largely shaped by how other people react and behave within different settings (Nystrom, 2011). In a qualitative study, taking a phenomenological approach, Nystrom (2011) conducted eight interviews to explore the consequences of being closely related to a PWA. The author suggests that a large proportion of PWA are primarily supported by informal carers being dependent
upon family members, close friends and carers for care and support. She concludes that living with the individual with such a communication disability can result in being used as a bridge between the person and the surrounding world. Advancing age and possible declining medical and mental health of the carer can increase anxiety for patient and family (Nystrom, 2011).

Halle & Le Dorze (2014) interviewed 12 significant others of persons who became aphasic as a result of a stroke with the aim of understanding their experience of aphasia rehabilitation. The authors revealed that the rehabilitation process was focused upon the needs of PWA, with minimal consideration of their caregiver needs. Given the pivotal role family members or carers play in the rehabilitation and adaptive process for PWA, this is concerning. Halle & Le Dorze (2014) conclude that a greater sensitivity to significant others is required from rehabilitation professionals, especially SLTs, to assist families in re-establishing functional communication. Carers and PWA frequently suffer from anxiety, depression and a reduced quality of life, with marital and family relationships and an individual’s role within the family all subject to significant change (Hilari & Botting, 2011).

Given the evidence above, improving the quality of life for the person with aphasia and their families has to be an important goal of any intervention. Despite existing literature demonstrating the pervasive and significant effects of aphasia on family members, rehabilitation programming, policy and funding are not well developed.

2.1.3 Impact of aphasia on the rehabilitation process
The persistence of aphasia is an obstacle to the rehabilitation progress and can have a significant impact on quality of life, not only for the person themselves, but also their family, friends, colleagues and carers. There is evidence that PWA spend less time in communication and more time alone than people without aphasia (Godecke, Armstrong, Hersh & Bernhardt 2014). PWA may experience a longer length of stay in hospital (Gialanella & Prometti 2009) and increased morbidity and mortality than those without aphasia (Hilari 2011). Guyomard, Fulcher, Redmayne, Metcalf, Potter & Myint (2009) conducted a large retrospective database study of men and women with stroke admitted to the hospital between 1997 and 2001. Aphasia was present in 41.2%, of patients studied: dysphagia (swallowing difficulty) in 50.5%, and 27.7% had both conditions.
Having either or both conditions was associated with greater mortality and longer length of hospital stay. Hersh (2016) discusses the impact of aphasia during the early period post stroke, with a particular focus upon the transition from hospital to home. She describes patients’ experiences of this transition process, which can be stressful and uncertain, PWA feeling removed from the discharge planning and decision making process due to their communication limitations. Hersh (2016) endorses the need to involve PWA more actively in their rehabilitation in order to increase the efficiency and effectiveness of interventions.

The presence of communication disorders has been linked to increased risk of experiencing an adverse event in hospital. Hemsley, Werninck & Worrall (2013) used a narrative method of inquiry to describe adverse events experienced or witnessed by PWA and their spouses in a hospital setting. Inappropriate discharge home, or an inadequate discharge plan, was the most commonly occurring adverse events. The authors conclude that these events were distressing to participants and recommended that hospital procedures should better recognise the impact of aphasia on an individual’s ability to access information provided and participate in decision making. Hemsley et al. (2013) identified higher rates of medical errors and reduced accessibility to health care for people with communication disorders.

Given this evidence, it is arguably accurate to surmise that the presence of aphasia can add significantly to the cost of stroke-related care. A study undertaken in South Carolina USA, by Ellis, Simpson, Bonilha, Mauldin & Simpson (2012) with a cohort of individuals who had suffered an ischaemic stroke, examined the contribution of aphasia to the cost of care. The study of 3200 patients identified that those with aphasia incurred a greater cost of their care than those with no obvious communication disorder. The authors propose this is due to increased cost related to length of stay, increased support required on discharge from hospital and related post stroke disorders, for example depression. These findings are important given the increasing limitations on health and social care budgets: they also help to understand the complexity of variables that contribute to aphasia rehabilitation.

Aphasia is also reported to be one of the most feared outcomes after stroke. Hilari, Northcott, Roy, Marshall, Wiggins, Chataway & Ames (2010) explored the factors that
predicted psychological distress in the first six months post-stroke, in a sample including PWA three months post-stroke. 93% of those with aphasia experienced high distress, compared to 50% of those without aphasia. Hilari (2011) explored stroke outcomes for those with and without aphasia and concluded that PWA participated in fewer activities and reported a more negative quality of life than those with a stroke but no aphasia, thus potentially impacting on the individual’s ability to respond positively to rehabilitation.

2.2 The role of Health Care Professionals with people with aphasia

When working with PWA, the SLT will often be working as part of a Stroke or multi-disciplinary team (MDT), following a stroke care pathway, of which aphasia will be a component part. This is regarded as fundamental to delivering effective care across the stroke pathway (Clarke, and Forster 2015) enhancing effective communication between healthcare staff and patients and helping to maintain patient safety. The National Stroke Strategy (2007) emphasises the need for inter-disciplinary input at the key points of the stroke journey.

The role of the multi-disciplinary team (MDT) is the preferred model of service delivery within stroke care, enhancing decision making and co-ordination of care, resulting in improved outcomes for the client and their families (Tyson, Burton & McGovern 2014). A MDT approach involving a range of health care professionals, including SLT, physiotherapy, occupational therapy, stroke specialist nursing staff and clinical psychology, is considered to be one of the mechanisms that contribute to the enhanced outcomes of specialist stroke care over generalist services (Langhorne, Bernhardt & Kwakkel 2011). The authors argue that the more effective and organised the MDT is, the more positive the patient experience.

Clarke & Forster (2015) discuss the contribution of the MDT in improving stroke recovery, collaborative team working and a focused organisational culture being key contributors. They report that patients and families value information and explanations from the team members, and when this need is met, they are reassured, feel safe and have confidence in the team. A study conducted by Hewitt, Sims, Greenwood, Jones, Ross & Harris (2014) contradicts this suggestion however. The majority of the stroke patients and carers interviewed in this qualitative study were not explicitly aware or concerned about the
MDT workings; rather their main concern was that the appropriate intervention was provided in a timely manner. The authors conclude that the challenge is to:

“engage the patient and significant others as essential members of the inter-professional team” (Hewitt et al 2014,p8)

2.2.1 The role of SLT with PWA
SLTs play a unique role in identification and assessment of those with aphasia, central to this is the ability to identify levels of comprehension and expression as well as retained communication abilities. This implies the need for on-going and seamless availability of input, from the acute stage, to rehabilitation, and into the community. The International Classification of Functioning (ICF) is a useful framework to demonstrate the SLT aims for aphasia therapy

Impairment: To regain lost function, including understanding of language and ability to use expressive language.

Activity: To minimise communication disability by ensuring maximum use of current abilities. This may include compensatory strategies and alternative means of communication.

Participation: To enable participation according to individual’s circumstances and preferences, develop social skills and confidence, promote independence and decision making and increase social integration.

Wellbeing: To maximise individual’s sense of well-being and quality of life and facilitate the development of coping strategies.

The long term and wide reaching impact of aphasia has implications for the role of SLT. The PWA requires contact with a SLT, not just in the initial stages of recovery, but for some it is appropriate as part of the long-term care package. Enderby, Pandyan, Bowen, Hearndean, Ashburn, Conroy, Logan, Thompson & Winter (2016) argue that the rehabilitation potential for PWA should not only be considered early on, but needs to be reviewed on a regular basis over many months, if not years. Those who may not benefit from early intervention may well benefit at a later stage. The SLT may also be required to educate and work with other people in the life of the person with aphasia, which may
require input from SLT a number of years after the initial onset of aphasia (Enderby et al 2017).

The provision of SLT for stroke related communication difficulties, including aphasia, is a standard care procedure (Brady, Kelly, Godwin & Enderby, 2016) with the aim of improving language functions and communicative abilities and assisting with the adaption process to living with aphasia, as described above.

Aphasia rehabilitation is co-ordinated by the SLT, the process including assessment, differential diagnosis, intervention and onward referral to other agencies, reflecting the key stages of the aphasia care pathway (Verna, Davidson & Rose, 2009). Optimum timing and intensity of SLT have been studied widely, with minimal consistency in the evidence base regarding the optimum time to commence interventions (Foster, Worrall, Rose & O’Halloran 2016).

Evidence suggests that intensity of therapy can be a significant factor influencing outcomes in aphasia treatment. A prospective, randomized controlled trial undertaken by Bakheit, Shaw, Barrett, Wood, Carrington, Griffiths, Searle & Koutsi (2007) in which aphasic stroke patients were randomly allocated to receive intensive or standard SLT for 12 consecutive weeks, concluded that intensive SLT, as delivered in this study, did not improve the language impairment significantly more than standard therapy.

A Cochrane Review, completed by Brady et al. (2016) with 39 RCTs involving 2518 participants, concluded that the potential benefits of intensive SLT over conventional intervention were confounded by significantly higher dropout rates from the intensive programme. Definitions of intensity and optimum length of an episode of care remain uncertain (Enderby et al 2017).

The impact of the communication changes for the individual and their families may necessitate support and intervention in different ways for a significant period of time (Power, Thomas, Worrall, Rose, Togher, Nickells, Hersh, Godecke, O’Halloran, Lamont, O’Connor & Clarke 2015). In this study, PWA and their families highlighted perceived gaps in the intervention they received, including reduced opportunity for intensive and long-term rehabilitation options as well as lack of timely and accessible health-related
information. Similar findings are reported by Worrall, Sherratt, Rogers, Howe, Hersh, Ferguson & Davidson 2011.

The long term and wide reaching impact of aphasia has implications for the role of the SLT. The individual with aphasia requires contact with a SLT, not just in the initial stages of recovery, but for some it is appropriate as part of the long-term management of PWA (Ferguson, Duffield & Worrall 2010).

2.3 Information needs about aphasia

Obtaining timely and relevant health information and resources is recognised as a crucial feature of understanding and beginning to accept the impact of sudden and life changing conditions such as stroke. A consistent theme in stroke related research is the need for more information about a patient’s progress and prediction of recovery. A Cochrane review completed by Forster, Brown, Smith, House, Knapp, Wright & Young (2012) concluded that providing information to stroke patients and their carers enhances their knowledge, and therefore satisfaction, and may reduce depression and anxiety. Furthermore, findings from a qualitative study conducted by Tyson, Burton, McGovern & Sharifi (2013), in which focus groups were used to collect data about the service users view on the post stroke rehabilitation processes, support the findings from Forster et al. (2012). Participants in this qualitative study required regular, consistent objective information presented in laymen’s terms, avoiding the use of health jargon. The results of this study have clear implications to improve clinical practice, notably the importance of providing timely, consistent post stroke information in an appropriate format. Aphasia intervention extends beyond treating the specific condition: it has to involve assisting families and friends in coming to terms with the significant changes to an individual’s ability to communicate, as has been discussed above. This will involve providing relevant and timely information.

A qualitative study undertaken by Avent, Glista, Walllace, Jackson, Nishioka & Yip (2005) used focus groups consisting of adult family members to identify information needed by families during initial rehabilitation and more chronic phases of aphasia. Family members who participated in this study rated timely information about aphasia as the most
important, followed by psychosocial support and hopefulness. The specific type of information required by families was dependent upon time since onset of the aphasia.

Hinckley, Hasselkus & Ganzfreid (2013) explored the perceptions of PWA and their families about the provision of aphasia related information. Responses to an online survey and focus group themes revealed that accessing information remains difficult, several years after the work completed by Avent et al. (2005). Participants in the 2013 study reported a barrier to finding information and resources. PWA frequently did not recall the information they received in the early stages of their aphasia, while others reported that they were not able to understand the type of information due to the nature of their communication impairment and overall medical condition. Timely, appropriate, and meaningful information for all those involved in the management of aphasia remains an area of need. Hinckley et al. (2013) conclude by saying that PWA and their families do not receive all of the information they would like; further work is needed to ascertain the format, timing and availability of relevant resources.

2.4 Enabling PWA to contribute to rehabilitation decision making

Patient or client-centred care has, for a number of years, been widely accepted as an essential component of health care delivery, with the core aim of establishing a partnership among practitioners, patients, and their families, to ensure that service planning decisions respect patients’ preferences (McPeake, Quasim & Daniel 2014). The increase in patient and public involvement (PPI) care has been promoted by a number of policies and guidelines, to ensure those directly involved in the receipt of healthcare have an opportunity to consult and collaborate on what is provided, how it is provided and what changes are needed.

The NHS Patient Experience Framework (Department of Health, 2011) highlights the importance of care providers having patient centred values, respecting preferences and expressed needs, the provision of emotional support and welcoming the involvement of patients and their family and friends. Policy drivers have continued to recognise that quality of care not only depends on the treatment given, but also the way in which it is delivered. It is now firmly embedded in UK healthcare policy that service users must be involved in decision-making with regard to service design and delivery.
Within these political drivers, there has been increasing engagement with service users in healthcare design. McPeake et al. (2014) discuss the unique perspective people receiving care will have and the importance of ensuring that the service user has an opportunity to engage in the decision making process. This should include involvement in the design of research tools, information sources and questionnaires. The authors emphasise that the ultimate aim is to improve care, however they do also stress the need to ensure any interaction is meaningful and not just a token gesture. The impact of any feedback given by the service user must be transparent and it is also important to recognise that involving service users needs careful planning; the logistical difficulties should not, however, be underrated.

To explore an aphasia care pathway, it was essential to ask for the opinion of those directly involved with it, notably PWA themselves. This group are, however, often excluded from stroke related research, despite the fact that they will have significant opinions, experiences and recommendations to make. Brady, Frederick & Williams (2013) highlight the degree to which people with aphasia have been excluded from full participation in some areas of stroke research. The authors propose that the option to make reasonable adjustments to research documentation and procedures should enable many PWA to participate. The validity and the potential impact of any exclusion of people with aphasia from stroke research should be closely considered in relation to the impact it may have on the evidence base for this group of people. This is not routinely occurring. Rosewilliam, Sintler, Pandyan, Skelton & Roskell (2015) conducted a study to explore practice of goal-setting for patients in acute stroke but excluded people with communication difficulties. Patients were eligible to be included in this study if they were medically stable, had intact cognition and reasonably understandable communication; this latter point was not defined. The frequently made supposition that people with aphasia lack the capacity to make decisions for themselves, and thus also be involved in research, is flawed and has the potential to lead to inequalities in access to care and involvement in evidence based practice decisions and research.

Jayes & Palmer (2014) conducted a study to explore the experiences of stroke research staff in seeking consent from people with communication difficulties: they concluded that for research staff to work more effectively with this population, study protocols need to
be more inclusive of people with communication difficulties. In addition, researchers require effective access to ethically approved, accessible communication resources and appropriate training (Brady et al. 2013). PWA are typically excluded from studies due to their assumed inability to give informed consent to participate, to complete self-report mood scales or psychiatric interviews. The authors argue that PWA can and have been, included in post stroke research by using adaptive or, modifying measures. One example quoted by Hilari et al. (2010) is the use of visual analogue scales: the authors also make recommendations about how stroke research needs to change to ensure the valuable views of people with communication difficulties are included.

Of 14 randomized controlled trials included in a Cochrane review completed by Foster et al. (2012) investigating at the provision of information to stroke patients and their carers, only one included people with aphasia. Brady et al (2013) highlight the degree to which PWA have been excluded from participation in some areas of stroke research and the potential clinical consequences. They discuss the need for the provision of more accessible research information and clear, accessible consent processes, to enable PWA to participate in a meaningful way. The authors also advocate the importance of considering the benefits to stroke research of inclusive and accessible research approaches.

The National Institute for Health Research (NIHR) Clinical Research Network for stroke (2014) recognised that not enough PWA were involved in their research studies. Funding to engage a stroke and aphasia specialist to develop aphasia resources has been recognised as a priority. These resources, designed to assist researchers to be more inclusive and enable patients with aphasia to engage in research, include signposting to existing sources of help, advice to facilitate communication, and a set of phrases and matching images which can assist with writing stroke research information. There are also templates which can be populated with the details of a research project, thus assisting in creating accessible documents for all stages.

Having provided evidence to explain the impact of aphasia and the importance of including PWA in research, the next section will discuss the strategy employed to identify the evidence base for aphasia care pathways.
2.5 Search strategy

A comprehensive, systematic review of the literature was conducted using logical search terms to examine relevant electronic databases, to address the first objective of this programme of study. This was to conduct a comprehensive review of the literature into clinical care pathways, with particular reference to those used for people with aphasia following a stroke.

This review has followed a structure recommended by Greenhalgh (2010). A specific search strategy was applied and studies were selected according to inclusion and exclusion criteria, as illustrated in table 2.1 below.

Table 2.1 Inclusion and exclusion criteria

<table>
<thead>
<tr>
<th>Inclusion criteria</th>
<th>Exclusion criteria</th>
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<tbody>
<tr>
<td>• Peer review journals</td>
<td>• News articles</td>
</tr>
<tr>
<td>• Primary research focusing on care pathways and aphasia</td>
<td>• Letters to the editor</td>
</tr>
<tr>
<td>• Articles published between 2000 and 2015</td>
<td>• Articles describing aphasia therapy</td>
</tr>
<tr>
<td>• Articles published in English</td>
<td>• Care pathway articles with a very specific medical focus</td>
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</tbody>
</table>

The literature search aimed to generate a comprehensive list of relevant primary research related to the study title. Sources of evidence searched included electronic bibliographic databases, journal periodicals and forward tracking using citations within articles recovered. This review only considered English language publications and included research published in Australia, Canada and USA. Literature continued to be collected and assimilated into the literature review until March 2017.

Three electronic databases were searched, as illustrated in table 2.2, Pub Med, CINAHL and Psychinfo, selected as being the most relevant for the subject matter.
Table 2.2 Electronic databases searched

<table>
<thead>
<tr>
<th>Database</th>
<th>Description</th>
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<tbody>
<tr>
<td>Pub Med</td>
<td>This includes over 18 million citations from MEDLINE and other life science journals for biomedical articles back to the 1950s</td>
</tr>
<tr>
<td>PsycINFO</td>
<td>An abstract database of psychological literature from the 1800s to the present day.</td>
</tr>
<tr>
<td>CINHL</td>
<td>Nursing and Allied Health database. Updated bi-monthly. Mostly English language nursing journals.</td>
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</tbody>
</table>

A search of the Cochrane Library for systematic reviews was also completed.

In addition to searching electronic resources, hand searches of relevant journals were also made. This involved reviewing journals and books by hand, using online alerts, in order to identify relevant publications. The reference citations of all retrieved publications were searched manually to maximize the evidence retrieved to inform the review. A list of the journals searched manually is provided in table 2.3.

Table 2.3 Journals searched manually

<table>
<thead>
<tr>
<th>Journal</th>
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<tbody>
<tr>
<td>• Aphasiology</td>
</tr>
<tr>
<td>• Clinical Rehabilitation</td>
</tr>
<tr>
<td>• Disability and Rehabilitation</td>
</tr>
<tr>
<td>• International Journal of Language and Communication Disorders</td>
</tr>
<tr>
<td>• International Journal of Speech and Language Pathology.</td>
</tr>
<tr>
<td>• Journal of Speech, Language, Hearing Research</td>
</tr>
<tr>
<td>• Stroke</td>
</tr>
<tr>
<td>• Bulletin of the Royal College of Speech and Language Therapists.</td>
</tr>
</tbody>
</table>
2.5.1 Search terms

The search terms used were “care pathway”, “aphasia” and “service delivery”. These were then combined with the clinically relevant terms stroke and Speech and Language Therapy. MeSH headings for each database were searched, as shown in table 2.4.

Table 2.4 MeSH headings

<table>
<thead>
<tr>
<th>Terminology</th>
<th>Medline</th>
<th>CINAHL</th>
<th>Pscych</th>
</tr>
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<tbody>
<tr>
<td>Aphasia</td>
<td>Aphasia</td>
<td>Aphasia</td>
<td>Aphasia</td>
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<tr>
<td></td>
<td>Brocas aphasia</td>
<td>Brocas</td>
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<td></td>
<td>PPA</td>
<td>Aphasia conduction</td>
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<td></td>
<td>Conduction aphasia</td>
<td>Aphasia trans cortical</td>
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<tr>
<td></td>
<td>Wernicke’s aphasia</td>
<td>Aphasia anomia</td>
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<td></td>
<td></td>
<td>Landau Keiffer Synd</td>
<td></td>
</tr>
<tr>
<td>Care pathway/</td>
<td>Integrated pathway</td>
<td>Critical pathway</td>
<td>Critical pathway</td>
</tr>
<tr>
<td>Clinical pathway</td>
<td>Care map</td>
<td>MDT care</td>
<td>Delivery of h/care</td>
</tr>
<tr>
<td></td>
<td>Critical pathway</td>
<td>Neural pathway</td>
<td>Integrated service</td>
</tr>
<tr>
<td></td>
<td>Clinical pathway</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Service delivery</td>
<td>Delivery of healthcare</td>
<td>Health service needs</td>
<td>H/care delivery</td>
</tr>
<tr>
<td></td>
<td>Delivery of integrated care</td>
<td>Evidence based pathway</td>
<td>H/care accessibility</td>
</tr>
</tbody>
</table>

2.5.2 Search results

The initial database search identified 570 results for care pathways and 7814 articles for aphasia. These two key terms were combined and three articles were obtained across the three databases, all relating to post-stroke depression and aphasia, and were therefore excluded. MeSH headings were then applied to the two key terms, aphasia and care pathway, providing only one result referring to depression, and so also excluded. Boolean operators “and”, “or” and “not” were applied.
The search was then extended to include stroke and care pathways, stroke being the biggest causal factor of aphasia (Hallowell and Chapey 2008). Thirteen results were obtained, and when the title and abstract were reviewed seven were selected. Given the limited number of articles relevant to review, a further search was undertaken applying the wildcard principle, *speech therap?* and *care pathway*, providing six further articles relevant to review. A final search was undertaken applying the terms aphasia and journey, with the limits applied, five articles were accessed. A total of seventeen articles were selected (see appendix 2), following application of CASP (see section 2.5.2 below) three of these articles were excluded.

Following this initial literature search, electronic alerts were set up, to ensure any newly published evidence relevant to the subject matter could be critically reviewed and included, as relevant. Onward searching and hand searching of relevant evidence was also conducted.

2.5.3 Quality Appraisal

Critical appraisal, the process of systematically appraising and applying clinical evidence, is an essential part of evidenced-based clinical practice (Dollaghan 2010). To assist the critical appraisal of the chosen articles identified in this literature review, studies and reviews were evaluated using criteria from a qualitative checklist (Greenhalgh 2010) and the critical appraisal skills programme (CASP, 2013). This strategy was applied, enabling a systematic and consistent appraisal of all papers.

The qualitative checklist included the following questions:

- Was there a clearly formulated question?
- Was a qualitative approach appropriate?
- How were the setting and participants selected?
- What data collection methods were used, were they described in sufficient detail?
- What method of data analysis was used?
- What quality control measures were used?
- Are the results clinically important?
- Are the conclusions justified by the methods used?
- Are the findings transferrable to other settings?
2.6 Appraisal of the literature

This section examines the literature relating to the development of clinical care pathways within the NHS, before focusing specifically upon aphasia care pathways. Evidence identified within this literature review has been summarised in an evidence table listing key characteristics of individual studies and the level of evidence, (appendix 2).

There is no one universal definition of a care pathway. For the purposes of this study the definition to be used, based on that provided by De Bleser, Depreiter, De Waele, Vanhaecht, Vlayen & Sermeul (2006) is:

“a plan of care which aims to achieve a continuum of care, improving quality, reducing risk, increasing patient satisfaction and optimising the efficient use of resources” De Blesser et al. (2006) p652

2.6.1 Care pathways in the National Health Service (NHS)

Clinical or care pathways are increasingly being used in health care settings as a structured plan of care, which can be easily shared with patients and families and designed to implement clinical guidelines and protocols. Within local NHS services there are established and extensively used care pathways, for example falls, diabetes, stroke and end of life care pathways.

First introduced within the NHS in the 1980’s, clinical care pathways, integrated care pathways (ICPs) patient journeys and care maps are interchangeable terminologies to describe tools which promote organised and efficient patient care, based on the best available evidence and guidelines (De Bleser et al. 2006). A care pathway defines the essential steps in the care of patients, with the aim of making a specific diagnosis, organising and improving the quality of care and providing learning tools for all those involved in following the pathway.

Parker, Claridge and Cook (2005) applied a mixed methods approach to investigate the attitudes of HCPs about the use of ICPs within stroke care. Findings from a survey, interviews and focus groups, suggested a negative attitude towards care pathways. HCPs were not in favour of their professional autonomy being questioned, with junior staff
more sceptical about care pathways than senior staff. The authors concluded that the involvement of staff at all levels is paramount when developing an ICP.

Evans-Lacko, Jarrett, McCrone & Thornicroft (2010) summarise the important parameters of a care pathway which include referral, diagnosis, interventions, and discharge planning. The authors promote the importance of including all levels of staff in pathways development and evaluation, facilitating continuous improvements and ensuring the care pathway allows for multifaceted interventions.

There is a body of evidence to support the effectiveness of care pathways for specific diagnostic groups of patients. A study to develop and implement a Care Pathway framework for people with Parkinson’s disease (PD) and their carers, to facilitate more comprehensive and integrated health and social care, was undertaken by Holloway (2006). The contribution of a PD care pathway to the management of the illness was evaluated through semi-structured interviews with participants and their carers and focused interviews with the participating neurologist and specialist nurse. The people with PD and their carers were positive about the Care Pathway, in particular, a problems and needs form, which they felt facilitated active engagement in their own care and improved communication about the short and longer term aims of interventions. The neurologist and specialist nurse were equally enthusiastic, reporting benefits relating to increased multi-disciplinary working and communication and reduced duplication of information. The National Institute for Clinical Excellence (NICE) include a care pathway for people with Parkinson’s Disease; this includes sections relating to referral, diagnosis, intervention and management and palliative care.

There is evidence, from systematic reviews of the care pathways for total knee and hip replacements, that they can be effective in improving the quality of care and promoting multi-disciplinary team working. Kim, Losina & Solomon (2003) compared the outcomes of total hip or knee arthroplasty for patients who were treated using clinical pathways as opposed to patients treated without these pathways. Kim et al. (2003) concluded that clinical pathways were successful in reducing costs and length of stay in the acute care hospital, with no compromise in patient outcomes. However, interpretation of these studies is complicated by substantial methodological limitations, particularly the use of historical controls and failure to account for length of stay in rehabilitation facilities.
meta-analysis of care pathways, conducted by Barbieri, Vanhaecht, Van Herck, Sermeus, Faggiano, Marchisio & Panella (2009) demonstrated that clinical pathways can improve the quality of care, although it was not possible to conclude that the implementation of clinical pathways is a cost-effective process. This was because the studies analysed did not include the cost of the development and implementation of the pathways. Based on the results obtained, Barbieri et al (2009) concluded that clinical pathways for hip and knee replacements have a positive impact on the organisation of care if the care process is structured in a standardised way, teams critically analyse the actual organisation of the process and the multidisciplinary team is highly involved in the re-organisation.

Care pathways for use with people with chronic obstructive pulmonary disease (COPD) have also been developed and evaluated. Lodewijcky, Sermus, Panella, Denecker, Leigheb, Decramer & Vanhaechetand (2011) undertook a systematic review, the aim of which was to explore characteristics, impact and outcomes of care pathways for COPD care. The studies described some benefits of a care pathways model, for example, positive effects on blood sampling, daily weight measurement, arterial blood gas measurement, referral to rehabilitation, length of stay, readmission, and in-hospital mortality. However, the studies reviewed by Lodewijcky et al. (2011) described few positive effects of the care pathways on diagnostic processes or on clinical outcomes. Due to limited statistical analysis and weak design of the studies, the internal validity of results is limited. Therefore, based on these studies, the authors concluded that whilst benefits of a care pathway for COPD can be identified, the evidence is inconclusive, indicating a need for further trials.

O’Brien, Whitehead, Jack & Mitchell (2011) conducted a qualitative study to explore the diagnostic experiences of people with Amyotrophic Lateral Sclerosis (ALS), also known as Motor Neuron Disease (MND) and the potential value of a care pathway for this progressive condition. Face-to-face interviews with people with ALS were completed: current and former family carers were also interviewed. Findings indicate that the diagnostic experience was unsatisfactory and distressing. There was failure to recognize the significance of some symptoms by patients, carers and primary and secondary care health professionals, which ultimately delayed diagnosis. Delivery of the diagnosis was frequently unsatisfactory despite international guidelines on the subject. Immediate post-
diagnosis support often compared negatively to that provided for people with cancer. This study, by O’Brien et al. (2011) illuminates the need for a clinical care pathway for people with ALS/MND, as identified by those with direct experience of the condition.

In other clinical areas, the evidence in favour of care pathways is less convincing. There has been considerable debate regarding the role of end of life care pathways, developed as a model to improve care of patients who are in the last days of life. The care pathways were designed with an aim of ensuring that appropriate management occurs at the appropriate time and is provided by the most appropriate health care professional. A systematic review of end of life care pathways was undertaken by Costantini, Alquati & di Leo (2014). The authors screened 3028 titles and included one Italian cluster RCT in the systematic review, which concluded that there is limited available evidence concerning the clinical, physical, psychological or emotional effectiveness of end-of-life care pathways. The authors conclude that the evidence supporting the role of such care pathways is currently limited and further research is needed to understand their potential benefits.

2.6.2 Stroke care pathways
A number of studies have been conducted with the aim of evaluating the effectiveness of care pathways within stroke care. A systematic review, completed by Allen & Rixson (2008) investigated the strength of evidence to support the effectiveness of care pathways in stroke care. The authors reported on five studies and concluded that stroke care pathways can be effective in ensuring patients receive timely and appropriate assessment and intervention, as well as impacting positively upon the length of hospital stay. Limitations of care pathways were identified by Allen & Rixson (2008) including a lack of flexibility to meet diverse patient need of the stroke patient or pay insufficient attention to carer needs. The authors also state that it is unclear whether the economic benefits of care pathways justify the cost of their implementation. A cluster randomized trial, investigating the effectiveness of stroke clinical care pathways, was conducted by Panella, Marchiso, Brambilla, Vanhaecht & Di Stanislao (2012). The study involved the random allocation of patients into either a stroke care pathway group or a usual care group. The main finding of this study was:
“Care delivered using care pathways to patients with stroke was significantly more evidence based than that delivered to patients with stroke receiving usual care and this seemed to translate to more effective treatment, because implementation of care pathways resulted in a significant improvement in outcomes”, (Panella et al 2012, p6).

A qualitative study, aiming to identify the experiences of patients, carers and staff involved with a hospital stroke care pathway, was undertaken by Morris, Payne & Lambert (2007). Focus groups and semi-structured interviews were used to obtain participants’ opinions. The researchers did not however, include senior managers in the professionals groups’ selection, thus potentially important and significant data was omitted and opportunities to discuss the wider context of the service and influences of clinical and policy guidelines, lost. Four themes were identified by Morris et al. (2007) information, staff attitudes, availability of care and considering the whole person in context. The carers group identified an additional theme of burden of care. Morris et al (2007) proposed that care pathways, within stroke care, facilitate multidisciplinary structured care, time-specific clinical interventions and a definition of the responsibilities by discipline. This study has contributed to the development of stroke clinical service guidelines and service configuration.

The impact of care pathways on the end of life care following stroke, was explored by Cowey, Smith, Stott, McAlpine, Mead, Barber & Walters (2014). A mixed methods study was used, integrating qualitative interviews with a quantitative case note review. Relatives of deceased stroke patients and health care professionals were interviewed: a multivariate analysis was performed on case note data. Findings suggest that family views strongly influenced end-of-life care and that while involving families in these decisions is paramount, clinicians should avoid giving families the impression they are being asked to make major decisions. Written information was useful for some families but not for all; more important was rapid easy access to staff to provide personalised support and advice. Cowey et al. (2014) conclude that clinicians should continue to involve families in shared decision making and whilst care pathways can provide the framework for this, they should be used flexibly.
2.6.3 Aphasia care pathways

The nature of services for people with aphasia has been a subject of considerable discussion over recent years. Variability in service delivery has been identified at local, national and international levels (Verna, Davidson & Rose 2009). Along the continuum of care for PWA, the delivery of services is likely to be either individual, or group interventions or a combination of these. A multinational study conducted by Katz, Hallowell, Code, Armstrong, Roberts, Pound & Katz (2000) examined access, diagnostic, treatment, and discharge patterns of patients with aphasia in Australia, Canada, United Kingdom and America. The study found international variation; Australian SLTs provided the least amount of group therapy service compared to those working in UK, Canada or America. Current data on types of intervention provision is limited.

There is currently minimal evidence or agreement to support the specific format or role of an aphasia care pathway. A literature search, combed the key terms care pathway and aphasia, identified articles relating to post-stroke depression and aphasia and were therefore excluded from this review. Recommendations about aphasia-specific processes were also lacking. The Royal College of Speech and Language Therapists, RCSLT (2014) aphasia guidelines, provide the most comprehensive coverage for aphasia management (Rhode et al. 2013) however does not include any specific reference to an aphasia care pathway. Evidence-based practice is increasingly becoming embedded into the delivery of effective health care, however, as argued by Worrall, Thomas, Rohde, Rose, Togher & Ferguson (2013) further research and application of findings into interventions for PWA, is needed.

Power, Thomas, Worrall, Rose, Togher, Nickels, Hersh, Godecke, O'Halloran, Lamont, O'Connor & Clarke (2015) utilised the Delphi Technique (Earl Slater 2004) to develop a framework of care in aphasia rehabilitation. This technique includes a number of individuals across diverse locations and areas of expertise, who are asked to comment on a number of questions. It is a structured process, using a series of email or internet cycles until group consensus is reached. In the study, conducted by Power et al. (2014), panellists included SLTs, researchers, service managers, clinicians and policymakers in Australia. Using this methodology, the researchers illuminated eight domains of care relating to aphasia management:
- Receiving the right referrals
- Optimising initial contact
- Setting goals and measuring outcomes
- Assessment
- Providing interventions
- Enhancing the communication environment
- Enhancing personal factors
- Planning for transition

(Power et al 2104 p 7-10).

Within each of these eight domains, a number of sub headings were identified. The authors aim is for these domains and statements to form crucial components of an Australian Aphasia Rehabilitation Pathway.

Rose, Ferguson, Power, Togher & Worrall (2014) reported on aphasia rehabilitation practices of SLTs in Australia, using a web based survey to gather information about key practices along an aphasia care pathway. The study revealed a number of findings including the wide variation in approaches to aphasia rehabilitation dependent upon the client’s needs and their specific situation, the need to educate community and health care practitioners to improve communication access for PWA and the significant challenges in working within aphasia rehabilitation. The authors advocate that an Australian Aphasia Rehabilitation Pathway is needed to drive change and further the evidence base to support interventions.

Within a care pathway, aphasia becomes something that can be measured. Arguably, valid and reliable data collection supports the development of equitable clinical service delivery (Law, Rush, Pringle, Irving, Huby, Smith, Conochie, Haworth & Burston, 2009). Stroke service users have identified they require information about the purpose of key stages in the treatment processes, notably assessment, goal setting and outcomes (Tyson, et al. 2014).

The terminology used to describe the journey for a PWA has been investigated. Ferguson, Worrall, Davidson, Hersh, Howe & Sheratt (2010) explored the metaphors used by PWA, family members and SLTs to describe their experiences of aphasia rehabilitation
and recovery, with the words “journey” “battle” and “product” being the most frequently used metaphoric concepts expressed by the 18 participants interviewed. The authors conclude that it is important for clinicians to reflect upon the variation in terminology between their perspectives of the rehabilitation process or care pathway and those of their clients and families. Pathways may be considered a clinical term, journey may be a more appropriate description from the clients viewpoint. These findings provide alternative terminology to use with PWA when asking for their view and experiences.

2.7. The implications of the literature review for clinical practice
The evidence suggests that clinical care pathways can provide patients, families and health care professionals with clear expectations of care, provide a means of measuring progress and outcomes, promote team-working and facilitate evidence based practice. In order to achieve adequate implementation the potential barriers must also be considered, planned for and incorporated directly into the pathway with full engagement among clinical and management staff.

Within stroke care, pathways are used within the acute and early rehabilitation stages of a patient journey (RCP Stroke guidelines, 2016). However, this systematic literature review has not sourced any evidence for a pathway for aphasia. Whilst SLTs provide interventions for PWA, there is limited guidance for working with the complex condition of aphasia to implement best practice across the continuum of care. An evidence based aphasia care pathway, in a format that can be shared with those who are directly involved in its implementation, would enable clinicians to more explicitly and consistently implement evidence-based practice and demonstrate clinical effectiveness. An accessible version of an aphasia care pathway would provide a valuable mechanism for including the PWA directly in their therapeutic care.

2.8 Aims and objectives of the aphasia care pathway study
The national drivers for stroke care in the UK, notably the NICE Stroke Guidelines (2010) and The Royal College of Physicians (RCP) Stroke Guidelines (2016) state that a transparent and timely service for people with aphasia should be provided, however, there remain questions about the way the services are delivered.
Consequently, the work detailed in this thesis, evaluates an aphasia care pathway in the South East region of the United Kingdom. It illustrates the perceptions and experiences of stakeholders in the pathway and helps contribute to the knowledge base of an SLT specific pathway as well as provide information at a more general care pathway level.

2.8.1 Research aim and question
The study aimed to explore and illuminate, through a mixed methodology, the experiences and use of an aphasia care pathway from the perspective of the service user receiving the pathway and health care professionals delivering care, to address the research question “Is a specific Aphasia Care pathway necessary to provide a responsive, high quality and evidence based rehabilitation to PWA and their families”. As discussed in chapter 2, the current research does not include specific evidence for aphasia. This question was addressed through the following objectives.

2.8.2 Research objectives
- To undertake an exploratory qualitative study to illuminate the experiences and perceptions of people with aphasia and their carers, receiving post stroke aphasia interventions and of health care professionals (HCPs) delivering care pathways.
- To use the qualitative data to inform and develop a survey to measure the use of an aphasia care pathway by SLTs
- To undertake a descriptive survey of SLTs practicing in the United Kingdom, to determine the number of therapists working with PWA using an aphasia care pathway, its strengths, limitations and future developments.
- To identify how the aphasia care pathway could be improved through experiences of the stakeholders.
- To recommend what an aphasia care pathway should look like and how could it most effectively be communicated to those who need to use it.

Objectives one and two were considered through a qualitative design, using focus groups and interviews to collect the data, objective three was measured through a quantitative design, using a survey to SLTs working with PWA. Findings from the qualitative and quantitative data were synthesised and explored further, using a mixed methods approach.
2.9 Summary

This study is concerned with the significance of an aphasia care pathway. The literature review here adds to the growing body of knowledge about the role and value of care pathways within the NHS. It also highlights that the evidence for an aphasia care pathway is limited, suggesting further research is needed. Given the incidence of aphasia and the impact upon the individual, family members and professionals working with PWA, this needs to be explored and described so that the interventions and support can be enhanced. This in turn may provide a method for providing an accessible version of a care pathway that can be shared. A mixed methodology, using sequential embedded, exploratory design was appropriate, in order to meet the aims and objectives of the study.

The following chapter will discuss the mixed methodology and the qualitative arm to the study.
Chapter 3: MIXED METHODS DESIGN – the qualitative study

This chapter details the qualitative methodology applied in this study and the findings from the data collection. The chapter consists of eight sections:

- An introduction to mixed methods and qualitative research
- Sampling procedures for the qualitative element of the study
- Recruitment methods
- Qualitative data collection procedures
- Ethical considerations
- Data analysis procedures
- Results of the qualitative data collection
- Discussion and conclusions

3.1 Introduction to mixed methods research

In order to explore an aphasia care pathway from the perspectives of people involved in its implementation, it was necessary to select a methodology that gave members of this population an opportunity to describe their experiences richly and openly, in order to ensure the data collected reflected their perspectives and histories. For this type of exploratory research, aiming to describe personal perceptions, a qualitative methodology was selected. In order to add breadth to the research and provide a measure of the use of aphasia care pathways within the SLT profession, a quantitative study was also conducted. Each of these two research approaches provides distinctive, yet complimentary evidence and combined, they offer a perspective to inform both policy and practice (Ritchie, Lewis, McNaughton & Ormston 2014).

Historically there has been academic debate about the incompatibility of qualitative and quantitative research, due to the supposed fundamentally opposing philosophy (Glogowska 2011). Qualitative research has been linked with an interpretivist view, where knowledge is produced by exploring and understanding the social world, focusing on meanings and interpretations. The research process is largely inductive, building knowledge by making observations to provide the basis for a theory or model of working. Quantitative research falls into a positivist paradigm, which assumes that the world is generally stable and predictable, conforming to common norms and patterns, where
knowledge is based upon careful and structured observations to confirm or disprove a hypothesis. Quantitative research typically addresses questions regarding effectiveness, causality, incidence and prevalence, diagnosis and screening. (Greenhalgh 2010).

Deductive logic is associated with the quantitative approach, a top down approach to the gaining of knowledge. In contrast, an inductive approach starts with specific observations and measures, forming patterns and ideas, from which tentative hypotheses may be formed. These are then explored, with the result that the process ends with the development of general conclusions or theories (Newell & Burnard 2011). The inductive approach is open-ended and exploratory. Within qualitative research, the inductive approach allows for the examination, analysis and interpretation of observations, for the purpose of discovering underlying meanings and patterns of relationships. This includes classifications of types of phenomena and entities in a manner that does not involve mathematical models (Newell & Burnard, 2011). Deductive reasoning is concerned with testing or confirming hypotheses, commencing with devising a theory relating to a topic of interest, producing hypotheses, which are then tested. Specific data is collected, analysed and used to confirm or disprove the original hypothesis.

Increasingly, it has being argued that the dichotomy between qualitative and quantitative research is a false one and that to answer a research question fully and effectively both approaches are necessary. This is supported by Ritchie, Lewis et al. (2014) who propose a “toolkit approach”, whereby the methodology is chosen for its aptness for answering the research question, rather than any pre-existing philosophical allegiance. Furthermore, Silverman (2011) emphasises the need to see qualitative and quantitative research methods as either complementary strategies, appropriate to different types of research questions, or viewing the same research question from different perspectives, to give a richer, more complete picture. Mixed methods research is the standard terminology for research where qualitative and quantitative methods are appropriate to answer the topic of interest (Creswell & Plano Clark 2011). It can provide the researcher with broader, deeper and more meaningful information, to maximise the strengths of the qualitative and quantitative approaches, to address questions that may be inadequately answered by one approach (Ozawa & Pongpirul, 2013).
3.1.1 Application of mixed methodology in research

Mixed methods research is increasingly being reported in journals and handbooks and a number of arguments justifying its use are emerging (Glogowska 2011). Given the increasing complexity of health care and the need for a range of methodologies to understand and evaluate these complexities, mixed methods has become more established as a valid approach. There has also been a growing recognition of the importance of understanding the impact of the delivery and organisation of health services, with a focus on processes as well as outcomes (O’Cathain, Murphy & Nicholl, 2007). Health care research can benefit from a mixed methods approach as it allows for triangulation of data, building a comprehensive picture, reducing the risk of bias and enhancing the validity of the findings. This is increased by checking the findings from one method against another. Whilst a quantitative approach can provide statistical data and trends and identify whether an intervention can work, it has a passive outcome and will not explain people’s experiences of a specific question. A qualitative approach can illuminate and provide an in-depth knowledge of the participants’ perspectives of a topic or activity (Creswell & Plano Clark 2007).

Within health care research, mixed methods research has made some significant contributions (Ozawa & Pongpirul, 2013). The approach permits the researcher to view problems from multiple perspectives and develop a more complete understanding of a clinical problem. It allows for service users experiences to be explored, whilst also understanding the extent of the situation. Mixed methods studies can enhance the depth of understanding by presenting various stakeholder perspectives and offer rationale for health systems performance, improving the usefulness of findings in e.g. clinical applications. For example, Glogowska (2011) provides an overview of the application of mixed methods research within the field of Speech and Language Therapy, arguing that it is appropriate given the multi-faceted questions within the field of communication disorders, be they developmental or acquired. Mixed methods can provide a more comprehensive and in-depth answer than a single method approach. Secondly, there are examples of studies within the field of stroke that have used mixed methods research. Clark (2009) argues that a more complete understanding of the stroke experience can be gained. Integrating quantitative and qualitative methods, through a mixed-method
research design, provides a more complete account of reality of living with stroke related difficulties. The quantitative data indicated that physical and cognitive disabilities were strongly and negatively associated with well-being following stroke, but the data did not provide an understanding of the reasons for this association. Results from the interviews helped to explain the underlying mechanisms by which residual physical and cognitive disabilities are associated with a reduced sense of well-being following stroke, self-identity and motivation. Clark (2009) proposes that the qualitative findings help to explain why functional independence score, a quantitative measure, may not accurately predict long term recovery.

Furthermore, Ekstam, Johansson, Guidetti, Eriksson & Ytterberg (2015) conducted a mixed methods study to explore the perceptions of the severity, personal factors, use of rehabilitation services and rating of caregivers burden for individuals directly affected by a stroke. Semi structured interviews, analysed using content analysis and a questionnaire, analysed statistically, were used. A strength of this study was the opportunity to compare perspective of need and dependency, with the caregiver burden providing valuable knowledge for future resource planning.

Bowen, Hesketh, Patchick, Young, Davies, Vail, Long, Watkins, Wilkinson, Pearl, Lambon Ralph & Tyrell (2012) completed a mixed methods study investigating the effectiveness of enhanced communication in the early stages of post stroke aphasia and dysarthria. The study involved a randomised controlled study (RCT) allocating participants to an intervention or control group, followed by a qualitative study, which was prospectively included to support the interpretation of the trial findings. Qualitative interviews with participants from both groups of the RCT provided rich detail on service users’ perceptions. The RCT data was analysed statistically using regression methods, whilst thematic content analysis was used to analyse the qualitative data, both leading to consensus that communication therapy had no added benefit beyond that from everyday communication in the first four months after stroke.

Grohn (2013) utilised a convergent, parallel, mixed method design, where qualitative and quantitative data were collected simultaneously to develop a comprehensive understanding of participants’ experiences of living with aphasia. Interviews were conducted and analysed using thematic analysis and a self-report assessment tool
developed to measure a range of outcomes and collect data for the quantitative component of the study. Qualitative and quantitative data were initially analysed and reported separately and then synthesised, by purposefully selecting two participants to be further analysed using a case study methodology. The synthesis of the quantitative and qualitative findings allowed the researcher to identify key factors, critical in attaining either a more positive or negative outcome at the end of the first year post stroke. This illustrates how mixed method research can be utilised to produce a holistic approach to the management of aphasia.

3.1.2 Categories of a mixed methods design

Four categories of mixed methods design are identified by Creswell & Plano Clark (2007).

Triangulation: used to obtain different but complementary data, the aim being to gain a thorough understanding of the research problem. It enhances the validity and credibility of a study, giving cross verification of the results and findings. Rutherford, Theadon, Jones, Hocking, Feigin, Krishnamurthi, Kent, Barker-Colli & McPherson (2014) report on a mixed methods study aiming to extend the understanding of the impact of stroke. Semi structured interviews explored issues of importance to stroke survivors and their family, the perceived impact on people’s sense of recovery, adaptation, future hopes and key strategies most helpful in living life after stroke. This qualitative component complemented the quantitative data, uncovering the richer detail of life as a stroke survivor.

Embedded: when one research design, qualitative or quantitative, plays a primary role and the other a secondary role. Campbell, Quilty & Dieppe (2003) used qualitative component to help explain results of a RCT to test the effectiveness of a package of physiotherapy treatment for osteoarthritis. The authors nested a qualitative study, to supplement clinical quantitative data, with information from patient reported outcomes and concluded that RCTs need reliable and valid patient based outcome measures to determine whether an intervention is effective.

Explanatory: qualitative data used to explain the quantitative results. This approach was used in a study by Victor, Ross & Axford (2004) as cited by Creswell & Plano (2007) where qualitative data from interviews and patient diaries provided valuable insight into the
patients’ perspective on the causes and impact of knee osteoarthritis. This data helped to explain data from a quantitative arm of the study trial that evaluated the effectiveness of a primary care-based patient education programme. The authors conclude that the results highlight the importance of synthesising information from both paradigms when evaluating complex interventions.

Exploratory: quantitative data used to explain the qualitative data, whereby the researcher explores how individuals describe a topic, beginning with interviews or focus groups before using the information to design and implement quantitative data collection. Cowey et al. (2014) used this approach to explore an end of life care pathway for people who had suffered a stroke, utilising themes from interviews with relatives and health care professionals to plan and implement a case note review. For example, emerging interview reports about inconsistent and inadequate weekend decision-making led to the inclusion of collection and analysis of specific days of the week when an end of life care pathway was used. This helped to identify clear processes in place within normal working hours, with inconsistencies of practice at weekends.

3.1.3 Mixed methods data analysis
Cresswell & Plano Clark (2007) provide guidelines for the analysis of mixed methods data, the exact methods used will depend upon the design used. Concurrent data analysis, appropriate for triangulation and embedded designs, involves conducting a separate initial data analysis for each of the qualitative and quantitative databases. The data sets are then merged to produce a complete picture of the topic of study. Sequential data analysis (Cresswell & Plano Clark 2007) applies to explanatory and exploratory designs, the purpose of which is to use information from the analysis of the first data set to inform the second data base.

3.1.4 Mixed methods purpose statement
Creswell & Plano Clark (2007) recommend that researchers use a mixed methods purpose statement, or study aim, to include the following issues: intent, design, data collection method and rationale. The statement for this programme of research is as follows:

The mixed methods study reported here addressed an aphasia care pathway from the perspective of different stakeholders: the design was used to gain service user experience
to inform a national quantitative survey. An exploratory, sequential mixed methods design (figure 3.1) was used in which qualitative data was initially collected, the findings of which informed the collection of the quantitative data. Sequential data analysis procedures were followed, data was analysed separately and then synthesised. In the study reported here, qualitative data explored the experiences and perceptions of the users of an aphasia care pathway: quantitative data was then used to define variables identified within the quantitative arm of the study. Collecting and analysing qualitative and quantitative data, determines the extent to which both sets of data converge, contradict, illustrate and explain the experiences of aphasia care pathway users.

Figure 3.1 Sequential embedded and exploratory design model

The aim of this study was to explore a local aphasia care pathway and collect data from SLTs practising in the field of aphasia about the use of care pathways nationally. It aimed to contribute to the understanding of the complexity of how PWA, carers and HCPs perceive the aphasia journey. To acquire this knowledge, a mixed methodology research was selected, to contribute to the understanding of the phenomena being studied, collecting and analysing qualitative and quantitative data. By using both quantitative and qualitative methods to explore the aphasia care pathway, the researcher sought to gain a more comprehensive understanding of the pathway experience. The rich qualitative data embedded in the experiences of the pathway users, obtained from focus groups and interviews informed the quantitative element of the research, the survey to SLTs. This ensured the survey questions were grounded in the experiences of the pathways users.

Qualitative research, as defined by Srivastava & Thomson (2009) is a
“process of understanding, based on distinct and methodological traditions of inquiry that explore a social or a human problem. The researcher builds a complex, holistic picture, analyses words, reports detailed views of informants and conducts the study in a natural setting.” (p 73)

It focuses on the beliefs, experiences and interpretations of participants, addressing psychosocial dimensions, aiming to gain an in-depth interpretation of the specific topic of research, gaining from participants’ detail of experiences, perspectives and histories (Ritchie, Lewis et al 2014). The frameworks for qualitative research questions aim at interpreting, understanding and explaining a wider phenomenon, to understand behaviour in a natural setting. Other goals attributed to qualitative research are understanding a phenomenon from the perspective of the research participant and understanding the meanings people give to their experience, “What” “How” and “Why” questions. What influences behaviours, why people behave the way they do, how people are affected by the events that go on around them, how opinions and attitudes are formed, why cultures and practices have developed in the way they have (Silverman 2010).

Within qualitative research an inductive approach is taken. Markham, van Laar, Gibbard & Dean (2009) promote the qualitative approach as encouraging participants to:

“Use the richness of their own words to explore and describe their experiences in relation to the research question” Markham et al. (2009) (p 749)

Qualitative research has its roots in philosophy and human sciences. The philosopher, Max Weber, regarded as one of the founders of sociology, played a key role in developing ethnographic research methods, the study of human behaviour within a culture, and was an advocate for the qualitative approach (Bowling 2014). The majority of early qualitative research was dominated by ethnographic and participant observation studies. Ritchie, Lewis et al. (2014) describe the strong research tradition that emerged from the grounded theory developed by sociologists, the purpose of which is to generate comprehensive explanations of phenomena that are grounded in reality.

Qualitative approaches have developed and evolved. Today it encompasses a range of techniques used in a naturalistic, interpretive way which are concerned with understanding the meanings people attach to phenomena e.g. actions, beliefs or values, within their social worlds. Data collected is observational and consists of the words,
artefacts and actions of those studied in an inductive approach. Qualitative research includes a range of techniques including observation, interviews, focus groups, biographical methods and analysis of documents and texts (Ritchie, Lewis et al. 2014). It is primarily concerned with practice and process rather than outcomes, focusing on the process that is occurring instead of the outcome of that process. The focus is on participants' perceptions and experiences and the way they make sense of their lives. For this reason qualitative research is conducted in the natural setting, typically involving fieldwork in which the researcher observes and records behaviour and events in their culture as it usually occurs.

Qualitative data analysis is inductive, as the depth of the data is more important than the recruitment of large samples. It is context specific, the aim is not to generalise findings, rather to provide an understanding and interpretation of the topic of debate or interest. A number of methodologies exist including Phenomenology, Grounded theory and Ethnography. Phenomenology aims to understand, constructs or concepts people use to give meanings to a particular phenomenon, whilst Grounded theory develops emerging theories by identifying categories from the data and relationships between them. The intention of Ethnography is to understand the social world of people, achieved by the researcher immersing themselves in the community to produce detailed descriptions of culture and beliefs.

Within this study, it was decided not to use one of the distinct methodological approaches described here. Instead, thematic analysis, using a thematic framework approach, was chosen as it emphasises the pinpointing, examining, and recording of patterns or themes within the data.

“Framework analysis provides an excellent tool to assess policies and procedures from the very people that they affect” (Srivastava & Thomson 2009 p 72).

The identification of patterns of meaning across a dataset assists in answering the research question. The aim of this study was to describe participants’ perceptions, rather than develop a theory of aphasia pathways, thus thematic analysis was appropriate to use.
The research process, including the sampling, data collection and analysis was set within an iterative framework. This involved frequent reflection following each data collection episode and refinement of interview and focus group questions as required. This cycle is fundamental to the aims and rigour of qualitative research, as it ensures a revisiting of the data as new and additional questions emerge, new connections are unearthed and a deepening understanding of the material develops (Bowling 2014). Consequently the researcher progressively refines and refocuses understanding of the issues being explored.

3.2 Ethical considerations

Within the National Health Service (NHS) it is mandatory for research studies involving patients to be reviewed by an ethics committee, whose principles are based on the World Medical Association Helsinki Declaration (1964).

The study was conducted according to core ethical principles of the Economic and Social Research Council (ESCR) Framework for Research (2012):

- Research should be designed, reviewed and undertaken to ensure integrity and transparency.
- Participation in the research must be voluntary: there must be no coercion or compulsion to take part.
- All those involved in the research must be fully informed about what their participation entails and the risks, if any, that they may encounter.
- Confidentiality of information provided during the research process is strictly respected, all data collected is anonymous
- Avoidance of personal or social harm is paramount

Ethical principles must be adhered to when undertaking qualitative research, as although it does not raise the same obvious adverse consequences as biomedical experiments, any research should not make unreasonable demands upon the participants (Bryman 2012). The protection of the participants’ interests, in matters of research, frequently relies on the professionalism and personal integrity of the researcher or the research team (Ritchie, Lewis et al 2014). Informed consent must be applied, participation must not involve coercion, anonymity and confidentiality should be preserved. Informed consent is
a mechanism for ensuring that people understand what it means to participate in a particular research study, so they can decide in a conscious, deliberate way whether they agreed to participate. It was mandatory that this was obtained from all prospective participants. The consent forms, available in appendices, were developed from the standardised versions issued by the Local Research Ethics Committee, they were personalised by using the title of the study. The participant and the researcher each signed this consent form. The original was securely stored and a photocopy was given to the participant.

3.2.1 Ethical approval

Ethical approval and sponsorship was sought from NHS Ethics (Berkshire B) Solent NHS Trust and the University of Portsmouth. Following minor revisions approval was granted. A copy of the ethical review and favourable opinion, received from the NHS, University and Health Trust can be found in appendix 3. The researcher ensured that procedures agreed by the ethical committee were strictly adhered to and that sensitivity was shown towards the participants as the nature and impact of an acquired communication disorder, such as aphasia, can result in an individual becoming distressed and agitated. The researcher should be mindful, during the data collection phases, of what the research means for the participant and consider from their perspective how they would want to be treated (Silverman 2010). These ethical principals were considered prior to and during the collecting data for this research project.

3.2.2 Ethical procedures

Information explaining the study was provided to all potential participants before they were asked to make a decision about taking part. It contained information describing the purpose and process of the study and was given to each potential participant who was approached to be in the study, to enable them to make an informed decision as to whether they wished to participate. Contact details for the researcher were also included in the information, enabling participants to make contact at any time to request further clarification, or if any queries arose. Information was provided in an accessible format for PWA to facilitate their ability to understand and retain the material and ask any questions. All information sheets, consent forms and the guidelines for referrers were
reviewed, before the study commenced, by relevant individuals and amendments made as necessary. Copies of the above are available in the appendices.

The information sheets also explained what to expect during the interview or focus group, including opportunities to bring a friend or family member to the venue, planned comfort breaks and the coverage and questioning to expect. Participants were advised in the information sheets that all sessions were to be recorded, to assist with accurate data analysis and that they could choose to leave the study at any time, without their decision affecting any treatment they were receiving.

3.2.3 Confidentiality and anonymity

The importance of confidentiality and anonymity of information shared at all times was made explicit in the information provided and reinforced in face to face contact. This is particularly relevant in qualitative research when information about personal experiences and feelings are being collected (Kuper Linguard & Levinson 2008). Qualitative studies challenge the anonymity of participants as the more information that is given by the participants as their stories unfold, the easier it may be for them to become identifiable to others. Care was taken to ensure that the information given would not result in the participant being identified in publications and in the literature, no real names were used, and participants were asked if they would like to review their transcripts in order to highlight anything they felt could identify them as an individual. They were also advised they could exercise the right not to answer a question or to say more than they wanted to, if this was appropriate.

Keeping responses confidential is important in qualitative research: there may, however, be times when a researcher becomes aware of information that may involve someone being at risk or a malpractice having been conducted. This requires the deliberate disclosure, in the best interest of individual or service (Ritchie Lewis et al. 2014). This was stated in the information sheet provided to all participants, explaining that disclosure of information provided during the focus group would only take place if the issue revealed was related to a high degree of risk, personal loss or harm to the PWA or their carer. The participants would be informed prior to any disclosure being made. The researcher was bound to abide by their professional code of practice, the Health and Care Professions Council (HCPC) and report the risk to the appropriate person.
All personally identifiable data was stored separately from research transcripts. Each participant was given a number which was assigned to their research data. No personally identifiable information was shared with the researcher supervisor or SLT colleagues undertaking peer validation. All information provided in the focus groups and interviews were stored confidentially, in line with the Caldicott Principles (1997); all data and transcripts collected were securely stored.

3.2.4 Protection of participants

Focus groups and interviews all took place in a quiet environment. If in a clinical setting, a notice was placed on the door advising a research group or interview was taking place and not to disturb.

Whilst facilitating the group or interview, the moderator also observed for any signs of anxiety or distress, the researcher was a SLT with extensive experience of working with people with aphasia in 1:1 and group setting, including the management of related emotions. The researcher ran the group by herself, colleagues were available within the SLT department should additional supported have been needed. A quiet area was available for use by anyone who was distressed and needed some time away from the group and participants were advised that they could leave the group at any time should they wish. As explained in the information provided to participants, if they were receiving direct, regular SLT, this would not be affected by any decision to discontinue with the study.

Close observation of behaviours during data collection that may indicate people with aphasia were unhappy about being involved were undertaken, by the researcher, using expert clinical judgement and experience. The client group concerned may have not been able to overtly state their distress due to the nature of their communication difficulties. The option for a natural break was included in the group timing plan, to allow the researcher to speak with the individual in a quiet area and offer them the opportunity to withdraw if they wish. A family member or friend was invited to attend and wait in an adjoining room in case they were required to support their relative or friend and take them home early if necessary. A refreshment break was incorporated into the focus group, ensuring participants were treated with dignity and respect at all times was a priority.
There were no identifiable risks to participants who chose to participate in this study, equally there was no intended clinical benefit for those taking part in the study. Both these points were clearly stated in the information sheets. Feedback, ideas and information obtained from the study was intended to enhance the services for PWA. This was also explained to participants in the information sheets. During data analysis, all participants were assigned a number to maintain anonymity.

3.3 Sampling and recruitment

Within any study the sampling and recruitment strategies are integral components of the research design as they influence the usefulness of the data collected, the type of analysis and the opportunity to draw inferences from the findings.

Within qualitative research, the selection of participants needs to be monitored carefully to ensure the final sample meets the requirements for diversity and representation; this is known as purposive sampling. Protocols for recruitment are needed, with transparent selection criteria, together with accessible and comprehensive recruitment materials. These may include information leaflets, letters and explicit channels for recruitment. In this study, it was essential that a rich diverse sample of PWA, carers and HCPs was obtained including the following: age, gender, severity of stroke, time since onset of aphasia and length of time working in NHS and agenda for change banding. Three main groups were recruited: PWA, carers of PWA and HCPs, drawn from medicine, nursing, physiotherapy, occupational therapy and clinical psychology. It was important to recruit a range of professionals, from different disciplines, to gain a breadth of understanding from HCPs working with PWA and their families.

3.3.1 Sampling

Qualitative research studies use non probability samples, namely purposive sampling, in which samples are chosen purposively for the ability to illuminate the subject being studied. Purposive sampling was used to recruit participants with particular features or characteristics that enabled detailed exploration and understanding of the research question. With purposive sampling, cases are chosen because they are considered to be representative of the wider group of interest. It has two principal aims, as discussed by Ritchie, Lewis et al. (2014), these being to ensure all relevant issues are covered and that
each key criterion can be explored in detail. The sample is not intended to be statistically representative, as it is in quantitative research, rather members are chosen as it is anticipated they will have relevant opinions and interpretations to the topic of interest.

Patton (2002) proposes a number of categories of purposive sampling methods; the method selected being influenced by the specific aims of the research. The types of purposive sampling, as discussed by this author and also Ritchie, Lewis et al. (2014) include:

- **Maximum variation sampling** identifies the characteristics of the population and then sample people that match these characteristics. An advantage of this form of sampling is that it can capture unique or diverse variations that have emerged in adapting to different conditions (Patton 2002).

- **Typical or critical sampling**, where cases are chosen on the basis that they specifically demonstrate a particular position in the organisation or structure and are believed to be like the majority. It involves taking a sample of “typical”, or average for a particular phenomenon.

- **Homogenous sampling** includes cases which share important characteristics, to reduce variation, and facilitate group interviewing, this is in contrast to heterogeneous sampling, a deliberate strategy to recruit a variation of participants, for example direct experience of a clinical intervention, time since onset of a disability.

- **Snowballing or chain sampling** involves asking people who have already been interviewed to identify others who they believe fit the selection criteria. This is particularly useful for potentially small or dispersed population but carries the risk of compromising the diversity of the sample.

- **Extreme case or deviant sampling** is used to select cases that are unusual or special and has the potential to reveal unexpected and non-considered data.

- **Convenience sampling** refers to selection made on the basis of who is available, the cases that can be studied most easily, cheaply or quickly.
Purposive sampling procedures, of whichever category, are designed to capture elements of both similarity and differences, as both elements are essential to the task of generating new knowledge (Palinkas, Horwitz, Wisdom, Duan & Hoagwood (2015).

Qualitative studies, exploring the impact of aphasia, have used purposive sampling in various ways. A purposive sampling approach was used by Law, Huby, Irving, Pringle, Conochie, Haworth & Burston (2010) in a study exploring the direction for the development of aphasia services in Scotland. The method of purposive sampling enabled the researchers to illuminate experiences of aphasia from the perspective of people of different ages, genders, health and geographical settings. Foster, Worrall, Rose & O’Hallaran (2016) explored an aphasia care pathway within the acute setting, from the perspective of SLTs. Maximum variation purposive sampling was used to recruit SLTs into the study in order to identify central themes relating to acute aphasia management. In both studies, purposive sampling allows for the topics of research to be fully illuminated and applied in other similar settings.

3.3.2 Role of gatekeepers in the recruitment process
Gatekeepers, individuals through whom potential participants are contacted (Ritchie, Lewis et al. 2014) were used to recruit participants for the three groups within the study: this involved briefing individuals through whom potential participants are initially contacted. This approach was used by Paul & Saunders (2009) who conducted a qualitative study exploring the experiences of communication with partners of individuals with aphasia. Participants were recruited following contact with gatekeepers at regional health care facilities and area stroke support groups.

Participants recruited into this study, were identified by Stroke Association Communication Support Service (CSS) Co-ordinators, SLTs and service team leads or line managers for specific HCPs.

The gatekeeper is potentially the participant’s first contact with the research and will play an important role in helping them decide whether they will take part or not and there are some potential ethical issues to consider when using this method of recruitment (Ritchie, Lewis et al. 2014). The gatekeeper within health care research has a responsibility to protect potentially vulnerable people. There is a potential risk that the gatekeeper may
unfairly exclude some people from the opportunity to participate, or put undue pressure on the person to take part. A further risk is that the gatekeeper may be selective in who they approach. It is also important that all the relevant and intended information is provided in its entirety.

To mitigate these risks, methodologically and ethically, the gatekeepers used in the study were briefed face to face about the research, with on-going email dialogue as required. Information sheets were provided for the gatekeepers to send to potential participants (appendices 4, 5 and 6), which they followed up with face to face or telephone contact to discuss participation. It is recognised that the risks could not be entirely mitigated: the decision about taking part in the study would always ultimately be made by the individual themselves (Ritchie, Lewis et al. 2014).

3.3.3 Sample for the aphasia care pathway study
In this aphasia care pathway study, maximum variation sampling was used to recruit PWA, carers and HCPs into the study as a representative sample of participants with shared characteristics e.g. experience of aphasia, was needed. In order to understand the experiences of aphasia care pathway stakeholders, a sample that maximised the diversity relevant to the research question was needed and maximum variation sampling provided this.

3.3.4 Sample size in qualitative research
Qualitative samples are small in size, compared to samples driven by statistical generalisation. If the data is accurately analysed, there will come a point when minimal new evidence is obtained and data saturation has been reached. This exists when subsequent episodes of data collection do not reveal any further new ideas or patterns. The researchers can accurately anticipate what may be revealed in subsequent interviews or groups (Ritchie, Lewis et al. 2014). The purpose of qualitative research is not to make statements about incidence or prevalence, rather to provide data rich in detail. Sample sizes need to be kept small to enable thorough analysis of the information provided by the interview or focus group. This point is emphasised by Foster et al. (2016) who discuss the importance of not having a pre-established or rigid number of participants to recruit, rather that saturation is about achieving a sample which best represents the research topic. Mason (2010) in a review of sample sizes for qualitative higher degree studies,
suggests a minimum of 15 and a maximum of 50 participants are required to achieve saturation in most studies. O’Reilly & Parker (2012) emphasise that the number of participants is only one factor and that the topic of study, length of interview and depth of analysis will have an equal impact on breadth of data generated. They explain that saturation is about achieving a sample which best represents the research topic, rather than a specific number.

In this study, saturation was achieved when the selection of participants sufficiently represented the population of PWA, carers and HCPs and later interviews were no longer generating new topics that had not been explored in earlier interventions. This was achieved after three focus groups for PWA, seven interviews with carers and ten interviews with HCPs.

3.3.5 Sample 1: People with aphasia.

The recruitment of PWA to the study was via the Stroke Association CSS, organised within the Portsmouth and South East Hampshire area. The CSS co-ordinators provide support to PWA and their carers, organising workshops and other support networks with access to a data base of PWA, they were therefore an appropriate group to use as gatekeepers. All PWA attending the groups are referred by a qualified SLT. Each group is co-ordinated by a paid member of the Stroke Association and it was they who referred people to the study, having considered the following inclusion and exclusion criteria:

PWA were included in the study if they fulfilled the following criteria:

- 6 months post onset of stroke with a diagnosis of aphasia as made by a qualified SLT. The time since onset allows for the people with aphasia to have experienced the care pathway in some detail.
- Currently or previously receiving SLT within Solent NHS Trust, to ensure previous access to an aphasia care pathway and likely to have valid contributions to make
- Able to give informed consent, with the option of written or pictorial support to enable them to communicate their consent in line with the Mental Capacity Act (2005).

PWA were excluded if one or more of the following applied:
- A diagnosed cognitive impairment, following assessment by a medical practitioner.
- A severe or global aphasia, as diagnosed by the SLT.

The above exclusion criteria were selected as they were likely to prevent the individual from communicating informed consent to participate and or limit their ability to contribute to the focus group, even with facilitation of their communication. The CSS coordinators were provided with a pack of information (appendix 4) to ensure the process of referring potential participants was explicit and consistent. All potential participants were given written and verbal information about the study in an accessible format (appendix 4). During the pilot phase of the study, the information had been reviewed by PWA. With their consent, contact details were provided to the researcher, who then contacted the potential participant and arranged a time to meet with them, to discuss the information sheet, answer any questions and obtain written consent as appropriate. A copy of the consent form used for PWA is available in appendix 7.

The Mental Capacity Act (2005) was not relevant to recruitment as the proposed study did not recruit people who were mentally incapacitated, according to the Act.

3.3.6 Sample 2: Carers of PWA

The recruitment of carers of PWA to focus groups was conducted by SLTs in acute and community hospital settings within Solent NHS Trust. The following inclusion applied.

- Carer for a PWA with a minimum of 6 months post onset of aphasia. The time since onset allows for the carers to have experienced the care pathway in some detail.
- Provided informed consent to participate.

There were no exclusion criteria.

Referring SLTs were provided with a pack of information to ensure the process of referring potential participants was explicit and consistent (appendix 5 and 8). All potential participants were given written and verbal information about the study (appendix 5). With their consent, contact details were provided to the researcher, using a standard referral form (appendix 8) who then contacted the potential participant and
arranged a time to meet with them to discuss the information sheet, answer any questions and obtain written consent if appropriate. A copy of the consent form is available in appendix 9.

3.3.7 Sample 3: HCPs

HCPs were recruited in consultation with Solent NHS Trust or Portsmouth Hospital Trust service managers, who recommended staff to be invited to participate in interview. HCPs were included in the study if they had:

- A minimum of one years’ experience of working within a stroke service, to ensure they have relevant exposure to stroke and aphasia care pathways and views to contribute in the interview setting.
- Given consent to participate

There were no exclusion criteria.

Service managers were given copies of a study information sheet to share with potential participants, see appendices 6 and 9. Contact details were provided to the researcher who then contacted potential participants. A consent form was signed by participating HCPs (appendix 10) prior to beginning the interview. Table 3.1 illustrate a summary of the recruitment strategy.

Table 3.1 Summary of recruitment strategy

<table>
<thead>
<tr>
<th>Sample</th>
<th>Gatekeeper</th>
<th>Information provided</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. PWA</td>
<td>Stroke Association CSS co-ordinators</td>
<td>Inclusion / exclusion criteria Study information sheet in accessible format Referral form</td>
</tr>
<tr>
<td>2. Carers</td>
<td>SLTs Solent NHS Trust</td>
<td>Inclusion / exclusion criteria Study information sheet Referral form</td>
</tr>
<tr>
<td>3. HCPs</td>
<td>Clinical leads or managers of relevant HCPs, nursing or medical staff.</td>
<td>A summary of the study Inclusion / exclusion criteria information Information sheets for HCPs outlining the study Referral form</td>
</tr>
</tbody>
</table>
3.3.8 Participant consultation before recruitment

A consultation process with PWA, carers and HCPs to explain the research and request feedback regarding the planned recruitment and data collection techniques was completed prior to the data collection phase of the study. This aimed to enhance the validity of the findings. Feedback was received about the length, venue, and size of the focus groups, how materials should be presented and how feedback should be provided in the later stages of the project. During this process, opinions were sought about the setting for the focus group. PWA indicated they would be willing to attend a health care setting, as these are known to be accessible, convenient and comfortable for participants. Meetings with service managers of the HCP groups to be included in the study took place and agreements made about recruitment and involvement of participants within this group.

All consent and referral forms and information sheets were piloted and amendments made following the constructive feedback provided. Four individuals with aphasia reviewed the information sheet for PWA, resulting in some changes being made. The changes related to the number of pictures to support the written text, all those who contributed to the piloting of the information leaflet indicated the number of pictures needed to be reduced and key highlighted words increased. There were some changes to wording to make the information clearer. Consultation with PWA regarding the setting for the focus groups found that they had a preference for a group in a health care setting.

An important part of interview preparation in qualitative research is the piloting of the topic guides and interview schedule, as both are key elements in the data collection phase. This was conducted with participants, who were similar to those included in the main study. Two PWA were asked to review the focus groups guide, they completed this as a pair, commenting upon the issues covered. The interview schedule was piloted to ensure the structure and format of the questions were appropriate. It also alerted the researcher to elements of her own interview techniques, reflect on the experience and revise the questions accordingly. Two carers and one HCP, not included in the final interview process, agreed to take part in the pilot phase. The significant learning points for the pilot phase were the need to ask for clarification or expansion of a response and the importance of being cautious about using leading questions.
The referral form and information sheet were also peer reviewed by a Physiotherapist and an Occupational Therapist. Amendments were made, increasing the amount of details about the study and why the HCP views were important as a result.

3.4 Data collection

When conducting qualitative research it is essential to select a method of data collection that will best answer the research question (Silverman 2010) and can effectively be utilised by the researcher within the time and resource available. A number of potential data collection methods are used in qualitative research including interviews, focus groups, direct observations and a range of electronic or textual techniques.

Focus groups and one to one interviews were selected to illuminate the views and opinions of PWA, carers and HCPs, as being most appropriate for the aphasia care pathways research question and within the skill base of the researcher.

3.4.1 Focus groups

Focus groups were used to obtain the opinions of PWA about the care pathway. This method of data collection is frequently used in qualitative research, allowing a group of individuals with a common interest or experience to give their perceptions, opinions, beliefs and attitudes towards a given topic. Questions are asked, in an interactive group setting, where participants are free to talk with other group members, allowing them to hear others responses and make additional comments or suggestions. It is well recognised in the literature that the focus group has the potential to raise consciousness and empower participants (Ritchie, Lewis et al. 2014). This is relevant for PWA who may be reluctant to contribute verbally in many situations. Although this approach may be more logistically challenging, the wealth and depth of the data collected is arguably more powerful and meaningful (McPeake et al. 2014).

In addition, the use of focus groups was the preferred method of gathering qualitative data from PWA, because the researcher felt that there would be value in individuals within the group being able to cue or prompt each other in ways that the researcher would not be able to do in an individual interview. Palmer & Patterson (2013) discuss that whilst PWA need to be included in research, their voice is stronger within a peer group setting than a mixed membership group. There are few examples within the
aphasia literature of focus groups being used with PWA to collect qualitative data. Hinckley et al. (2013) used focus groups, consisting solely of PWA, to gather information about aphasia resources and information needs. The participants recruited using maximum variation sampling, were all PWA ranging in time since onset from 6 months to 20 years. The rationale given by the authors for using focus groups was to provide a forum for PWA to interact with others in a similar position in a safe, supportive environment whilst contributing valuable experiences and insight to the research topic.

In recognition of the communication difficulties for people with aphasia, adaptations were made, notably that the study was explained to potential participants in an aphasia friendly manner, with language appropriate information sheets describing the process to be followed when consent to taking part was obtained. See appendix 4 for a copy of this information.

3.4.1.1 Setting for the focus groups

The setting for the focus groups for PWA required careful consideration. The venue had to meet health and safety needs, this included wheelchair access and disabled toilet facilities. The physical arrangements of the chosen room had to be considered, to ensure there was sufficient space for up to four wheelchairs, but equally not too large to appear overwhelming. A table in the middle of the group, accessible to all, including wheelchair users, was required for pen and paper and other supported conversation resources to be placed on, together with the recording equipment. These resources included picture communication charts, individual laminated pictures arranged in key topics, for example, health and well-being, activities of daily living, social activities and laminated sheet with key words for sorting. A flipchart stand was required to write down key words, as part of the supported conversation technique. Hot and cold drinks were available: access to a kitchen was therefore also a requirement. In response to the feedback received, the focus groups were held in the SLT Department at Queen Alexandra Hospital Portsmouth. This venue met all the above criteria: it was also possible to use hospital transport to escort PWA to and from the groups as needed.

Four participants were invited to each focus group: this number was decided following consultation with people with aphasia. This is in line with the study conducted by Hinckley et al. (2013) where focus groups for PWA consisted of three to five participants.
Participants were invited to the group by letter, see appendix 12, with a follow up phone call to answer any questions.

3.4.1.2 Focus group topic guide

A broad agenda of topics to explore is necessary for qualitative data collection: a topic guide helps to provide this (Ritchie, Lewis et al. 2014). A guide was written for the focus groups for the aphasia care pathway study, outlining the key issues for discussion, to ensure relevant issues were covered systematically throughout the study. A topic guide was designed, taking into account the evidence relating to care pathways and the aphasia journey. The concept of a care pathway was introduced using metaphors to describe the impact of aphasia (Ferguson, Worrall et al 2010), discussion about the stages of an aphasia care pathway was also important to include (Code & Petheram 2011) and “who should be doing what and when” (Bowen, Hesketh et al 2012). A copy of the guide is available in appendix 11. The aims and objectives of the study were also considered. The main headings for the topic guide were driven by the stages of a focus group, as discussed by Ritchie, Lewis et al. (2014) as summarised in table 3.2.

Ground rules were set at the beginning of the group: participants were prepared for the setting of these rules during the one to one meeting when consent was obtained. Confidentiality was paramount: discussions were to be confidential and should not to be shared outside the group, as stated in the information sheet. Participants were advised not to share personal information in the group, nor to be explicit about their own medical history. A digital recorder was used to record the focus groups; participants were reminded of this at the beginning of the session. The importance of turn taking, with one person talking at a time, was emphasised. This was to help to ensure all had an opportunity to participate and to facilitate the recording and transcription process. Participants were encouraged to ask for clarification if they were unsure of anything that was discussed; in recognition of the potential slow verbal processing of PWA, they were reminded that all views were important.

The agenda for the group was also discussed at the beginning of the session. The intention was for the group to run for approximately one hour and fifteen minutes, with a break for coffee after approximately forty five minutes.
The impact of language overload was also considered. There is a risk that, due to the effects of aphasia, individuals may experience an overload of verbal information (Brennan, Worrall & McKenna, 2005). To minimise this, materials were presented in a variety of mediums and a summary or recap of each question covered was provided. A flipchart was used to summarise each question addressed, using key words and symbols. Participants were encouraged to indicate if there was anything that they needed to be repeated or rephrased. The groups were audio taped: this was clearly stated in the participant information sheet and on the consent form.

3.4.1.3 Stages of the focus group

An understanding of group processes provides a useful insight into focus groups. Ritchie, Lewis et al, 2014, identify five sequential stages that groups frequently evolve through. Whilst the researcher had been providing group therapy for PWA for a number of years, these key stages were not known to her and yet provide very valuable insight and guidance. The stages are summarised in table 3.2.

Table 3.2 Stages of a focus group

<table>
<thead>
<tr>
<th>Stage</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Forming</td>
<td>Settling in period, reliance on moderator. Participants may be anxious. Sharing of background information to “break the ice”</td>
</tr>
<tr>
<td>Storming</td>
<td>Participants establish roles, potential for intra group conflict</td>
</tr>
<tr>
<td>Norming</td>
<td>Development of group cohesion, participants become more interactive and positive, a calmer phase</td>
</tr>
<tr>
<td>Performing</td>
<td>Interactive group work, cohesiveness</td>
</tr>
<tr>
<td>Adjourning</td>
<td>Summing up, “termination” of the group</td>
</tr>
</tbody>
</table>

Ritchie, Lewis et al (2014)

3.4.1.4 Enabling activities in focus groups

Enabling activities or techniques are frequently used in research involving focus groups (Merriam & Tisdell 2015). They can offer alternative methods of participation and help to focus the discussion, aiding expression and the refinement of views and provide
participants with additional and alternative methods of exploring and responding to the research question. These techniques are particularly useful to people with communication impairment, as they can help the processing of information and provide a means of expressing themselves that do not rely wholly upon speech.

Card sorting and ranking exercises are used within qualitative research as one version of an enabling technique. Neufeld, Hamson, Rempel, Larocque, Dublin, Stewart & Hughes (2004) argue that use of the card sorting tasks make it easier for participants to contribute more fully and enable the researcher to explore experiences and knowledge in greater detail. In card sorting exercises, participants are shown a number of written or pictorial examples of an issue or question and asked to order them, either within pre-established groups or with free choice about how the words could be categorised.

A study by Kerr, Hilari & Litosseliti (2010) explored the information needs of PWA and carers. In this study, the aim of which was to understand information to include on a website about living with a stroke, a modified closed card-sorting technique was used. Participants were shown cards containing the names of broad headings or groups, taken from an existing stroke website and asked to place keyword cards within these pre-established groups. The aim of card sorting, as discussed by Kerr et al. (2010) is to generate an overall structure for information, as well as suggestions for further grouping or categorisation of information provided.

In the aphasia care pathway study, enabling activities included card sorting tasks, visual methods, rating scales and pictures of key stages of the care pathways. PWA were asked to identify key stages of the care pathway utilising a card sorting task and to suggest the most important difference between them. A similar task was used to encourage discussion regarding who should provide which aspect of the care pathway, job titles and visual representations of the key professionals involved in the aphasia care pathway were provided for sorting under yes, no or maybe headings.

Projective techniques, as discussed by Merriam & Tisdell (2015) are designed to facilitate a freer discussion and help individuals access thoughts or beliefs that may not immediately be communicated. Supported conversation techniques for PWA (Kagan Black, Duchan, Simmons-Mackie & Square 2001) are used when communicating with
PWA, which mirror a number of projective techniques. In this study, word association or circumlocution was encouraged by participants, who were asked for example “what comes to mind when I say ....” Similarly PWA were asked to write or draw a key word to communicate a message, a process referred to as construction within projective techniques.

The use of pauses and probes are important features of qualitative data collection and were included in the focus group topic guide (Ritchie, Lewis et al. (2014). The aim of these techniques is to facilitate interactions and explore relevant themes. They help ensure a deeper exploration of the pertinent issues, in line with the objectives of the study. The researcher, who conducted the focus groups and interviews, was an experienced SLT with an expertise in running groups for people with aphasia and able to use appropriate pauses, prompts and probes.

Visual supports were used as prompts to encourage PWA to relate to their own experiences for example, examples of the pathway were provided, to illustrate the core stages.

3.4.1.5 Reflections following focus groups
Following each focus group, the researcher reflected upon the content of the session, in particular evaluating the implications of any significant non-verbal or group behaviours. Audio recordings were correlated with a non-verbal or para linguistic behaviours, for example whilst PWA 2 was describing his hospital stay and frustrations, he was shaking his fist. Similarly a incident of laughter correlated with a PWA with minimal spoken output gesticulating in response to a question about long term rehabilitation.

Data was analysed after each session, in contrast to quantitative data, which is analysed at the end of the data collection process. In practice, reflection following the pilot and first complete focus groups resulted in the structure of subsequent groups being amended, notably the use of some additional ice breaking tasks before commencing the detailed discussions and 1:1 activities feeding back into the whole group.

3.4.2 Interviews
Face to face, in-depth, semi-structured, interviews were chosen as the method of data collection to obtain the view of carers and HCPs, maximum variation sampling having
been used to recruit participants. The interview is one of the most widely used methods in qualitative research, used to obtain information about behaviours or experiences, opinions or beliefs, feelings, knowledge, and demographic information (Ritchie, Lewis et al. 2014). It allows for a focused, detailed investigation of a person’s perspective on a given topic or experience and for sensitive issues to be discussed or more detail to be obtained. Semi structured interviews are defined as an interview within which the interviewer asks key questions and probes for further information (Seidman 2014). As with focus groups, it is informed by a topic guide, which enables an experienced interviewer to probe the answers in detail but the order and content of the prompts can vary depending on the individual’s responses.

Studies exploring experiences and perceptions of aphasia from stakeholders’ perspective have also used the interview as one means of data collection. Nystrom (2011) explored the consequences of being closely related to a PWA, interviewing partners and adult children. Given the research question, Nystrom (2011) justified the selection of the interview as the most appropriate method of data collection. It allowed for participants to describe their personal experiences and actual life situation in as much detail as possible, probing questions were used to encourage enhanced reflection as appropriate.

In the aphasia care pathway study, the use of semi structured interviews ensured relevant topics were discussed, including the advantages and limitations of care pathways, (Allen, Gillan & Rixson 2009) whilst also allowing the carers and HCPs the use of their own words in order to give their experiences and opinions. The semi-structured interviews involved a number of broad questions relating to care pathways, experiences of aphasia interventions and the specific aphasia care pathways. The interviewer had the opportunity to probe and clarify responses whilst encouraging the respondent to take the lead and shape their own narrative, giving them a degree of control over the conversation.

There are some challenges or disadvantages of using the interview method. It can be time-consuming and expensive, especially if it is necessary to have help transcribing the interviews (McKenna, Hasson & Keeney 2006). There is a risk that the interview can be prone to reflexivity on the part of the interviewer. This occurs when there is a lack of objectivity of how a situation is being evaluated. The risks can be minimised by using
critical thinking to reflect on the information being analysed and by asking a colleague to be involved in the analysis and evaluation to bring rigour and objectivity to the process.

3.4.2.1 Setting for the interviews with carers and HCPS.
Carers’ interviews took place in their own home or the hospital setting, whichever was most convenient for the carer. If a PWA was attending an SLT outpatient appointment, the interview was conducted by the researcher with the carer whilst the session was taking place separately. HCPs were interviewed in the health care setting in which they worked.

3.4.2.2 Interview topic guides
An interview guide was developed to recognise the importance of planning in order to explore key issues and subtopics and help to guarantee consistency in the collection of data. The interview was semi structured, it was important not to expect specific answers to pre-set questions, rather to ask participants to reconstruct their experiences and explore their meanings (Seidman, 2013). A copy of the interview guides used with carers and HCPs are available in appendices 14 and 15.

Interviewees were reminded of the purpose of the interview which was planned to last no longer than an hour. In keeping with the ethical proposal for this study, care was taken to minimise burden for carer participants by explaining their right to withdraw or finish the interview at any stage. Verbal carer consent to participate was audio recorded at the start of each interview.

It is important to recognise the advantages and limitations or challenges of using audio recordings within this piece of qualitative research, Seidman (2013). The recording of the carers and HCPs interviews facilitated credibility and dependability of the data collection procedure helping to provide an accurate verbatim account of what was said. The audio recording allowed for a more neutral and less intrusive system of recording than taking notes and in turn a more thorough examination of what was reported. It also permitted repeated inspection and exposure of the interviewees’ answers, giving the researcher increased opportunity to immerse herself in the data.
However, audio recording may influence the dynamics of the social encounter of the interview: the recording equipment may be off-putting or daunting for interviewees. Within the aphasia care pathway study this was not observed.

A digital recorder was used to record the interviews, this was stored in a locked drawer to maintain confidentiality, and recordings were transferred to a home password protected computer as soon as possible. The researcher was the only person who had access to the recordings.

The researcher did not have access to secretarial support to transcribe the data, however this was arguably an advantage as it provided an opportunity to relive the interview experience, and become immersed again in the data.

3.5 Data analysis in qualitative research
The process of qualitative data analysis involves preparing the data for analysis, conducting different analysis, moving deeper and deeper into understanding the data, representing the data and making an interpretation of the larger meaning of the data (Ritchie, Lewis et al. 2014). The aim of the analysis of the data collected for the aphasia care pathway study was to provide credible and trustworthy findings, providing an in-depth description of PWA, carers, and HCPs experiences of an aphasia care pathway.

The approach used for data analysis was a pragmatic approach to thematic analysis based on the framework method (Ritchie, Lewis et al. 2014). The thematic framework approach classifies and organises data successively, using initial codes, concepts and themes. Once codes and themes are judged to be comprehensive, they are charted in their own matrix where every respondent is allocated a row. This process allows the analyst to move back and forth between levels of abstraction e.g. case or theme based analysis without losing sight of raw data.

3.5.1 Introduction to the thematic framework analysis
The thematic framework approach was selected because it uses a matrix-based analytical method to provide a systematic way of managing the data, which is considered rigorous. The framework approach to the analysis enabled a systematic description and an interpretation of significant units of meaning, from a large body of data, in order to illuminate and shed light upon the experiences of PWA, carers and HCPs. This approach
provided transparency and an audit trail of decision making to enable other researchers to be able consider whether the findings are trustworthy (Srivastava & Thomson 2009).

Framework analysis is well referenced in the literature as an effective method for analysis of qualitative data within health related research (Vale, Bosely, Patrova & Dale 2011). Within aphasia specific research, a framework approach was used by Northcott & Hilari (2011) who explored why people lose their friends after a stroke. All the iterative analytic processes inherent in the framework method were carried out in the study by Northcott & Hilari (2011) through immersion in the data, discussion and collaboration.

Table 3.3 Stages of thematic framework analysis

<table>
<thead>
<tr>
<th>Stages of analysis</th>
<th>Features of the phase</th>
</tr>
</thead>
<tbody>
<tr>
<td>Familiarisation</td>
<td>Immersion in the raw data reading and re-reading transcripts, listing key ideas and themes</td>
</tr>
<tr>
<td>Identifying thematic framework</td>
<td>Identifying key issues, concepts and themes as linked to the aims of the study. Development of a thematic framework sorted hierarchically into main and sub themes</td>
</tr>
<tr>
<td>Indexing / coding</td>
<td>Thematic framework is systematically applied to all the data, annotating transcripts with codes from the index, supported by short pieces of text as appropriate</td>
</tr>
<tr>
<td>Charting</td>
<td>Development of charts summarising views and experiences</td>
</tr>
<tr>
<td>Mapping and interpretation</td>
<td>Charts used to identify patterns and associations to search for explanation and meaning</td>
</tr>
</tbody>
</table>

(Pope, Zeabland & Maya p320)

Thematic framework analysis classifies and organises data, using initial codes, concepts and themes and includes five stages of analysis, as summarised in table 3.3.

3.5.2 Managing the data

Data was managed using a computer assisted qualitative data analysis system, MAX QDA and analysed according to inductive, deductive and some apriori themes. Computerised categorisation and analysis packages, such as MAX QDA are becoming increasingly popular and arguably make the process of qualitative data analysis more systematic and rigorous, as discussed by Bowling (2014). They enable the researcher to handle a large
amount of data systematically, improving validity and auditability of qualitative research. They also allow for data to be efficiently stored in one place. The researcher can then search for strings of words, phrases in context, facilitating the filtering and reorganising of data set. Patterns of text can be identified and diagrams, maps, and other visual representations, of the data produced, increasing the rigour of analysis (Flick 2009).

It is paramount that any computer assisted software used must not be seen as a replacement for the critical role of the researcher within the familiarisation and immersion of the raw data (Rodik & Primorac 2015). Some data analysis software packages have been found to be unintuitive to use, thus increased time and energy has to be spent learning how to use them. There may also be an increased pressure on the researcher to focus on volume and breadth, rather than on depth and meaning. It is therefore imperative that the actual analysis is completed by the researcher: the software package is a tool to assist in this process (Flick 2009).

The researcher was mindful of the advice in the literature when using MAX QDA as a tool to assist with the data analysis of the aphasia care pathway study.

3.5.3 Identifying concepts and themes
After re-reading the transcripts, the process of systematically identifying key concepts and themes, commenced. Initial themes were identified inductively, referring back to the aims of the study, to investigate the aphasia care pathways from different perspectives. Themes are descriptive and act as a thread between the units of meaning and assist in organising the data (Silverman 2006). Each initial theme was identified by the use of key words or phrases, copied from the highlighted text. A number of inter relationships were found within the themes and consequently a number of indexing codes belonged to more than one theme. These are illustrated in appendix 15.

Initial themes that emerged included understanding and communicating the care pathways, range and availability of SLT interventions in aphasia, information giving, managing expectations and longer term support. The themes were continually and systematically grouped and re-grouped, identifying similar content to reflect the text as a whole, the list of themes and sub-themes was revised several times during this stage to focus the analysis and reduce overlapping of themes.
An initial framework to index codes for analysis was established (appendix 16). Specific words and phrases that had significant meanings and characteristics within the text were highlighted. For example “*to be honest with you the communication has not been great.*” (carer2) was coded as “communicating the care pathway and “information giving / expectations.

Within qualitative analysis, it is common to identify some themes in advance, usually referred to as ‘a priori’ themes (Bazeley 2011). This is because a research project has started with the assumption that certain aspects of the phenomena under investigation should be focused on. In this study, a priori themes included the timing and intensity of SLT interventions, provision of aphasia related information and adapting to the impact of aphasia.

The coding of data was an open, transparent process and negative or deviant cases were all searched for in the data. This is the process of selecting or searching for cases that are considered outliers, or that, on the surface, appear to be the 'exception to the rule'. Negative case analysis is an important component within the qualitative method, essential to the rigor and validity of data analysis, in order to develop a richer, more in-depth understanding of phenomenon being studied (Mays & Pope 2000).

3.5.4 Validity of data

Validation is concerned with the extent to which the validity of evidence has been verified, identifying how well the participants meaning have been interpreted. Within qualitative research, there are two main methods of validating data, triangulation and member or participant validation (Miles, Huberman & Saldana 2014).

3.5.4.1 Triangulation

Validation is significantly improved by using a combination of methods, a process known as triangulation (Mays & Pope 2000): this provides a more in-depth data set and allows the researcher to validate findings, increasing their reliability. In this study, investigator triangulation was selected as one means of validating the data. Two interviews were randomly selected and analysed by an SLT peer, blind to any existing coding conducted by this author.
3.5.4.2 Participation validation
This involves taking the research evidence either back to the participants themselves or to a group with similar characteristics. This is also part of a process of error reduction. Respondent or participant validation was used in this study: the researcher attended a Stroke Association CSS conversation group, to present the key themes.

A summary of key themes was also sent to carers interviewed, including a cover letter asking for any feedback. This was to demonstrate openness and transparency throughout the research process. In addition the option of a visit from the interviewer was offered, to clarify the transcripts at any time, however nobody requested the written copy or a visit. An invitation to attend a presentation and discussion about the findings was also sent to the PWA and carers who participated in the focus groups or interviews, the aim of which was to validate the findings. The response to this invitation was minimal and the event did not take place.

3.5.5 Positionality
This refers to the need for qualitative researchers to take account of their own position in relation to the research participants and research setting, the ability to distance or “bracket” personal experiences and expectations from a study (Merriium & Tisdell 2015).

The focus groups and interviews for this study were carried out by the same facilitator, a specialist SLT with a number of years’ experience working with PWA. This role involves formal and informal assessment of an individual’s communication skills, strengths and needs, providing therapy and support to the individual themselves and significant others, notably family, friends or carers. The researcher is experienced at organising and facilitating a variety of therapy and conversation groups for PWA, applying interventions in a subtle and sensitive manner, aiming to minimise an individual’s experience of any significant sense of failure or distress.

3.5.6 Rigour and reflexivity
There are several ways in which the researcher can conduct qualitative studies in a rigorous manner, Bowling (2009). Research should be conducted in an explicit and systematic way, with a transparent design, data collection, analysis and interpretation.
To enhance the rigour of this study, a research proposal detailed the above and peer
review of the transcripts of the key themes was completed. This allowed for on-going review and scrutiny of the data.

Reflexivity is defined as thoughtful, conscious, self-awareness, reflecting on any potential sources of bias and reporting on these (Ritchie, Lewis et al 2014). A reflexive approach was achieved in a number of ways. The researcher was already part of the topic under investigation by virtue of her clinical background. SLT researchers are often familiar with the research setting and the potential participants. In this study, the researchers’ professional and specialist clinical background potentially could have biased the data collection and analysis. This was mitigated by the process of reflexivity whereby preconceptions or assumptions which could have contaminated the research process and findings, were noted and bracketed from the study.

As discussed by Tufford & Newman (2010), bracketing enables the researcher to reach deeper levels of reflection, across all stages of qualitative research: selecting a topic and population, designing the interview, collecting and interpreting data, and reporting findings. The opportunity for sustained, in-depth reflection may enhance the accuracy of the research and facilitate more profound and multifaceted analysis and results.

3.6 Analysis of the qualitative data in the aphasia care pathway study
The analytical approach applied to the data was based on the principles of Framework Analysis, as discussed in section 3.5.1. The phases of familiarisation, identifying themes, charting, mapping and interpretation were followed.

3.6.1 Familiarisation
The audio recorded focus groups and interviews were transcribed verbatim and a word document was created for each interview, which was then imported into MAX QDA.

Unlike a quantitative study, data analysis occurred iteratively following each interview or focus group, rather than at the end of data collection. In this way, themes emerging within the data were available as potential prompts or probes during subsequent interviews of groups, the basis of qualitative iteration (Srivastava & Hopwood 2009). Following a process of familiarisation with the data, transcripts were searched for any significant units of meaning relating to the research question. These significant units of meaning were indexed with one or more descriptive labels in a process of open coding.
Transcripts were read a number of times, in order to gain an overall sense of the material and rich detail which contributed to the knowledge and understanding of the challenges and concerns experienced by PWA and carers. Throughout this process, the researcher became aware of key ideas and recurrent themes and documented them for future reference.

3.6.2 Identifying themes and codes
This phase took place after familiarisation as emerging themes were recognised. Some arose from a priori themes (Bazeley 2011). These were the themes or labels that the SLT would expect to see emerging within a piece of aphasial related research, based on clinical, professional experience and the related evidence base. These words or phrases consisted of units of meaning grouped together and given initial codes or labels. i.e. categories of analysis, for example, a word or phrase such as “intervention” or “disability” were used to label sections of text. The key issues, concepts and themes expressed by the participants formed the basis of a thematic framework used to filter and classify the data (Srivastava & Thomson, 2009). Whilst a priori themes can help to accelerate the initial coding phase of an analysis, it remains important to maintain an open mind and not force the data to fit the a priori issues or focus solely on these themes (Ritchie, Lewis et al. 2014). By focusing on data that correspond to priori themes, material that does not relate to them may be overlooked. In addition, the researcher may fail to recognise when an a priori theme is not proving to be the most effective way of characterising the data. To prevent these pitfalls, it is crucial to recognise a priori themes as tentative, equally subject to redefinition or removal as any other theme.

An analytical framework was systematically applied to all the data, annotating transcripts with codes from the index, see appendix 15. This process is applied to all the textual data that had been gathered, namely the transcripts of interviews. MAX QDA was used to organise the data and allocate codes, see appendix 16 for example of this process. Codes or labels were then combined into conceptual semantic relationships, subheadings that were drawn during the thematic framework, which were then worked into final main themes, see appendix 17. The coding of data was an open, transparent process and negative cases were included in the data, if they were present.
Initial coding was conducted by the author: however the analysis, including interpretation and naming of codes and themes was discussed with the academic supervisor. Initial codes were chosen both a-priori (Bazeley, 2011) based on the literature review and the researcher’s clinical knowledge and by open coding, with emerging codes developed by a process of constant comparison within and between interviews. Themes from the focus groups with PWA, interviews with carers and interviews with HCPS were initially identified separately and then combined (table 3.10). As analysis progressed, new codes were iteratively applied to transcripts previously analysed.

3.6.3 Validation of the data
This refers to the checking of the validity of findings or conclusions, by triangulation or cross checking with other sources. Peer validation or investigator triangulation was selected as one means of validating the data. Two interviews were randomly selected and analysed by an SLT peer, who was provided with the framework of codes, (appendix 15) and asked to use a blank table to list the codes identified in the two scripts. The SLT was asked to add any additional codes or raise any queries relating to definitions of codes. See appendix 18 for emerging themes from peer validation and the feedback received.

Table 3.4 illustrates the questions raised by the SLT involved in the peer validation process. These questions were considered and amendments made to the final version of the themes.
Table 3.4 Peer validation process

<table>
<thead>
<tr>
<th>Question</th>
<th>Response</th>
</tr>
</thead>
<tbody>
<tr>
<td>Code for specific information needed?</td>
<td>Linked to information giving code</td>
</tr>
<tr>
<td>Code encompassing feeling of wanting to have a goal to work towards?</td>
<td>Goal setting</td>
</tr>
<tr>
<td>Code about emotional support being provided</td>
<td>Emotion</td>
</tr>
<tr>
<td>Code to capture the feeling that there needs to be a core consensus/ agreed pathway</td>
<td>Guidelines / National Drivers</td>
</tr>
<tr>
<td>Code for the patient being involved in the care pathway?</td>
<td>Patient centred</td>
</tr>
</tbody>
</table>

The research findings from the aphasia care pathway study were taken back to a group of PWA attending a Stroke Association conversation group. Twelve members were present during the researchers two hour visit. A brief presentation was given, outlining the research and the purpose of the validation process. Analysis was not discussed at this stage, it was important not to bias the participants. Small groups, consisting of three participants per group were then formed to discuss labels or key words they would use to describe their experience of the aphasia care pathway, from their own experiences. Table 3.5 summarises these findings, which illustrate close association to the themes identified by the researcher through the process of framework analysis. Following the testing of the themes with members of those groups from whom the data were originally obtained, it was concluded that the meanings or interpretations assigned to the data have been validated by this process.
Table 3.5  Themes from participation validation

<table>
<thead>
<tr>
<th>Members key word / label</th>
<th>Associated theme</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not ready for SLT early on</td>
<td>Aphasia care pathway</td>
</tr>
<tr>
<td>Not sure of the plan</td>
<td>Aphasia care pathway</td>
</tr>
<tr>
<td>SLT not a priority in hospital</td>
<td>Aphasia care pathway</td>
</tr>
<tr>
<td>Too much focus on Inpatient SLT</td>
<td>Aphasia care pathway</td>
</tr>
<tr>
<td>Delay in SLT once at home</td>
<td>Aphasia care pathway</td>
</tr>
<tr>
<td>Therapy stopping far too early</td>
<td>Aphasia care pathway</td>
</tr>
<tr>
<td>Support needed 2 / 3 years on</td>
<td></td>
</tr>
<tr>
<td>Not enough information</td>
<td>Information giving</td>
</tr>
<tr>
<td>Information too complicated</td>
<td>Information giving</td>
</tr>
<tr>
<td>Family not kept informed</td>
<td>Information giving</td>
</tr>
<tr>
<td>Family overload</td>
<td>Psychosocial / impact</td>
</tr>
<tr>
<td>Hopelessness</td>
<td>Psychosocial / impact</td>
</tr>
<tr>
<td>Frustration</td>
<td>Psychosocial / impact</td>
</tr>
<tr>
<td>Anxious / scared</td>
<td>Psychosocial</td>
</tr>
</tbody>
</table>

A summary of the key themes for the initial data analysis was also sent to the carers interviewed, with a cover letter asking for any feedback. In addition, the option of a visit from the interviewer was offered, to clarify the transcripts at any time, however nobody requested the written copy or a visit. An invitation to attend a presentation and discussion about the findings was also sent to the PWA and carers who participated in the focus groups or interviews. A total of fifteen invitations were sent, eight people replied, of which only one was able to attend the event and therefore it was decided not to pursue the event. An individual visit was offered to the carer who had expressed an interest in attending to give feedback, however this was declined.

3.6.4 Summary of the qualitative data analysis

Figure 3.2, below, summarises the process of data analysis.
3.7 Results from the qualitative data analysis

This section will provide detailed results about the PWA, carers and HCPs who participated in the focus groups, interviews and the thematic analysis that was produced.

Three focus groups, one and a half hours in length were organised for PWA, a maximum of four participants were present for each group. Table 3.6 displays the characteristics of PWA who attended a focus group. Seven interviews were held for carers and twelve for HCPs, all lasting for an average of 45 minutes. Tables 3.7 and 3.8 summarise the key characteristics of carers and HCPS.
Table 3.6 – Characteristics of PWA who attended a focus group

<table>
<thead>
<tr>
<th>Identification PWA and grp</th>
<th>Gender</th>
<th>Age</th>
<th>Time since onset (years)</th>
<th>Categorisation of stroke</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 FG 1</td>
<td>F</td>
<td>50</td>
<td>7</td>
<td>L CVA</td>
</tr>
<tr>
<td>2 FG 1</td>
<td>M</td>
<td>68</td>
<td>3</td>
<td>L CVA</td>
</tr>
<tr>
<td>3 FG 1</td>
<td>M</td>
<td>83</td>
<td>4</td>
<td>L CVA</td>
</tr>
<tr>
<td>4 FG 1</td>
<td>F</td>
<td>39</td>
<td>4</td>
<td>R CVA (haem)</td>
</tr>
<tr>
<td>5 FG 2</td>
<td>F</td>
<td>71</td>
<td>2</td>
<td>L CVA</td>
</tr>
<tr>
<td>6 FG 2</td>
<td>M</td>
<td>62</td>
<td>3</td>
<td>L CVA</td>
</tr>
<tr>
<td>7 FG 2</td>
<td>F</td>
<td>67</td>
<td>2</td>
<td>L CVA</td>
</tr>
<tr>
<td>8 FG 2</td>
<td>M</td>
<td>50</td>
<td>1</td>
<td>R CVA</td>
</tr>
<tr>
<td>9 FG 3</td>
<td>M</td>
<td>63</td>
<td>3</td>
<td>L CVA</td>
</tr>
<tr>
<td>10 FG 3</td>
<td>M</td>
<td>64</td>
<td>5</td>
<td>L CVA</td>
</tr>
<tr>
<td>11 FG 3</td>
<td>F</td>
<td>55</td>
<td>2</td>
<td>L CVA</td>
</tr>
<tr>
<td>12 FG 3</td>
<td>M</td>
<td>54</td>
<td>1</td>
<td>L CVA</td>
</tr>
</tbody>
</table>

Table 3.7 Characteristics of carers who were interviewed

<table>
<thead>
<tr>
<th>Identification Carer</th>
<th>Relationship to PWA</th>
<th>Age of PWA (years)</th>
<th>Years since onset of aphasia</th>
<th>Employment Status</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Partner</td>
<td>46</td>
<td>2</td>
<td>Employed</td>
</tr>
<tr>
<td>2</td>
<td>Husband</td>
<td>56</td>
<td>1</td>
<td>Self employed</td>
</tr>
<tr>
<td>3</td>
<td>Wife</td>
<td>73</td>
<td>1</td>
<td>Retired</td>
</tr>
<tr>
<td>4</td>
<td>Husband</td>
<td>55</td>
<td>1</td>
<td>Employed</td>
</tr>
<tr>
<td>5</td>
<td>husband</td>
<td>54</td>
<td>1</td>
<td>Retired</td>
</tr>
<tr>
<td>6</td>
<td>Wife</td>
<td>67</td>
<td>3</td>
<td>Retired</td>
</tr>
<tr>
<td>7</td>
<td>Wife</td>
<td>62</td>
<td>2</td>
<td>Employed</td>
</tr>
</tbody>
</table>
Table 3.8 Characteristics of HCPs interviewed

<table>
<thead>
<tr>
<th>Identification HCP</th>
<th>Professional Group</th>
<th>Gender</th>
<th>No of years working in stroke</th>
<th>Agenda for change banding (as relevant)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>PT</td>
<td>F</td>
<td>20+</td>
<td>7</td>
</tr>
<tr>
<td>2</td>
<td>OT</td>
<td>F</td>
<td>20+</td>
<td>8a</td>
</tr>
<tr>
<td>3</td>
<td>OT</td>
<td>F</td>
<td>15</td>
<td>7</td>
</tr>
<tr>
<td>4</td>
<td>PT</td>
<td>M</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>5</td>
<td>SLT</td>
<td>F</td>
<td>2</td>
<td>5</td>
</tr>
<tr>
<td>6</td>
<td>SLT</td>
<td>M</td>
<td>14</td>
<td>7</td>
</tr>
<tr>
<td>7</td>
<td>OT</td>
<td>F</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>8</td>
<td>CP</td>
<td>F</td>
<td>15</td>
<td>Not stated</td>
</tr>
<tr>
<td>9</td>
<td>Stroke nurse</td>
<td>F</td>
<td>10</td>
<td>Not stated</td>
</tr>
<tr>
<td>10</td>
<td>Consultant</td>
<td>M</td>
<td>20+</td>
<td>N/A</td>
</tr>
<tr>
<td>11</td>
<td>GP</td>
<td>M</td>
<td>20+</td>
<td>N/A</td>
</tr>
<tr>
<td>12</td>
<td>Commissioner</td>
<td>F</td>
<td>15</td>
<td>N/A</td>
</tr>
</tbody>
</table>

Following analysis, the main themes from the focus groups and interviews were identified, as illustrated in tables 3.9

Table 3.9 Themes from the focus groups and interviews

<table>
<thead>
<tr>
<th>Themes from focus group data</th>
<th>Themes from interviews with carers</th>
<th>Themes from interviews with HCPs</th>
</tr>
</thead>
<tbody>
<tr>
<td>Reality of aphasia journey</td>
<td>Communicating key stages of aphasia care pathways</td>
<td>Role of care pathways in NHS</td>
</tr>
<tr>
<td>Being kept informed</td>
<td>Providing information in suitable format at right time</td>
<td>Information Giving</td>
</tr>
<tr>
<td>Timing of SLT</td>
<td>Timing of SLT</td>
<td>Role of telemedicine</td>
</tr>
<tr>
<td>Amount of SLT</td>
<td>Goal setting</td>
<td>Role of goal setting</td>
</tr>
<tr>
<td>Importance of longer term SLT provision</td>
<td>On-going SLT provision</td>
<td>Acute vs long Term provision</td>
</tr>
<tr>
<td>Staying motivated</td>
<td>Impact of stroke and aphasia on whole family</td>
<td>Holistic approach</td>
</tr>
<tr>
<td>Accessible version of an aphasia care pathway</td>
<td>Accessible version of an aphasia care pathway</td>
<td>Communicating pathways</td>
</tr>
</tbody>
</table>
After initial coding which were then integrated into overall themes was completed, related codes were grouped, by meaning, into higher order themes as illustrated in table 3.10.

3.7.1 Interpreting the data
This was completed by reviewing themes in the context of individual participants accounts as well as examining the data across participants. Some were identified as important or significant because the participant kept returning to them, whereas others may have only been expressed once, but in a powerful and emotive way, indicating they were equally meaningful. Deviant codes were explored, to allow for a deeper analysis of the data. The transcripts were frequently revisited, to retain a focus of the sight of the context in which themes are identified in individual accounts.

Table 3.10 Main themes with examples of contributory codes

<table>
<thead>
<tr>
<th>THEMES</th>
<th>CONTRIBUTORY CODES</th>
</tr>
</thead>
<tbody>
<tr>
<td>Characteristics of care pathways in the NHS</td>
<td>Accountability, advantages, awareness, communicating the pathway, disadvantages, format, specific vs generic.</td>
</tr>
<tr>
<td>Aphasia specific care pathways</td>
<td>Family involvement, intensity, managing expectations, stages of intervention (assessment, goal setting) outcomes, who does what when.</td>
</tr>
<tr>
<td>Information giving</td>
<td>Expectations, Format (1:1 or group, face to face or electronic, verbal or written) timescales</td>
</tr>
<tr>
<td>Psychosocial issues</td>
<td>Acceptance, adaption, empowering, family response, financial, motivation.</td>
</tr>
</tbody>
</table>

3.7.2 Summary of themes
Four major themes were identified during the transcribing, analysis and validation process, the themes were common to the three groups involved in the interviews and focus groups, PWA, carers and HCP’s. A summary of the findings for each group is presented below.
PWA were enthusiastic to discuss the impact of the stroke related communication difficulty, which they described as life changing and the type, timing and intensity of SLT provided. They were not overtly aware of a specific aphasia care pathway and none reported knowledge of generic care pathways within the NHS. The provision of information about what had happened to them, what to expect in terms of therapy and follow up and long term outcomes and expectations was reported with some variety. Overall they had been provided with information about their aphasia, however individual differences were found about when, how and in how much detail that information should be provided. The concept of a map outlining the potential aphasia journey, was generally supported. The role of “telemedicine” including apps for IPADS and computer software was discussed by one of the focus groups as having a positive impact on their aphasia journey but not available as freely as would be liked. Support from rehabilitation services and the voluntary sector (Stroke Association Communication Support Services) were described as key features of the care pathway.

Carers of PWA had a greater awareness of the role of care pathways in the NHS, however understanding of a specific aphasia care pathway and involvement in the key stages of decision making was variable. Key issues for carers focused upon information giving, long term support and their own involvement in the rehabilitation process. The importance of maintaining a positive but also honest approach to the aphasia rehabilitation was reported to be very important: keeping the PWA motivated was paramount.

HCPs, as would be expected, had an informed knowledge of care pathways in the NHS and were able to discuss how, when and why they are used and the advantages and challenges of their application. Their exposure to the specific aphasia pathway was less evident. The need to provide timely and appropriate information was identified as a key factor in stroke management, as was the importance of remaining positive but honest in their approach / management.

The four common themes have been identified, as summarised below:

- Experiences of care pathways in the NHS
- Characteristics and value of an specific aphasia care pathway
- Provision of aphasia related information and keeping users informed
- Psychosocial factors

Quotations taken directly from the interviews and focus groups are used to provide examples and to illustrate the themes identified.

3.7.3 Theme 1: characteristics of care pathways in the NHS
This theme describes participants’ understanding and awareness of care pathways within the NHS, both the general concept and aphasia specific care pathways.

People with aphasia (PWA) were asked to select key words that best described the pathway they had experienced since suffering their stroke and associated aphasia. Laminated key words were provided to assist with the process, as were used in a study by Ferguson et al. (2010).

The three words consistently rated highly were nightmare, expedition and experience.

The following comments were generated:

PWA 3: *expedition but never reach where you are going* - *long haul*

PWA 6: *experience But is not ... not pleasant Yes that’s right*

WA 4: *nightmare, not wake up*

The care pathway discussion, for PWA, then focused upon the aphasia care pathway and whether the participants were aware that there was a plan or pathway being followed. Respondents were uncertain as they were often unable to remember much of the early stages following their stroke.

Interviewer (I): Can you remember being told by the SLTs that there would be a plan for your care around the communication problems?

PWA 2: *6 weeks?* (seemed a little unsure) *No... no I don’t remember Maybe I don’t remember*

Carers of the PWA also had a very limited awareness of the existence of a planned pathway of care following the stroke their family member/ friend had suffered. They were each asked about their knowledge of a stroke care pathway.
I: Were you aware there was a plan or map?

Carer 1.: No one explained it to me in those terms, I knew and I expected him to get Speech therapy, but I did not understand there was a structured pathway

Carer 1.: And if you had of known that would it have been helpful do you think?

Carer 1: Yes because I would have found out about it and asked some questions

Carer 2: I was aware there was a pathway, but not what it consisted of.

I: Would it have been useful to have known more about it?

Carer 2: I think it would have been very useful not just in the now, but the total pathway, because to be honest with you the communication has not been great.

Carer 3: Not to start with because it was like new to me, I have not had anyone in my family who has had a stroke or anything like that so I did not know what the journey would be.

Carer 4: I think the communication of the pathway and it is understanding of it for some people would have been a nightmare, because the information has been scatty. I use the internet a lot so got information myself

The HCPs interviewed, as was anticipated, were all aware of the existence of CP within the health care system, some in more detail than others.

HCP 2: If I had to describe what a CP is, I think I would describe it as the journey a patient goes on and part of that journey is the contribution different MDT make in that process, so it is definitely something which occurs over a period of time. Using EBP, ensuring service is value for money

HCP 4: Seamless progressions, evidence based, providing a quality service with outcomes measured at every stage.

The HCPs were also asked about the advantages and challenges of using care pathways within the current health system, a range of responses

HCP 7: it helps people to understand what their role and contribution is, what their responsibilities are within that, and it does allow you to have some way of
measuring if it is working or not, so it is kind of a measurable process you can look into if you want to as well. So its about that ownership of role and it gives you a structure you can measure and be accountable to as well.

HCP 4: it reminds us of the different stages of somebody with a particular diagnosis, so it kind of collates different parts of managing that diagnosis, so it is almost like a reference point, so you have got the information there as you need it. I think you can use it like a map if you need, if you need to work your way through a particular set of stages and that will remind you of particular interventions,

The challenges significantly outnumbered the advantages:

HCP 6: financial challenges at all stages. More challenges at end of what is seen as rehab phase – need for longer term provision, who will provide what. This is when people tend to fall off the CP – risk that due to acute pressure, patients in rehabilitation phase are pushed off the pathway. Long term provision is biggest challenge.

The nature of the condition or diagnosis for which the care pathway is developed was felt to influence its effectiveness.

HCP 9: for a more routine need I think it lends itself to a care pathway very well. But I think the nature of our client group (stroke) where they are much more complex, no two patients with a stroke are ever the same, the complexity of cognitive, emotional, physical, communication difficulties that they have, it just does not easily lend itself to.

The level of clinical experience was reported to be a significant factor with regards to the appropriateness and success of the implementation of a care pathway.

Given the changing needs of the ageing population a term a “shopping trolley of need” was referred to by a few participants, individual, diagnostic pathways may be a thing of the past, as summarised by the quotes below.

HCP 12: Every patient is different, with potentially a range of disorders and you are trying to generic commission pathways based on different levels of complexity. So I think for me, an ideal pathway is something that has a formal structure but
within that there is an element of freedom to make it adaptable to each individual patient.

HCPs were also asked to comment about how care pathways / the planned care provision for an individual patient are currently communicated with the individuals concerned

HCP 1: It depends on the care pathway, some are quite complex, but absolutely. It often needs explanation of why, with all these things, do patients understand why you are doing it and do they think they are going to get better care as a result, they embrace it.

The practicalities of doing this were also discussed:

HCP 6: I think there is a role for it, but you are probably talking at the rehab end because I think, practicalities being what they are, we would struggle to engage with patients and relative in the acute phase as things are changing on a day by day basis, If you are developing a CP should there be patient engagement around the development of it?

3.7.4 Theme 2: Characteristics and value of an aphasia care pathway
This theme incorporates codes relating to aphasia, including the stages of intervention that the stakeholders would expect to happen, who should do what at which stage of the aphasia care pathway or intervention, intensity of therapy and outcomes. A key item for discussion was regarding the timing of intervention, in particular from the perspective of the people with aphasia. This theme differs from theme one as it addresses the specific experiences relating to aphasia, in contrast to generic care pathway issues.

3.7.4.1 Awareness of an aphasia care pathway
Participants were specifically asked to describe their understanding and experience of the aphasia care pathway and whether they were aware that there was a plan or pathway being followed. PWA were generally vague, reporting they could not remember much about the acute and post-acute phase of their aphasia.

I: can you remember being told by the SLTs that there would be a plan for your care around the communication problems?

PWA 2: Yes I think so
I: Can you remember at what point in those 2 months that was explained to you

PWA 2: 6 weeks (seemed a little unsure)

Carers were similarly unsure.

Carer 2: coming out of hospital and starting therapy was a bit disjointed, there could have been a bit more help in getting the next stage involved. It was a bit.. here you go, you are on your own now.

Similarly the HCP’s interviewed had only limited knowledge about a specific aphasia care pathway. One respondent held negative views about care pathways and did not support the role of an aphasia care pathway.

HCP 6: it is either going to be ridiculously complex into what those decisions are going to be possible to get it down onto paper - it is either going to be simple, in which case it is going to be meaningless and generic or its going to be very complex.

3.7.4.2 Core stages of the aphasia care pathway

PWA reported a core understanding of what the key stages of the care pathway would be notably some assessment, goal setting, some 1:1 therapy. However, comments of not being able to remember, everything being too hectic, exhausting and confusing in the early stages of recovery and frustration about the lack of on-going individual or group interventions remain common.

PWA 4: I think it was two weeks or a week, really horrible, confusing, the ward was really hectic, I didn’t know what was happening. In bed all the time, wait to see Dr, frightening

PWA 5: Good is that you get SLT, but not enough, stopped too soon.

The topic of goal setting generated the most discussion from PWA. In general participants could recall the topic being mentioned, a key stage of the intervention for their aphasia rehabilitation, but struggled to be engaged in it. Instead, the role of the “professional” in setting the goals was identified, with several respondents indicating they did not feel they had adequate knowledge or expertise to set realistic goals.
PWA 1: Didn’t know what to expect, wanted them to tell me not me tell them.

Carers were also asked about their understanding of the key stages of aphasia rehabilitation, with variable outcomes. Awareness and understanding increased with time and carers expressed how important the targeted communication rehabilitation was for continued improvement, both of the underlying impairment and confidence of the individual with aphasia.

Carer 2: I think once we got out of the chaos, no that is the wrong word, ... as things settled down I became more aware of the plan and able to ask, I could see how the therapy plan was coming together.

There remained, however, concerns that the rehabilitation plan was implicit, rather than specifically being explained to them.

Carer 5: you had to have some vision to see what was happening where it was all going, it was not explicit which is not good.

Several carers had concerns about the process of setting specific goals for aphasia rehabilitation, stating that involving the person with aphasia, whilst important to do, in reality was very difficult and limiting.

Carer 3: goal setting sounds good in theory, but for someone in there 40’s or 50’s who is recovering from the shock of it all, they may need pushing, that’s not the right word, encouraging, but for someone 85 or so goals may be a lot more difficult as quite a culture shock and it needs to be on-going, even if it was just once a month to sit down with the SLT say to talk about where they think they are and get the feedback from someone with experience would be very helpful.

This quote reflects several comments about how difficult goal setting is in reality, limited knowledge about the process and the suggestion that the health care professional needs to take a lead and act as an advisor about appropriate goals to be aiming for in a specific timescale. Several carers talked about their spouse’s willingness to go along with what was happening, rather than specifically contribute to individual goals; one described this behaviour as part of the individual’s pre stroke personality.
The implicit nature of the goal-setting process and the lack of adequate information about the process were some external factors resulting in people with aphasia being content with limited involvement or choosing to withdraw from goal discussions.

HCP’s were able to provide a more insightful awareness of the specific phases of the aphasia rehabilitation. The importance of keeping family members involved at each stage of the process was identified by several participants as being central to the success of the process.

CP 4: *In hospital care, one would hope that stroke would be early diagnosis, assessment and treatment, early input of specialist services which carries on when the person leaves hospital. Option for individual or group therapy and referral on to a voluntary group if appropriate.*

The role of telemedicine in supporting intensity of therapy was discussed by a number of the HCPs.

HCP 8: *- being able to use more remote ways of working and providing more intensive intervention, through computer software, apps on IPAD, all sorts of things, under the umbrella of telemedicine.*

3.7.4.3 Timing of SLT specific interventions

PWA and their carers were positive about the SLT they had received and the role it had played in their recovery. The timing and availability of provision was an issue frequently raised in the interviews and focus groups.

PWA 3: *A few months down the road, 6 months, because my perspective... was angry and next thing was acceptance and next thing was to practice my speech but not much speech therapy then*

PWA 6: *Took me a long time to cotton on help needed*

Some carers indicated that they felt therapy should be available when people are best able to access it and gain most from it, they may not have been ready for it at the time it was offered. The suggestion was that the service was organised for convenience of those funding and delivering the provision rather than for the benefit of the PWA and their families.
Carer 4: you have pigeon holed people who are following doing this and then it stops and there is nothing further. He did in the rehab hospital, but it was then almost as if we were on our own in those first weeks or so back at home

Carer 7: X just was not in the right frame of mind or focused enough when he had his therapy. He was still coming to terms with everything that had happened.

3.7.4.4 Who does what when?
The question of “who does what when” was also addressed to all three groups. All participants spoke of the importance of having access to formal therapy, provided by a qualified SLT in order to gain maximum benefit from the expertise of a professional and to maintain active engagement in the recovery process. People with aphasia and their carers had very similar opinions about this sub theme.

Carers and PWA were asked to comment on who should be providing the specific communication work

PWA 1: speech and language ... years of experience, so they have got lots of training and experience, yes yes

Carer 4: I don’t think anyone who was not trained would be able to do the work done by SLT.

The HCP’s were able to synthesise their own experience of working with support workers and volunteers when answering the question about who should be involved at what stage of the rehabilitation programme. Assessment, goal setting and therapy planning was identified as a core activity for the qualified practitioner to be leading on, the day to day provision of a therapy plan could be delegated, under the supervision of the qualified member of staff.

HCP 5: assessment is the domain of qualified staff and then an on-going treatment programme can be handed over to an assistant - under the guidance of the qualified clinician.

There was also recognition about the potentially complex nature of the stroke patient, particularly in the early stages of recovery, with an individual and their family members
coming to terms with the dramatic changes to their physical, communicative, social and cognitive status.

HCP 6: Stroke patients are complex, lots of emotional things going on and so on and so on, you need someone who is experienced in stroke being directly involved in their day to day management.

The importance of not under estimating the skill and expertise required for successful therapy outcomes was expressed by a number of respondents.

HCP 3: even if you are doing something fairly routine, as a skilled professional, I think you do it in a very different way and you do lots of other stuff as well, the quality of what you do when you have a skilled practitioner doing it is very different and you constantly adapt what you are doing.

The reality, in the current economic climate, of needing a balance between qualified, more expensive HCP’s and support workers or volunteers was also recognised.

HCP 7 - you are never going to get enough highly qualified SLTs to be able to give one to one input every single day for every single stroke patient, it is just not going to happen.

Carers in particular identified being kept included in the aphasia rehabilitation process as very important, the need to provide rehabilitation for the whole family.

Carer 2: S (SLT) has been really good but firm when she has to be. The process with her has been... we have organised session 4 weeks or so in advance. She has been very good at explaining what is happening next week and what goals are. This has helped me know what I can do to help x and better understand what he can and cannot do.

3.7.5 Theme 3: Provision of aphasia related information

The issue of information was identified as one of the important attributes of good quality care and a crucial element of the care pathway. Participants from all three groups made a substantial number of comments about the importance of adequate, timely and comprehensive information about stroke and aphasia, given in a format that suits them best.
Given that one of the objectives of this research was to recommend what an aphasia care pathway should look like and how to most effectively communicate this material to those who need to use it, the question of how and when information was provided and how it could be improved was a key topic for discussion.

PWA, questioned in the focus groups could remember little about the information provided in the early days post onset of their communication difficulty. For the majority this did not matter as they reported being in a place where they could not take it in, due either to their physical, emotional or cognitive status.

For carers, however, the timely provision of information about the stroke, aphasia and its impact was identified as a very important issue, one often not provided in the way they would have liked.

    Carer 2: I think people would have welcomed a bit more ... of firm, even if it’s not firm if you know what I mean information, this is where we are, this is where we are going... in some sort of written form, a very simple hand-out that most people could understand. It would have made a huge difference.

    Carer 5: Maybe the more you know...it can be frightening... but if you know enough, it can help.

Others carers reported being given information, but not in the amount of detail they would have liked.

    Carer 4: SLT gave me a leaflet, I can’t remember what is was called, it was very general, it didn’t seem very clear what I could do with X, it was helpful in general, but not specific and she also gave me a book about, talking and conversations.

HCP’s, mainly nurses and therapists, were described as being the main source of information during the hospital stay. Carers also described that having written information, pamphlets, hand-outs and brochures was helpful: however, it could not replace the one-on-one information provided by the clinicians.

The format of the information giving was also discussed: carers were asked if they had a preference between information in 1:1 or group setting,
Carer 4: *For me personally, I would have been happy to have been in a group, but for a lot of people I think they would prefer to be on their own.*

Providing Information in a version that the person with aphasia could process and retain was raised by several carers

Carer 1: *Absolutely vital to pathway in a format that is easy to share families and the patient themselves, the idea of some sort of visual, something to look at that indicates the journey to expect.*

A similar point was raised by a number of HCP with regard to engaging the client and families

HCP 7: *If it is something they can think about and process and manage, we should give them as much information as we can, and involve then in the decision, especially if there are choices within the pathway, I think if patients can make choices themselves, then that is the way we should negotiate the pathway with patients, alongside them. It may not always be possible because of the nature of the client group we work with, but we should try and do that when we can.*

The timing of the provision of information is a key question frequently asked, and whilst there is consensus between all groups interviewed that information giving is a key part of the aphasia care pathway, the timing of the information needs to be very flexible. It is important to ensure that the information is available when it can best be used and when PWA and their families are ready to use it. Giving information in the early stages was described as both good and bad.

HCP 10: *It seems to me that you should give them lots but that it should be layered, The whole basis of empowering the patient and carer is that they should have information pertinent to their condition.*

HCP 3: *All the evidence is that you need to keep giving patients information throughout their recovery, because you take on board what you can at that time and sometimes you are not ready to hear information about what the long term prognosis is, whilst you are still hoping for a good recovery.*

This belief was reinforced by several carers’ comments including:
Carer 2: There needs to be an element of flexibility – but you probably just need some core things, core messages at different points

The format in which the information was provided was discussed by several participants.

HCP 10: I would argue you should always talk to somebody first, having talked to hem first, you ought to be giving them a paper copy, if they have a computer at home, send it to them electronically, so they can browse it - Forward it on to other people, son in America, daughter in Spain, but it also says, don’t worry it is there for you on paper but I will also send it to you in an email so if you want to send it to your daughter or son

HCP 5: any information left needs to have a named contact, so you can have a dialogue, it’s all about continuity, accountability, responsibility

The role of technology, including telemedicine, in provision of information including mobile applications was highlighted by HCPs as potentially useful tools from the acute period to rehabilitation.

3.7.6 Theme 4: Psychosocial factors influencing response to the aphasia care pathway

The importance of being provided with hope and positivity was reflected in most of the discussions with participants. Retaining a sense of hope was important in order to keep motivated and focused upon the rehabilitation being planned and provided.

Carer 2: Certainly in the first 6 months when the mind and the body and the whole family are still in a lot of shock, but keeping hopeful and motivated was vital.

HCP 6: And then the fear sets in and there is all sorts of psychological problems that are nothing to do with, or they are to do with the original stroke, but it takes a while for those to bed themselves in and you think ...And it is a very busy time, the initial time after the stroke and then after that it is a very quiet time, lots of time to think and worry.

The impact of returning home was highlighted by carers and HCPs, in particular the reduction in peer support for people once at home. Carers reported deriving support in the hospital setting from professionals and other families in a similar position.
Carer 6: *I was nervous in the beginning, when she first came home as it was up to me to look out for her 24 hours a day, I felt the responsibility. I was checking up on her all the time.*

Carer 2: *coming out of hospital and starting therapy was a bit disjointed, there could have been a bit more help in getting the next stage involved. It was a bit.. here you go, you are on your own now.*

Several participants reported that they had been told that the person with aphasia would only progress during the first 6 – 12 months and not to expect much change after that time, this often resulted in the individual and carer becoming despondent and low in mood as this time period drew close or expired and this affected response to any ongoing intervention or opportunities for support from the Stroke Association. A wife of a gentleman with aphasia was very proud to disprove what she had been told about the time span for progress as her husband had continued to improve for over two years after his stroke.

Carer 2: *They said the first six weeks you will notice a dramatic change and then it starts slowing down. It might get to six months, some people do progress on but a lot of people do stay at the stage you are at six months. I think that is important to get that out because a lot of people do think that after six months that is it. If you read a lot of the internet stuff it actually says that you never stop because, you and I never stop learning…*

HCP 6: *what they can predict at two weeks is much more uncertain than what we can predict at six months.*

Retaining a sense of hope and staying motivated was a shared theme between PWA and carers.

PWA 3: *Just want to be ...best mum I can. Got to work at it...*

PWA 12: *Make myself do things, you know.. you have to get up, keep going, keep busy.*
Carer 8: I try to keep upbeat and tell him things will get better, even if inside I really don’t know how things will be in 6 months or a year. I must stay positive to keep him motivated.

Some participants identified that their experience of hope was fluid and changed in response to how they perceived their current situation and their future.

PWA 1: *Some days .. all great. Other days terrible, angry then happy.*

PWA 4: *Don’t know where I want to be in three months.. year’s time, changes all time... taking things day at time*

They also discussed feeling positive about where they currently were in terms of the recovery and how this contributed to how they relate to aphasia rehabilitation.

PWA 9: *Gone a long way... happy...want to do bit more and bit more ...*

Rehabilitation staff provided hope for some participants, when the therapist was perceived to be supportive and hopeful; it appeared to help the participants think positively. Seeing their own progress gave hope that they would continue to improve.

PWA 7: *few meetings with SLT... I went from no speech... to what I am now. Just talking to her helped me.*

Carer: 5 *The therapist has been really good, she set him tasks, she called them goals each week which kept him going, kept him positive, always pushing him. Day to day things like writing a shopping list ...*

Retaining hope and motivation appeared to provide some families with the stability they needed to engage in the rehabilitation process, by identifying priorities or areas of importance for the individual and agreeing how they might work towards them together.

Carer 7: *My husband was very keen to use his computer again and R (SLT) worked on a way of helping him do this, small steps first, until he was able to send an email. He was so made up when he did this.*

The role of clinicians in helping to improve an individual’s psychosocial wellbeing was identified by some of the HCPs interviewed.
HCP 8: Clinicians need to be aware of the impact of making sweeping statements about progress or lack of it, people can still make some more recovery for years after a stroke but they have to retain hope and motivation. Giving falsely pessimistic feedback will not help with this. Health and social care providers need to be mindful of hope.

3.8 Discussion and recommendations

This chapter presented the findings of the qualitative arm of the study, which aimed to explore an aphasia care pathway from the perspective of different stakeholders. Underpinning this work was a need to identify how the pathway for PWA and their carers could be further developed and illuminated, so as to be accessible to them. In addition, it has advanced the evidence base regarding aphasia care pathways.

The findings from this study extend the knowledge and understanding of aphasia care pathway, by providing credible evidence of the experiences of PWA themselves. The thematic framework analysis identified aspects of the impact of living with aphasia that are consistent with the literature. Findings from this study, in relation to readiness for aphasia interventions (Worrall et al. 2011), the intensity of aphasia therapy (Enderby et al. 2016), the importance of longer term support provided by SLT, (Grohn et al. 2014) and the need for flexible provision of aphasia related information (Hinkley et al. 2013) reflect previous research. Furthermore, the focus on psychosocial well-being for PWA and how hope and motivation relate to how clients engage in rehabilitation (Bright, Kayas, McCann & McPherson 2013); (Hersh 2015) are also recurrent themes in the results of this study and within the literature concerning aphasia and its impact.

The HCPs interviewed, identified benefits and limitations of care pathways, which mirror those discussed in the literature (Cowey et al. 2014). Care pathways can provide a summary of best practice and interpretation of clinical guidelines, a structure or map to follow and a measurement of outcome, (Foster, Worrall, Rose & O’Halloran 2016). Limitations were also identified, notably that they can be too prescriptive and or simplistic and patients do not fit into neat boxes, in particular those with co-morbidities (Mudge,Hart, Murugan & Kersten,2017).
However, in addition to these similarities with the literature, there are some differences. PWA and carers identified having access to formal therapy by a qualified SLT, in order to gain maximum benefit from the rehabilitation process. This is in contrast to the findings of Bowen, Hesketh, et al. (2012) who concluded that communication therapy had no added benefit beyond that from everyday communication in the first four months after stroke. This difference may be explained by a lack of understanding of the potential contribution of a health care assistant or volunteer, with appropriate training and competency. The research conducted by Bowen et al. (2012) has received a number of critical appraisals, in particular with reference to study design; its findings have been included in the 4th edition of the RCP stroke guidelines (2016). There is also consensus within the literature that goal setting is beneficial for the rehabilitation process (Power et al. 2015) however carers had concerns about the process of setting specific goals for aphasia rehabilitation. They maintained that involving the person with aphasia, whilst important to do, in reality was very difficult and dependent on the individual’s motivation and understanding of the process.

There is consensus within the literature that goal setting is beneficial for the rehabilitation process. Power et al. (2015) conducted a survey of 250 SLTs in Australia to develop and validate a national set of best practice statements for use in post-stroke aphasia rehabilitation. Goal setting was identified as one of the eight domains of care for PWA, a dynamic process that is reviewed throughout the continuum of care in order to reflect client and family context and wishes. SLTs involved in this consensus agreed that therapists should explain the goal setting process, including the potential benefits, to the client and their family in an accessible way and assist in the identification of goal areas. Power et al. (2015) conclude that collaborative goal setting between the therapist, client and family needs to be a central feature of the aphasia rehabilitation process. In the aphasia care pathway study, carers interviewed had concerns about the process of setting specific goals for aphasia rehabilitation. They maintained that involving PWA, whilst important to do, in reality was very difficult and dependent upon the individual motivation and understanding of the process.
3.8.1 Methodological strengths and limitations
This qualitative study demonstrates successful use of qualitative research methods, to engage the key stakeholders of aphasia care pathways in qualitative research concerning them. The results presented here complement findings elsewhere in the literature, illustrating that focus groups and interviews with PWA, carers and HCPS can be used successfully to collect qualitative data, provide opportunities to voice personal opinions and experiences and make a valued contribution to research. However practical strategies are required to enhance the effectiveness of the processes and experiences of those involved, (Carlsson, Pateson, Scott-findlay, Ehnfors & Ehrenberg 2007). The focus groups for PWA in the care pathway study were designed with their communication difficulties in mind and facilitated by the researcher, who was knowledgeable about the specific nature of these difficulties and their potential effects on the interviewing process. Carlsson et al (2007) identified a number of practical strategies to enhance the efficacy of the qualitative interview with people who have communication impairments. These included an appropriate sampling method, informed consent and close monitoring for fatigue and overload. Similarly, a strength of the aphasia care pathway study is derived from its rigorous design, data collection and data analysis processes. This study’s audit trail provides a mechanism for ensuring transparent and rigorous translation of the findings, enabling readers to reach similar conclusions to the findings presented in this chapter and then apply them to their own specific area of professional practice.

The qualitative methodology underpinning this study aimed to explore an aphasia care pathway from the lived experience of those with direct experience of stroke and aphasia. Qualitative approaches assume a naturalistic, unstructured and open ended approach to data collection (Ritchie, Lewis et al. 2014). All of the interviews and focus groups in this study occurred in natural settings, in either an SLT outpatient environment or an individual’s home. The focus groups provided a qualitative data collection tool sensitive to the needs of PWA, namely the importance of a reassuring environment, with people in a similar situation to themselves. They also ensured the study was grounded in the needs and opinions expressed by those with the most insight, namely PWA. The groups were structured; a topic guide, supported conversation (Kagan et al. 2010) and projective techniques (Merriam & Tisdell 2015) were all used. These prompts were designed and
used in order to support participant’s understanding, reflection and discussion of their aphasia journey. This structure was necessary as a result of the participants’ acquired language and communication difficulties, enabling them to contribute to the research. It is recognised that prompting participants can jeopardise the essence of their meanings and may result in some information being withheld (Kerr et al 2012). This was moderated by the use of a single interviewer for all the focus groups and interviews, thus contributing to a consistent data collection, minimising the potential for random bias in the findings.

A potential limitation was that participants for the qualitative arm of the study were recruited from one health trust: therefore only one aphasia care pathway was explored. The views obtained were retrospective, therefore a potential recall bias (Bowling 2014) of participants who were asked about events and experiences that may have happened as long as seven years ago (PWA.1). This potential risk was managed by providing an information sheet which detailed the aims of the study, to enable participants to give some thought to the topic before attending the focus group or interview. Participants were also encouraged to take their time to reflect and think through the sequences of events before responding to questions. The context specific nature of the research, focusing upon participants living within one geographical area, limits the breadth of the findings, however maximises the depth of data collected. The experiences of people with severe or global aphasia and cognitive difficulties are not represented in the data here. These individuals were excluded for methodological and ethical reasons because it was not possible to ensure that they had the capacity to comprehend the nature of the study and therefore an ability to make an informed choice of whether to participate.

There was also a risk that the purposive sampling was incomplete (Bowling, 2014). PWA were recruited through the CSS co-ordinators thus limiting the sample to participants who had attended or were currently attending a CSS group. Complete, theoretical, saturation was not achieved because, although participants were purposively sampled, they did not represent all sub groups of PWA, for example those of working age who could not access CSS, those who chose not to be referred to CSS.
3.8.2 Implications for practice

Despite the methodological limitations, the qualitative study demonstrates that PWA, carers and HCPS have the ability to reflect on and discuss their perceptions of an aphasia care pathway. It demonstrates that, despite experiencing acquired language difficulties, PWA can be directly involved in the process of decision making.

Furthermore, the four themes presented above also have the potential to be a focus for change and improvement within SLT services, with an impact on the quality and outcomes for PWA and their families. Consideration should be given to the timing of aphasia interventions, early may not be best, the provision of information relating to aphasia and how it can be managed. The development of an accessible version of a care pathway needs to be explored further.

3.9 Summary

In summary, this study’s findings provide credible knowledge of the experiences of the key stakeholders of an aphasia care pathway. It describes the themes shared by PWA, carers and HCPs and discusses how these relate to the literature. It also highlights the implications for future research and development in this area. These findings also provide further justification for the use of qualitative research methods with this population, allowing PWA, in particular, to contribute their experiences and perceptions.

Chapter four will discuss the quantitative arm of the aphasia care pathway study, the qualitative data discussed above being used to inform this phase of the research.
Chapter 4 MIXED METHODS DESIGN – the quantitative study

This chapter presents the quantitative study, informed by the findings of the qualitative presented in chapter 3. A qualitative methodology was selected to explore the perceptions of the pathway users. However, in order to add breadth to the research and provide some measurement of the use of aphasia care pathways within the SLT profession, a quantitative element was introduced. This chapter consists of four main sections:

- Introduction
- Method
- Results
- Discussion

4.1 Introduction to quantitative research design

Quantitative research, by definition, is concerned with quantities and relationships between different attributes. It involves the collection and analysis of data in the positivist tradition, where the assumption is made that knowledge is predictable and stable and consequently structured observations or experiments can be used to confirm or disprove a hypothesis, (Creswell & Plano Clark 2007). Quantitative research typically addresses questions regarding effectiveness, causality, incidence and prevalence, diagnosis and screening (Greenhalgh, 2010). It is appropriate when there is a pre-existing knowledge or practice, aiming to test a theory deductively, a top down approach to the gaining of knowledge (Bowling 2014). A hypothesis is constructed, based on existing theory and a research strategy designed to test the hypothesis. The literature review establishes the importance of the purpose and research problem and is used to help identify the hypothesis. The focus is upon closed questions, collecting numerical data from many participants, at a number of sites or locations, in contrast to qualitative research where participants are studied in their home, work or social setting. Within the quantitative methodology, data is collected from experiments, checklists, surveys or information available in accessible documents, for example census reports (Creswell & Plano Clark 2014).
4.1.1 Background to the quantitative study
In order to gather information on aphasia care pathway practices, a survey of practising SLT’s was conducted, the aim of which was to gain a greater understanding of SLTs knowledge, attitudes, and practices regarding an aphasia care pathway. Specific objectives were to ascertain the incidence of SLTs using an aphasia care pathway and if in use, how it was developed, introduced and monitored. Respondents were also invited to give their perceptions of any strengths and limitations of the pathways they were reporting on. A survey was the most appropriate method to employ to gather this data as the core question related to incidence and outcomes. The survey aimed to provide information about the frequency of the use of an aphasia care pathway, what core components the pathway should include and perceived advantages and barriers there were in its use. The survey also aimed to evaluate in the concept of an accessible, aphasia friendly version of a care pathway.

4.1.2 Aims and objectives of the study
The aim of this study was to determine the use of an aphasia care pathway, within the SLT profession in the UK. This aim was intended to be realised by the following objectives:

- To quantify the number of SLTs using an aphasia care pathway
- To identify the main sections of the pathway
- To determine the number of SLTs who supported an accessible version of an aphasia care pathway
- To extend and quantify the findings of the exploratory phase of the mixed methods study, by comparison, with the qualitative data findings of the focus groups and interviews detailed in Chapter 3.

4.2 Method
This section describes and justifies the study design, data collection and analysis of the survey.

4.2.1 Study design
For the quantitative arm of the aphasia care pathway study, a non-experimental, descriptive design (Bowling 2014) was selected. Non experimental research involves
variables that are not manipulated by the researcher and instead are studied as they exist (Bowling 2014).

A survey was identified as the most appropriate method of data collection: this is a traditional quantitative source of data collection, which seeks to describe what is happening in day to day clinical practice. The term survey refers to the selection of a sample of people from a pre-determined population, referred to as the population of interest. The researcher uses information from a sample of individuals to make some inference about the wider population (Bowling 2014). It is a cross-sectional, often inexpensive, descriptive data collection method, used where the purpose is to describe how many people in a given population possess a particular attribute or opinion at a particular time. It can help investigate the relationship between variables but does not determine causation (Oppenheim, 2000) and can be delivered to potential participants in a number of ways, including post, telephone, face to face and electronically (McPeake, Bateson & O’Neill 2014). A survey is used to obtain data, describing incidence or prevalence, allowing the researcher to convert participants’ responses into numbers and subsequently complete statistical description and / or analysis (Rattray & Jones 2007).

Quantitative research surveys can be either cross-sectional or longitudinal (Bowling 2014). Cross sectional surveys are carried out at one point in time, providing a snapshot of what is happening in the group being surveyed. In contrast, a longitudinal survey explores events or attitudes over time. This may be a cohort survey, following the same group of individuals over time, or trend surveys taking repeated samples of different people over time, using the same core questions. The aphasia care pathway survey was cross sectional, quantifying SLTs’ experiences of using a pathway as well as current behaviours and attitudes.

Archer, Wellwood, Smith & Newham (2013) used a self-complete questionnaire to determine the practice patterns of SLTs working with clients with post stroke dysphagia (swallowing difficulties). A web based survey was distributed to SLTs using the RCSLT Bulletin and Clinical Excellence Networks (CENs). The results of the survey highlighted the discrepancies between the evidence base and clinical guidelines and actual clinical practice. The authors concluded that a consensus statement was needed to guide future
dysphagia practice. The survey design and administration utilised in this dysphagia study were influential in the design of the aphasia care pathway survey.

4.2.2 Design of the survey
Careful consideration and thorough planning is essential when constructing a survey (Bowling 2014). An inappropriate tool and lack of rigour is likely to result in poor quality data, misleading conclusions, and unfocused or vague recommendations, (Boynton & Greenhalgh 2004). The design, wording, form, and order of questions can affect the type of responses obtained, and careful design is needed to minimize bias in results (Keeley, Clark, Brown & Sitzia 2003). Question wording, form and order can affect the type of responses received: the layout must be clear, professional and easy to read. Ineffective questioning techniques can create barriers, stifle the flow of information and restrict potential to collect accurate data (Bowling 2014). Questions need to be succinct and unambiguous in their wording (Boynton & Greenhalgh, 2004).

Within the care pathway survey, the terminology of each question was carefully considered so that questions were phrased in a positive style, to avoid causing any ambiguity or confusion. A list of topics relevant to the aims and objectives of the study was collated from the preliminary findings of the qualitative data. These included the frequency of use of an aphasia care pathway by SLTs, the purpose of the pathway if used, the core elements of the pathway, the value of an accessible version of the aphasia care pathway and advantages and limitations of an aphasia pathway. Results from the qualitative arm of the study revealed services users were advocates of a structured, systematic pathway, which included timey provision of information, clear communication about assessment and intervention phases of rehabilitation and was available in an accessible format. The survey questions were designed to reflect these findings.

Consequently, there are important steps to complete when designing and implementing a survey (Neuman 2006) as summarised in table 4.1. These were considered when devising the aphasia care pathways survey. Instructions for the respondent were provided at the beginning of the survey or at the start of each question if there was a variation in question types to avoid any ambiguity.
The survey opened with an introduction to its purpose and reiteration about the anonymity of responses, as also included in the cover letter or email sent prior to circulation of the survey. Question one of the survey was a broad closed question, asking participants if an aphasia care pathway was used in the SLT setting in which they worked. Questions then became more specific with some pre-coded responses, for example question two asked participants to rank the importance of potential headings within an aphasia care pathway. Seven headings were provided, including information giving, goal setting, interventions and therapy. The headings were taken from the findings of the qualitative data. It was decided that this approach would facilitate a clear, comprehensive and appropriate flow of questions, enabling the respondent to formulate, articulate, and transmit their answers effectively. There was close scrutiny of the questions to ensure they related to one or more of the study’s objectives. Demographic questions were asked at the end of the survey.

Responses to question 1 “do you use an aphasia care pathway in your clinical practice”, was classified into three categories using nominal codes, 1 = no, 2 = yes 3 = unsure. Nominal data was used for questions 1, 6, 9, 10 and 11 in this aphasia care pathway study. Nominal data refers to when numbers are used as labels, to classify responses into categories based on a characteristic, for example, response or non-response to an intervention.

Ordinal data is used in health related research to provide a more detailed level of information than is possible with nominal data. Categories can be graded, ranked or ordered and rating scales may be used to yield numerical scores on the attribute being measured. Questions 2, 3 and 12 use an ordinal scale. Measurement scales are commonly used when devising a survey, providing respondents with sentences that state beliefs about the particular attitude or issues being measured. There are four main scaling methods, used to assess attitudes, Thurstone, Likert, Guttman and Semantic Differential Methods (Bowling 2014). The Likert Scale (Likert 1923, as cited by Bowling 2014,) was used in this study survey. This method, originally developed from the Thurstone scale, is an attitude scale consisting of items, in the form of statements, with which the respondent has either to agree or disagree: numerical values are then given to each statement. The Likert scale was used for question two and three of the aphasia care
pathways survey eg, respondents were asked to rank in order of importance: headings within an aphasia care pathway (question 2) and the value of an aphasia care pathway, (question 3).

Demographic questions were also included, regarding the grade of respondent, with reference to Agenda for Change and length of time working as an SLT, to give an indication of levels of professional expertise, main area of working e.g. acute or community setting or both and employer information e.g. NHS, private organisation or independent practice. It was not considered to be relevant to the research question to include items relating to age or gender.

All participants should be given a cover letter or email which includes information and contact details about the organisation and person conducting the research, the aims of the study and how the information received for participants will be used, (Kelly, Clark, Brown & Sitzie 2003). Bowling (2014) argues that this good practice is likely to increase response rates, as participants are more likely to respond to a request if it comes from a legitimate, professional body, includes information about why their contribution will be beneficial and how the results will be used.

McPeake, Bateson & O’Neill (2014), debate the advantages of using web based or electronic surveys, both of which were considered by the researcher and a decision made to use a web based survey as the primary method of distribution. The main benefits of this approach included the design flexibility, time efficient and economical method of distribution and convenience for the respondent. The advantages and limitation of electronic surveys will be discussed further in section 4.6.1. The information which would have been contained within a cover letter for a postal survey, was provided at the beginning of the on line survey. It was also summarised in the item in the SLT professional publication Bulletin, inviting people to take part in the survey, to maximise response rates. See appendix 19 for a copy of the letter published in Bulletin, March 2015.
4.2.3 Piloting the survey

Piloting is an essential procedure to complete when constructing and administrating a survey, to strengthen the design process, address any design faults or serious errors in the measure and to control for face validity (Bowling, 2014). Face validity is important to evaluate if a survey measures what it intends to and ultimately, if the overall measure is useful for its intended purpose (Greenhalgh, 2010). Consequently, a survey should be tested on a pilot sample of members of the target population, as this process allows the researcher to identify whether respondents understand the questions and instructions,
and whether the meaning of questions is the same for all respondents, as debated by Kelly et al. (2003). These authors emphasise the importance of addressing the following points in the pilot process:

- Are the instructions clear and unambiguous?
- Is the wording understood clearly and in a similar way by all respondents?
- Is the coding system clear to follow?
- Are all reasonable alternatives to questions provided?
- Is the order of the questions logical?
- Are any ambiguous or leading questions identified?
- Do responses suggest that all relevant topics and issues have been included and has anything significant been omitted?
- Is the overall layout stimulating and inspiring for respondents to complete?
- How long did the survey take to complete?

Piloting of the aphasia care pathway survey provided an opportunity to evaluate how participants comprehended questions and the response formats. Furthermore, it enabled a calculation of the time taken to complete the survey.

The survey was piloted by six SLTs; three were working within Solent NHS Trust and three were working in other NHS organisations. Participants were asked to complete five short feedback questions, see appendix 20. An incentive was also provided to those who completed the pilot.

The survey was also reviewed by the researcher’s supervisor and professional doctorate clinical tutor and constructive feedback provided.

Ranking in questions 2 and 3 provided the most queries during the pilot phase of the survey. The two quotes below summarise this:

*Were any questions unclear or ambiguous – if so please state which and why?*
SLT 1: The “ranking” questions 2 and 3 – I first thought I had to put them in order of importance, but then realised that they could all be scored using the 1-5 scale you set out. Is it worth putting the 1-5 scale next to each question? (perhaps you already thought about this and discarded the idea?)

SLT 4: Not unclear, but tricky to answer. In question two, I don’t know whether you want to rank how important it is to deliver that aspect (if for some reason you were only to do some of these) or if this is how you must structure pathway documentation. Ranking in importance of what the client receives and how much of each element may be different than ranking what headings would help people to know what we do. I am sorry I don’t have a constructive suggestion how to overcome this minor confusion.

Following the pilot phase, some modifications were made taking into consideration the feedback provided

- Questions 2 and 3 were reworded to avoid ambiguity identified by SLT 4, a scale was provided for each sub question.
- Additional space for free text was added to Questions 4 and 5, with bullet points.

A statement about the length of time to complete the survey, based on the data from the pilot, was included, following feedback for those who piloted the survey. Feedback indicated the survey took between 10 and 15 minutes to complete.

4.2.4 Data collection

A survey can be distributed in a number of ways and can employ a range of methods to answer the research question. Common survey methods include electronic surveys, postal questionnaires or telephone interviews (McPeake et al. 2014).

The survey used in this study was self-completed and distributed using a web based survey tool and in paper form, see appendix 21 for a copy of the final survey.

In recent years, electronic surveys have increasingly been used and can be a valuable method of quantitative data collection. Bryman (2012) discusses two main types of electronic survey, web based and email delivery. A web based survey invites prospective respondents to visit a website where the survey can be located and completed on line.
This can allow for more complete population coverage, reducing participant burden and ensuring anonymity (Archer et al. 2013). Email surveys are either embedded in the text of an email or the survey is included as an attachment to an email that introduces it.

A number of the commercially available products facilitate the survey design process, allowing for an easier, more flexible and visually attractive design. Web based surveys have a further advantage of reducing inaccurate or item-missing data by providing a warning to respondents when they have left a question unanswered or incomplete. The logistics of carrying out a web based survey are more straightforward, they can be virtually paperless, making them easier to manage. There are no surveys to print: no handling of letters, labels, envelopes, or postage: and there are no completed paper surveys to organise and store (Dykema, Jones, Piché & Stevenson, 2013).

An evaluation of suitable online survey systems was completed and the Bristol On Line Survey (BOS) was selected, primarily for ease of distribution. It was available free of charge for students at the University of Portsmouth, with on-site expert advice available.

4.2.5 Sampling

The concept of sample is intrinsic to survey research. Usually it is impractical and uneconomical to collect data from every single person in a given population; therefore a sample of the population has to be selected (Kelly et al. 2003). The methods by which a sample is selected is integral to the external validity of the survey as the sample has to be representative of the larger population in order to ensure the findings are transferable (Bowling 2014).

Convenience sampling, a form of purposive sampling, as discussed in chapter 3, was used and a specialist population was identified, namely SLTs working with PWA. This approach was selected as it was not possible to state an exact population size for SLTs working with PWA.

SLTs receiving the monthly professional publication “Bulletin” or who were on the mailing lists of RCSLT CENs, or related organisations, were invited to complete the survey. Bowling (2014) emphasises the importance of ensuring the accessible population has been included in a survey; the strategy of using the professional publication and online networks provided this.
Sampling error must also be considered, this is the probability that any one sample is not completely representative of the sample from which it has been drawn, (Bowling 2014). This is discussed further in section 4.6.1.

4.2.6 Distribution of the survey

Any qualified SLT, working with PWA in any clinical setting, was invited to complete the survey. The survey was initially launched using a short article in the SLT monthly publication “Bulletin” (March 2015). In addition, clinical advisers for aphasia and members of Clinical Excellence Networks (CENs) for aphasia were contacted and asked to forward details of the survey to members. A request to complete the survey was also included in the RCSLT on line research newsletter. The survey was initially available on line between April and June 2015. The data collection period was extended for a further two months to gain a greater return. In addition to the online version of the survey, paper copies were distributed. The researcher attended SLT team meetings to distribute the survey and a total of 25 paper copies were distributed and completed in this way.

4.3 Analysis of the survey data

This section will summarise the results of the survey to practising SLTs examining the use of an aphasia care pathway. Descriptive statistics, using the statistical package SPSS (http://www.spss.com), predominantly frequency counts, were used to analyse questions 1, 3, 6 and 9 to 12. Cross tabulation was then used to explore the relationship between question 1 and questions 6-12. Open ended questions (questions 4, 5, 7 and 8) were analysed qualitatively, as recommended by Boynton (2004).

4.3.1 Descriptive statistics

Nominal data codes, classifying responses into categories based on a characteristic, was used for questions 1, 6,9,10 and 11 in the aphasia care pathway study. Ordinal data, grading or ranking data was used for questions 2, 3 and 12.

The research data was entered into an Excel spread sheet and exported into the statistical package SPSS 22 to support data analysis. Data cleansing checks were completed and identified corrections made; this involved checking the data sheets by hand for any missing data and any inputting errors. A small number (<10) of inputting errors were identified and corrected by this researcher.
Coding is an essential stage of survey data analysis. It is the method of organising research data and classifying it for analysis. A number or numerical code was assigned to responses in order for it to be entered into SPSS. Each question was defined, labelled and a number assigned to each of the possible responses as summarised in table 4.2 below.

Table 4.2 Coding instructions

<table>
<thead>
<tr>
<th>Question</th>
<th>SPSS</th>
<th>Coding instruction</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.Use of CP</td>
<td>CP used</td>
<td>0=no, 1=yes, 2=unsure</td>
</tr>
<tr>
<td>6. Accessible version of CP</td>
<td>CP AV</td>
<td>As above</td>
</tr>
<tr>
<td>9. No. of years working</td>
<td>Years working</td>
<td>1=0-5 2=6-10 3=11-15, 4=16-20 5=20+</td>
</tr>
<tr>
<td>10. Clinical setting where SLT works</td>
<td>Setting</td>
<td>1=acute, 2= community, 3=both</td>
</tr>
<tr>
<td>11. Primary source of employment</td>
<td>Employer</td>
<td>1=nhs, 2=private, 3=other</td>
</tr>
<tr>
<td>12. Grade of SLT</td>
<td>Grade</td>
<td>1=B5 2=B6 3=B7, 4=B8a 5=B8b 6=B8c</td>
</tr>
</tbody>
</table>

Descriptive analysis was undertaken to aggregate the survey question and describe the characteristics of the sample. Descriptive statistics were used to summarise and describe patterns in the data. The proportion of responses to each question was calculated and expressed in a percentage. A mean score and standard deviation was obtained for questions with a normal distribution, a median score and interquartile range (IQR) was calculated for data with an abnormal distribution, see appendix 22 for table summarising this data.

The categorical data is reported in tables and graphs as numbers (percentages) while continuous data are reported as mean, median (standard deviation/ interquartile range).

4.4 Survey findings

During the six month recruitment phase a total of 83 responses to the survey were analysed, 57 replied to the on line survey, a further 26 responses were obtained in paper form. Given that inferential statistics, which would require a core sample size of 100, were not used, 83 was a viable number for a descriptive statistical analysis.
The results of the descriptive analysis are provided on a question by question basis, followed by the results from chi-squared analysis. Based on the cross tabulation data described, no significant difference was found for use of the care pathways, when compared to the other variables, for example, years working, grade, clinical setting (see appendix 20).

4.4.1 Results of the descriptive analysis

*Question one* asked respondents if they used aphasia care pathway in their clinical setting. A total of 42% (no = 34) stated they did use an aphasia care pathway, as illustrated in figure 4.1 below.

Figure 4.1 No. of SLTs using aphasia care pathway

*Question two* asked participants to rank on a scale of 1 to 7, the potential headings of an aphasia care pathway, with 1 being not important and 7 being very important.

Information giving was ranked between 5 and 7 (important / very important by 78% of respondents (no=62). Goal setting and assessment were also both ranked highly. Onward referral received the lowest overall ranking, 51% of respondents (no= 42) identified this as important, by ranking as 5 to 7.

*Question three* asked participants to rank on a scale of 1 to 6 the value of using an aphasia care pathway, with 1 being not important and 6 being very important.
Providing a consistent therapy approach was identified as the most important value of an aphasia care pathway with 89% of respondents (no=63) ranking it between 5 and 7. All the other headings provided were ranked in a similar way.

**Question six** asked if the aphasia care pathway should be in a format that could be shared with PWA and their families, 88% agreed (no=72) as illustrated in figure 4.2.

Figure 4.2 Number of SLTs agreeing to statement regarding an accessible version of an aphasia care pathway

![Bar Chart](Q6 Accessable version of Aphasia care pathway)

**Question nine** asked how many years the respondents had been working with PWA (figure 4.3). SLTs working between 6 and 10 years was 31% (no=26) and 21% (no=17) had been working between 11 and 15 years.
Question ten requested information about the clinical setting the SLT responding to the survey primarily worked in. 42% (no=34) of respondents were community based, 27% (no=22) worked in an acute setting and 32% (no=26) worked in both. These results are illustrated by figure 4.4.

**Figure 4.4 Primary clinical setting where respondent worked**

<table>
<thead>
<tr>
<th>Response by Primary Clinical Setting / %</th>
<th>0.0%</th>
<th>5.0%</th>
<th>10.0%</th>
<th>15.0%</th>
<th>20.0%</th>
<th>25.0%</th>
<th>30.0%</th>
<th>35.0%</th>
<th>40.0%</th>
<th>45.0%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Acute</td>
<td>26.8%</td>
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<td></td>
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<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Community</td>
<td>41.5%</td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Both</td>
<td>31.7%</td>
<td></td>
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</table>
**Question eleven** looked at the primary employer of the respondents. 87% (no=70) of respondents worked for the NHS; the remainder worked either within independent practice or “other”.

**Question twelve** required respondents to give their work grade, according to Agenda for Change banding. 48% (no=39) were Band 6, or generalist SLTs and 37% (no=30) were Band 7, highly specialist SLTs. Figure 4.5 summarises the results.

Figure 4.5 Agenda for change banding of respondents

![Agenda for change banding of respondents](image)

4.4.2 Results of the qualitatively analysed questions

A thematic analysis was completed for the data from free text questions, 4, 5, 6, 7 and 8.

**Question four** asked respondents to give three advantages of using an aphasia care pathway.

Seven participants responded to these questions; the following three themes were identified:

**Theme 1: Consistency and clarity of provision**

- *useful for less experienced therapists*
- *makes the patient journey clear for the patient and family.*
- *useful to inform commissioners about the value of what we do.*

**Theme 2: Equity of provision**

- *provides an equity service*
- *allows for a more consistent approach to interventions*
- *allows for greater clarity of role, who does what*
Theme 3: Audit tool

- explicitly recognises when key standards have been achieved and when resources do not permit a full range of interventions.
- way to measure what is or is not provided
- Concrete tool to share with non SLT service managers to show the gaps between what the aphasia journey should be and what is current practice

Question five was also a free text question, asking respondents to give three limitations of using an aphasia care pathway, producing seven responses with the following three themes:

Theme 1: Non flexible approach

- potentially too constraining, reducing option for a flexible service
- reduced individualised approach, too prescriptive, process driven
- will not account for every scenario, may exclude people with alternative needs

Theme 2: Complicated process

- Still relatively abstract and difficult for some to understand, may be too SLT focused for the MDT

Theme 3: Keeping the pathways up to date and “live”

- in the reality of a busy and demanding clinical schedule, keeping any guidelines or pathways up to date, adding new evidence is a challenge

Question six was analysed quantitatively, as above, as well as qualitatively. Participants were asked to propose how an accessible version of an aphasia pathway might work. Seven of the 82 participants responded, two themes emerged, relating to the format of presentation:

Theme 1: A paper version

- flowchart of booklet format, with photos, keywords ...
- a picture, symbol or photo and single word or short phrase representing each activity or step.

Theme 2: An electronic version

- a DVD or “slide show” format
- an “app” for use on IPad
**Question seven** requested comments about who should be providing which parts of the care pathways. Twelve comments were received: the predominant theme was that assessment was the domain of the SLT, therapy planning for PWA would be led by the SLT with patient, MDT and family involvement.

- *Specialist roles must be reserved for the professional with the specific skills e.g. assessment and aphasia therapy planning for SLTs*.
- *SLTs to assess and negotiate goals, support for implementing these could come from assistants, voluntary sector, carers, depending on the intervention*”
- *Goal setting around aphasia should be an activity led by SLT but in liaison with patient, MDT and family*

**Question eight** asked for any further comments or opinions about an aphasia care pathway. Two responses were provided which have been themed together to describe how an aphasia care pathway can provide instruction and guidance.

- *I think it is a good idea, I have used pathways to explain our service to other professionals and patients and their families, though this is easier the simpler the pathways*
- *could the pathways show possible and definite stopping off points eg everyone will get x,y,z, whilst some will also get a,b."

4.5 Summary of survey findings
The survey reported here sought to identify the frequency of use of an aphasia care pathway by SLTs working with PWA. The eighty two respondents, predominantly band six and seven SLTs, working principally within community and acute settings, revealed an inconsistent use of an aphasia care pathway within clinical practice. Fifty nine per cent (no = 48) of respondents reported either that they did not use an aphasia care pathway, or were unsure if one was in use. There was however a strong trend towards the importance of an accessible version of aphasia care pathway. Eighty eight per cent (no=72) agreed that an accessible version of an aphasia care pathway should be available.
Information giving, goal setting and intervention were ranked the highest by participants as being important headings for an aphasia care pathway. The value of an aphasia care pathway in providing a consistent approach to therapy was ranked highly by the majority of respondents.

4.6 Discussion

Chapter four has presented the findings of the quantitative arm of the study which aimed to determine the use of an aphasia care pathway within the SLT profession. Underpinning this work was a need to measure both the frequency of use of an aphasia care pathway and to identify how many SLTs supported the concept of an accessible version. The survey has also clarified what the purpose of an aphasia care pathway should be and some of the important headings.

Demographic data suggests the respondents were comparable in terms of number of years working and clinical setting to those recruited in the UK and Ireland by Archer et al. (2013). In this study of post stroke dysphagia therapy, the authors were not able to provide an estimated target population, as the number of SLTs working with stroke patients is not accurately recorded within the UK. Similarly, in the aphasia care pathways study it was not possible to determine a response rate as the number of SLTs nationally working with aphasia is not available. The researcher contacted the RCSLT for details of the membership across all clinical specialities, this is approximately 13,000, however there is no breakdown from this figure of the number working with PWA.

Rose et al. (2014) used a web based survey of SLTs in Australia, to identify aphasia rehabilitation practices. Unlike the researcher in the aphasia care pathway study, Rose, Ferguson et al. (2014) were able to access a national database of SLTs working with aphasia in Australia. 188 Australian SLTs responded to the survey, representing 33% of the total potential target Australian population. Some findings were similar to the aphasia care pathway study, notably respondents identified the importance of providing PWA and family members with aphasia related information. The vast majority of respondents (97%) reported this should be a priority, stating verbal and written information as being the most likely format. Participants discussed the challenges in wanting to provide more frequent and comprehensive formal and informal education of PWA and their families,
however time and resources to do so was a challenge. In addition, the authors acknowledge the limitations of family availability to participate. These arguments are important to consider when making recommendation about how and when aphasia related information should be shared.

4.6.1 Methodological strengths and limitations
This quantitative study demonstrates successful use of quantitative research methods, to survey SLTs about an aphasia care pathway.

The design employed an appropriate sampling method and data collection method, comparable to that employed in researcher studies with similar objectives (Simmons-Mackie, Threats & Kagan, 2005) (Sirman, Beeke & Cruice, 2017) notably sampling SLTs with an expert knowledge of aphasia and the use of a web based survey for data collection.

The use of surveys, as a method of data collection in health-care research, was noted to be increasing as part of the emphasis upon evidence based practice. Bowling (2014) debates the importance of researchers having a solid understanding of the theoretical issues associated with this method of data collection. The author discusses the benefits of using a survey as a means of data collection, notably that it is a cost-effective way of finding out what people do and think, allowing the researcher to collect easy to count answers. The method can also easily be combined with other methods to produce richer data, for example focus groups, or interviews, as in the case of the aphasia care pathway study. A survey can cover a wide geography, where participants who are widely dispersed can be accessed and included in the sample. The growth of on line surveys makes this easier, web based surveys having the advantage of providing an initial analysis of the data. It is estimated that a web based survey is one third to one half of the costs of a comparable mail survey (Dykema et al. 2013). As they rely on computer assistance in addition to self-administration, web-based surveys offer greater ease and adaptability in designing questionnaires than do paper surveys. These strengths are relevant to the aphasia care pathway study. The method of distribution was efficient and inexpensive and the web based survey allowed for a more complete SLT population coverage for sampling. The Bristol on Line Survey software completed an initial analysis of the data, calculating the response rate to the individual questions.
There are limitations of the survey as a method of data collection that are important to consider (McColl, Jacoby, Thomas, Soutter, Bamford, Steen, Thomas, Harvey, Garrett, Garrett & Bond 2001). The researcher anticipated that a web based survey would yield a high rate of returns, due to the speed and ease of survey completion. In addition, the targeted individuals were considered to be “professionally active”. Given these expectations, the response rate, (no = 57), to the web based survey was disappointing. It is important to acknowledge that recruiting participants to complete a survey will be limited, for practical reasons, to those who are easily accessible and willing to participate. Whilst convenience sampling was used in the aphasia care pathway study, there was a risk of volunteer bias. This is the concept that people who volunteer to participate in a research study, may have some different characteristics to those who do not volunteer. Simmons–Mackie et al. (2005) discuss the risk of bias when using a survey to a targeted group. Their research regarding the use of outcomes measures within aphasia, involved a survey to SLTs working in this particular clinical area. The authors discuss the possibility of bias given that the sample source, e.g., members of an Aphasia Special Interest Group and or clinicians with an interest in the survey content. While this represents a flaw in the sampling design, the authors argued that membership of a special interest group represents a particularly “informed” group of SLTs, who would be more likely to be aware of current trends and issues. Thus there is potential for the results of the survey to represent the “best practices” of SLTs in the area of aphasia outcome assessment and should be interpreted with this in mind. A similar argument can be made with regard to respondents of the aphasia care pathway study, it is also possible that SLTs who responded to this survey represent a more professionally active and informed group of SLTs than a random sample of HCPC registered clinicians. Thus, the results should be interpreted with these considerations in mind.

A further challenge on the use of surveys, within health care research, is the possibility of a low response rate, which can result in bias, as non-responders may be systematically different from respondents (Cook, O’Dickinson & Eccles 2009). In addition, the targeted individuals were considered to be “professionally active”. Given these expectations, the response rate to the web based survey was lower than expected.
McPeake et al. (2014) draw on their experiences of developing and distributing electronic surveys to debate the benefits and challenges of this specific form of survey distribution. The responses are automatically copied to a database, so the need for separate data entry is eliminated and the need for data cleaning is greatly reduced. Many web based programmes have a facility to complete some level of analysis, including totalling the number of respondents, a summary of the numerical and narrative data, and options to merge, compare and cross tabulate the findings, all utilised in the study described here. McPeake et al (2014) discuss lower response rates and suggest survey saturation is a significant factor. Healthcare professionals are increasingly being asked to complete surveys, this may result in them only responding to those that are absolutely necessary or that are of direct interest to them. This arguably could have been a factor for the care pathway survey, the Bulletin publication frequently includes requests for SLTs to complete an on line survey. McPeake et al. (2014) suggest practical strategies to maximise response rates for electronic surveys, which include ensuring a clear explanation of the purpose of the survey is provided, having an accessible link to the survey, and being transparent about the anticipated length of time the survey should take to complete. They also recommend that reminders or alerts to complete the survey should be used if possible. A further short item requesting SLTs to respond to the survey was published in the SLT Bulletin, in June 2015, with the aim of increasing the response rate. A reminder email may have elicited a higher response rate. It is also possible that clinicians who did not complete the care pathway study did not feel the topic relevant to their clinical work.

There is no agreed standard for an acceptable minimum response rate, although, as discussed by Bowling (2014) it is generally accepted that a response of below 60% limits the quality of the research. The return rate for the Simmons-Mackie et al. (2005) survey was 33%. They used a finite list of SLTs who were members of a neurophysiology and neurogenic special interest group, so were able to provide an approximate response rate. Archer et al. (2013) received 101 fully completed surveys and concluded that they consider the sample size reasonable. Therefore, whilst the aphasia care pathway results are consistent with a low response rate to surveys to SLTs using similar sampling procedures, this should be considered relative to the generalisation of the results.
The study targeted SLTs working with PWA; the small sample (n=83) implies that conclusions drawn may not be representative of SLTs within this client group as a whole, however as the exact number of SLTs working with PWA is not known, it is not possible to confirm this argument.

The aphasia care pathway survey was administered in two forms, it is recognised that this brings a risk of inconsistency, however the evidence states that a combination of online and paper may be needed to maximise response rates. Kroth, McPherson, Leverance, Pace, Daniels, Rhyne & Williams (2009) conducted a review of surveys used in a primary care setting. The authors conclude that there remains an important role for the use of paper-based methods in survey research, and that both hard copy and electronic survey collection methods may be required to enhance clinician response rates.

A further challenge is a poorly designed survey. The format of the survey and the respondents’ understanding of the questions may influence the responses given (Bowling, 2014). For this reason it is important to conduct a pilot version of the survey before the final launch, to help to mitigate some of these challenges. The aphasia care pathway survey discussed here was both designed adhering to evidence within the literature and piloted. Amendments made to the wording of the questions and the layout in response to the feedback provided.

On reflection, cognitive interviewing could have been applied during the piloting of the aphasia care pathway study. This is a method for testing survey questions and can help to identify potential problems that may be faced (Willis 2004). Cognitive interviewing aims to explore the way in which people interpret a survey whilst analysing their cognitive processes. The survey is administered in a one to one setting, with participants being encouraged to think aloud as they answer the questions. This helps to identify misunderstandings, with modifications to questions being made on the basis of the findings (Miller, Chepp, Willson & Padilla 2014).

In summary, the findings of data collection regarding the use of an aphasia care pathway by SLTs working with PWA, provides an initial understanding of frequency of use and potential purpose of such a pathway. Due to the limited response rate, generalisation of the findings should be applied with caution. For this reason, any further study would
benefit from a revised data collection method, for example the Delphi Technique (Bowling, 2014). This cyclical technique allows for a large number of individuals, within an area of expertise, across diverse geographical locations to contribute numerical data, ideas and attitudes on a given topic, (Keeney et al. 2011).

A synthesis of the quantitative data reported in this chapter and the qualitative data will be discussed in chapter five.
Chapter 5 MIXED METHODS ANALYSIS

This chapter will describe the synthesis of the qualitative and quantitative data, within the mixed methods framework. Analysis in mixed methods research involves firstly analysing data using qualitative and quantitative methods, followed by further analysis of these data sets, synthesising the individual findings, in order to address the mixed methods question.

The chapter will provide:

- An introduction to mixed methods analysis
- A description of the concurrent analysis approach
- An interpretation of the qualitative and quantitative data

5.1 Introduction to mixed methods analysis

An exploratory, sequential mixed methods design was chosen for the analysis, (Creswell & Plano Clark 2007). The qualitative data was initially collected, the findings of which informed the collection of the quantitative data. Data was analysed separately and then merged to address the research question, “an in-depth exploration of an aphasia care pathway from the perspectives of the main stakeholders.”

O’Cathain, Murphy & Nicholl (2010) advocate a technique referred to as following threads, when synthesising qualitative and quantitative data. Issues identified from one method are used to inform the method or aid interpretation of the results of another. This begins with an initial analysis of each component, to identify key themes and questions requiring further exploration, as has been completed above. The researcher then selects a question or theme from one component and follows it across the other component; this is referred to as the thread. The effect of this will depend on the respective order of each approach. In this programme of research, the results of the qualitative focus groups and interview study were available prior to commencing the quantitative data collection. Consequently the survey questions were designed taking into account the qualitative findings. For example, qualitative findings from the focus groups and interviews illuminate a perceived lack of information about aphasia, findings...
consistent with previous research (Worrall, Sherratt et al 2011). As a result, a question about the importance of information provision was included in the survey asking participants about the most important components of a pathway. A flowchart summarising the mixed methodological approach taken in this study is provided in figure 5.1 below.
Figure 5.1 Flowchart summarising mixed methods research design
5.2 Data analysis methods

This programme of mixed methods research has followed recommendations for data integration described by Creswell & Plano Clark (2007). Within a mixed methodology approach, it is important to consider the timing of the qualitative and quantitative data collection, notably whether it is concurrent or sequential (Creswell & Plano Clark 2007). Concurrent analysis is used for triangulation and embedded designs, as discussed in chapter 2; this involves the comparison of the quantitative and qualitative data, in a discussion or a matrix. Sequential data analysis, appropriate for exploratory mixed methods, was applied in the aphasia care pathway study. This involved the use of analysis of the qualitative data to inform the development of the quantitative data collection, the identification of complimentary content areas represented in both data sets, the identification of differences between data sets including conflicting or absent data and a comparison and synthesis of results into a discussion.

The challenge is determining what qualitative findings to use when designing the quantitative phase (Creswell & Plano 2007) as the themes will be used to inform the quantitative data collection instrument, in the case of the aphasia care pathway study, a survey to SLTs. This study began with focus groups and interviews to explore the pathway from the service users’ perspectives, identifying themes about core features of an aphasia care pathway and its accessible format, therefore the sequential data analysis was applied. Figure 5.2 illustrates this design.
5.3 Interpretation of the qualitative and quantitative data

The following section describes, by discussing key topics, the results of the mixed methods analysis detailed above. It will identify complimentary content areas, represented in both data sets and any conflicting data. In this aphasia care pathway study, the qualitative element of the research allowed for a normally marginalised group, PWA, to have a voice in research concerning them. It has delivered rich data about service users experiences of exposure to the pathway and the contexts in which it is used. The quantitative element provides statistical evidence about the number of clinicians using the care pathway, with comparison to professional grade, length of time working within the field of aphasia and whether they are working in an acute or community setting. The preliminary findings of the qualitative data offered topics and issues to be addressed in the survey to SLTs, including:

- The advantages and limitation of care pathways
- The value of an accessible aphasia care pathway
- The role and importance of information provision as an integral part of an aphasia care pathway
- The process of goal setting within an aphasia care pathway
In addition, a question was included in the survey inviting respondents to offer any further opinions about aphasia care pathway. The aim was to encourage comments about the more holistic nature of aphasia, which had been identified during the focus groups and interviews, for example the psychosocial needs of PWA and family members.

5.3.1 Experiences of care pathways within the NHS
The interviews with HCPs and survey findings for SLTs, identified a number of advantages of using care pathways, these included a more consistent, equitable and evidence based approach to care, provision of an audit tool that could be used to measure outcome and an opportunity to clarify roles of the HCPs involved in the care provision. Similar disadvantages or limitations of care pathways were also identified by HCPs and the SLTs responding to the survey. The prescriptive nature of a care pathway raised concerns that they can be too rigid and not suitable for the complexity of a condition such as stroke and aphasia. Concerns were also raised about the resource implications, whilst an acute pathway may be funded, rehabilitation and longer term care is frequently restricted due to insufficient resource or investment. Findings were complementary; no specific contrasting data was identified. Taken together, these findings would appear to support the evidence base that the perceived benefits of care pathway implementation are varied and the ways an organisation or service applies pathway process are likely to be diverse (Evans-Lacko et al. 2010).

5.3.2 Characteristics and value of aphasia care pathways
The value of an aphasia care pathway, in promoting the role of timely and person centred intervention, was identified by PWA, their families and in the survey responses. The role of a pathway, in facilitating a consistent approach to therapy, was ranked highly by SLTs in the survey (63% ranking this from 5 – 7). Similarly, timely, person centred provision of intervention was highlighted as important by PWA and carers. Conversely, however, whilst 41% of practising SLTs responding to the survey, reported use of an aphasia care pathway, PWA and carers reported that an explanation of an aphasia care pathway and what it consisted of was not made explicit. Whilst SLTs may be using a pathway, the implication is that this is not being communicated effectively with the service users. Goal setting was identified as an important component of a care pathway by the HCPs interviewed. Similarly, of the SLTs surveyed, 69.5% ranked this aspect of intervention as
important or very important. In comparison, however, PWA and carers reported goal setting to be more challenging, potentially beyond their remit, highlighting the difficulties that PWA and carers may experience in this aspect of rehabilitation (Power, Thomas et al., 2015). Taking this into account, these combined results do not appear adequate to support the idea that goal setting is an integral part of an aphasia care pathway.

The researcher was interested in exploring the question “who should do what at which stage of the aphasia care pathway?” Whilst this question could not be detailed in the survey, respondents identified assessment (15.6%) and goal setting (15.8%) as being the domain of the SLT. Similarly, HCPs identified assessment, goal setting and therapy planning as core activities for the qualified practitioner to be leading on, delegating delivery of a therapy plan to an assistant practitioner, under the supervision of the qualified member of staff.

“Specialist roles must be reserved for the professional with the specific skills e.g. assessment and aphasia therapy planning for SLTs”. (HCP11)

Future research could measure the specific components of aphasia interventions that are the domain of the SLT and which could be delegated to SLT assistants or rehabilitation practitioners.

Underpinning this work was a need to explore the value of an accessible version of an aphasia care pathway, acceptable to PWA, their families and relevant HCPs. There was consensus amongst PWA and carers that it was vital, to the success of the pathway, for it to be in a format that was easy to share, a visual representation illustrating the journey to expect. Similarly, 88% of SLTs responding to the survey agreed with the statement that an accessible version of an aphasia care pathway should be developed, in line with the findings from the qualitative arm of the study. Given that information about healthcare should be provided in an accessible format (Mander 2015), it is important that aphasia interventions should be communicated to individuals and their families in a meaningful way. Taking this into account, the synthesis of the qualitative and quantitative data implies the need for an accessible version of an aphasia care pathway. Future research or clinical development, may wish to consider how an accessible version of an aphasia care pathway could be introduced at local and national level.
5.3.3 Provision of aphasia related information
An a priori theme was the format and timing of aphasia related information, strands from both the qualitative and quantitative day analysis signify consensus, though this may require further research and definition. PWA and carers commented on the provision of information along the pathway, indicating that providing too much information in the early stages was not beneficial. Similarly, SLTs responding to the survey identified information giving as an important feature of an aphasia care pathway. The survey did not allow for a detailed discussion of the exact format of this information and therefore no conflicting data was identified. Comparison suggests that the concept of timely aphasia related information was paramount. In previous research regarding the importance of aphasia related information, Foster, Worrall et al. (2016) identified the importance of providing information about the impact and management of aphasia at intervals appropriate for the PWA and family members, in a format that met their needs. Arguably, further investigation and consideration is needed regarding the resources necessary to implement and sustain this provision.

5.3.4 Psychosocial aspects of aphasia
Whilst concerns relating to the impact of aphasia upon the whole family, including adaption, motivation for rehabilitation and maintaining a sense of hope, were identified during the focus groups and interviews, it is important to note that the survey to SLTs did not yield any specific data that can be linked to psychological aspects of aphasia. The likely reason for this was that the survey focused more on the process of an aphasia care pathway rather than the impact of the communication impairment. The statement below was made by one SLT respondent, in an open question inviting general comments about aphasia care pathways, which corresponds to the findings of the qualitative data:

“A pathway must look holistically and address psychological care needs of those with aphasia” SLT (3456516)

Power et al. (2015) recommend SLTs should identify the clients and family’s need for psychosocial support alongside direct therapeutic interventions. Future research may wish to consider an increased focus of psychosocial interventions within an aphasia care pathway and the extent to which this is related to engagement and readiness for aphasia rehabilitation.
5.4 Summary of the mixed methods analysis

The mixed methods analysis has yielded a number of valuable conclusions which are detailed above. It is suggested that the mixed methods analysis has supported the rationale for using mixed methods described in chapter 2, including corroboration of findings, a greater understanding of process of the aphasia care pathway and a greater credibility of findings (Greene, Caracelli & Graham, 1989). A core purpose of mixed methods research is triangulation, seeking convergence and corroboration of results from different methods. This research has involved focus groups, interviews and a survey to achieve this. In addition, seeking elaboration and enhancement of findings is a core component (Creswell & PlanoClark 2007). The use of a mixed method approach has allowed for an expansion of the evidence base relating to an aphasia care pathway, by combining the experiences of the service user with data from practising clinicians.

The analysis has highlighted the value of qualitative research methods by showing the depth and range of data it produces. However, attempts to compare results have also highlighted the value of quantitative outcomes in maintaining a tighter definition of complex abstract concepts, for example specific data about the use of an aphasia care pathway in clinical practice by SLTs and confirmation of the core components of such a pathway.

Future research may benefit from sequential methods that use qualitative enquiry to define some of the core components e.g. information giving, goal setting and psychological support, then quantitative outcomes to determine how defined concepts are introduced and monitored.

The analysis has also highlighted some of the difficulties in fully integrating data from two research paradigms, due to the methodological difference in each approach. The focus groups and interviews allowed participants to share their experiences of an aphasia care pathway; the primary aim of the survey was to collect quantitative data about the actual use of a pathway in clinical practice. Consequently some comparisons cannot be made.

The following chapter will discuss the findings of the qualitative and quantitative arms of the aphasia care pathway study, critique the mixed methods approach, identify some
limitation of the study and propose the clinical implications of this exploration of an aphasia care pathway.
Chapter 6 DISCUSSION

The aim of this study was to explore an aphasia care pathway from the perspective of the service user receiving the pathway and HCPs delivering care. Findings from focus groups with PWA, interviews with family members and HCPs, synthesised with the results of a survey to SLTs, reveal four main themes: knowledge of care pathways, understanding of the aphasia care pathways, information giving and the psychosocial impact of aphasia.

This chapter will discuss the findings of the research, placing the aims and objectives of the study at the centre of a discussion, as a contribution to the evidence base. It will:

- Summarise the findings of the research
- Discuss the main strengths of this programme of research
- Consider the theoretical and methodological implications
- Provide a detailed breakdown of clinical and research implications and recommendations
- Review the study’s aims and objectives
- Reflect upon the Professional Doctorate Research Programme

In this aphasia care pathway study, the qualitative element of the research allowed for a normally marginalised group, PWA, to have a voice in research concerning them. It has delivered rich data about service users experiences of exposure to the pathway and the contexts in which it is used. The quantitative element provides statistical evidence about the number of clinicians using the care pathway, with comparison to professional grade, length of time working within the field of aphasia and whether they are working in an acute or community setting.

6.1 Summary of the programme of research

This programme of research aimed to explore an aphasia care pathway from the experiences of those with active involvement with it. The literature review in chapter 2 illustrated how aphasia can impact upon the lives of, not only the person with the condition, but also family members, carers and HCPs. However, although evidence based clinical care pathways are in use in the NHS, the literature review also demonstrated limited evidence for an aphasia specific care pathway. Therefore, an objective of this
programme of research was to illuminate the experiences and perceptions of people with aphasia and their carers, using focus groups and interviews to collect the qualitative data. A descriptive survey of SLTs working with PWA was then undertaken, findings from the qualitative data being used to inform the survey content. The principal findings from this programme of research are presented below.

6.2 Summary of the research findings
This section integrates and discusses the findings of the qualitative and quantitative data. Four themes have been identified:

6.2.1 Experiences of care pathways in the NHS
In this study participants were asked about their knowledge and understanding of care pathways. Recipients of services reported limited awareness of the concept of a care pathway, arguably concerning given that a key aim of a care pathway is to give the patient clear expectations of their care (Evans-Lacko et al. 2010). In modern society, people are increasingly expecting to be actively informed and engaged in decisions about their own health care, therefore ensuring care pathways are in a form that can be shared with the service users should be a goal for those developing and revising care pathways. Giving patients a voice in their health care, how it is organised and delivered, is a central theme of health initiatives and identified in the Health and Social Care Act (2012). This Act established new Health Watch patient organisations locally and nationally to encourage patient involvement across the NHS. The aim was to highlight people's experiences of care to the right decision makers, at the right time, to enable people and professionals to work together to tackle the significant health and care challenges. Whilst Patient centred care is central to the mission of healthcare, many find services difficult to navigate, disempowering, burdensome, and seemingly designed to frustrate (Richards, Coulter & Wicks 2015). The authors argue, quite rightly that feedback from patients and their families should be more rigorous and used to inform practice, not merely collated for research purposes. This is a challenge but one that health and social care professionals need to rise to in order to find better ways to listen to patients and ensure their voice is included. Better conversations are also core to realising shared decision making based on individual priorities and preferences. Mair (2015) develops this argument, stating that the quality of the information on which joint decisions are based needs to be improved.
The use of ever developing technology, including social media, rapid growth of networked patient communities, are changing the landscape, providing new opportunities to harness the energy and expertise of patients. The challenge to SLTs working with PWA is how to ensure these developments are being utilised and expanded upon, to meet the information needs of clients and family members. One carer interviewed in this study reported the use of the internet to research aphasia, it is anticipated that if the questions were asked today or in five years’ time, this number would be increased. As Richards et al (2015) conclude

Working collaboratively and sharing decisions about care, services, and research is challenging. It requires a sea change in mindset among health professionals and patients alike. But its rewards are rich and reaped mutually. (p 350)

HCPs were aware of the existence of care pathways within the health care system and several were able to provide a clear definition and discuss their advantages and limitations. Within stroke care, structured care pathways to improve outcomes have been in use for a number of years, as discussed by Panella, Marchisio, Brambilla, Vanhaecht & Di Stanislao (2012). The HCPs interviewed in this study all worked within a stroke setting. In addition, a number had been actively involved in the development and implementation of the stroke care pathway, thus allowing them to make an informed contribution.

The advantages of care pathways, identified by those interviewed and surveyed, were very similar to those stated in published work, notably De Blesser et al. (2006) and Evans Lacko (2010). Care pathways are recognised as a systematic and measurable way of working, improving the quality of care, in addition to providing a learning tool for less experienced members of the multi-disciplinary team. In the study reported here, the clinician’s negative attitudes regarding care pathways closely reflect those reported in the literature, that by being overly prescriptive they can threaten clinical autonomy and limit the opportunity to be flexible with the care provided (Allen & Rixson 2008). Some of the HCPs reported care pathways directly contradicted the aim of patient centred care, putting the patient into a prescriptive “box”, rather than looking at an individual’s needs. Care pathways are most effective in contexts where the trajectory of care is predictable (Allen, Gillen & Rixson 2009); however for complex and idiosyncratic conditions, an individualised approach to care is required. For example, as a consequence of the
population’s changing health care needs, together with increased life expectancy, people are presenting with co morbidities, or, as one of the interviewees in this study stated, a “shopping trolley of needs”, making care pathway working more challenging.

6.2.2 Aphasia specific care pathways

PWA carers and HCPs were uncertain about the existence of an aphasia care pathway, and were unable to recall information or intervention provided early on, in the acute or post-acute stages of the journey. One conclusion would be to suggest that a key priority for the stroke patient and their family in the early stages of rehabilitation is to regain as much physical independence as possible, in order to facilitate discharge home. Greater effort and resources may be directed towards physical therapy, with communication difficulties being a lower priority.

Studies investigating timing of aphasia interventions provide conflicting findings. Nouwens, Visch-Brink, Van de Sandt-Koenderman, Dippel, Koudstaal & de Lau (2015) conclude that, whilst an early start of treatment may be advocated and resourced, the evidence is however inconclusive. Godecke (2012) investigated the efficacy of an early aphasia therapy for patients following a stroke, in a randomised controlled trial and concluded that daily aphasia therapy, soon after a stroke, can improve communication outcomes of people with moderate to severe aphasia. The strength of any conclusions are however limited by the small sample size within this study. Studies demonstrate a lack of conclusive evidence about the most effective type and degree of intensity or duration of therapy, as concluded in the RCSLT Resource Manual for Commissioning and Planning Services for Aphasia (2014).

The decision of when to initiate aphasia treatment can be challenging for the SLT. Should it be as early as possible, when spontaneous recovery may be occurring, but when patients can be too medically unstable, fatigued or have an alternative priority, or later, when their condition is more stabilized? This decision may, in reality, be taken out of the hands of the SLT by the availability of resources. The Stroke Sentinel National Audit Programme (SSNAP) provides a high level summary of NHS Hospitals Trusts’ performance across ten aspects of stroke care. When the SSNAP targets were introduced in 2012, SLT achievement of the relevant indicators for stroke related communication and swallowing impairments was lower than other members of the MDT, requiring acute stroke services
to make some investment in SLT resource to ensure key targets were met. This has allowed for more timely assessment and intervention in the acute and post-acute periods. However, as this study reveals, this is not always in the best interest of the patient, who may not be able to benefit from intervention at this stage of their recovery. There remains a gap in investment in the longer term rehabilitation process; the time when PWA and their families are saying is the optimum time for them to benefit from regular therapy (Foster, Worrall, et al. 2016). International best practice consensus statements regarding the management of aphasia state that people with aphasia should be offered intensive and individualized aphasia therapy (Simmons-Mackie, Worrall, Murray, Enderby, Campbell, Rose, Pack & Klippi 2017). Additionally, the most recent Cochrane review (Brady et al 2016) suggests that high-intensity therapy leads to reduced aphasia severity and greater improvement in functional communication compared with lower-intensity therapies.

Whilst there is debate about the timing of direct intervention, there is a need for SLTs to provide assessment and guidance to the MDT, working with the PWA in the acute and early rehabilitation setting (Thompson and McKeever 2014). An understanding of the needs of PWA is essential to ensure appropriate and high level quality of care

Having access to formal therapy services across time has been reported as important to PWA and their families. Participants in a qualitative study, conducted by Grohn (2014) focusing upon living with aphasia, reported the value of personalised rehabilitation, which allowed for independent practice as well as 1:1 interventions. The provision of therapy played an important role in the individual being able to live successfully with their communication disability.

The role of telemedicine in supporting therapy, in particular the intensity of interventions, was identified by a number of the HCPs interviewed, the role of computer software and therapy “apps” in particular were highlighted. In a systematic review of the use of telepractice in aphasia interventions, Hall, Boisvert and Steele (2013) identify this as a viable method of service delivery for individuals with aphasia, which warrants additional research. The authors emphasise the importance of researchers’ on-going examination of the effectiveness of services for individuals with aphasia using robust research designs to enable the comparison of performance and outcome data. In addition, Hall et al. (2013)
suggest that a greater range of assessment and intervention services, which include functional therapy delivered via telepractice, should be examined. It is also stated that any tool used, e.g. computer software, is to augment, not replace face to face therapeutic interventions. Further exploration is warranted to determine the amount of support needed and rate of learning demonstrated.

Young, Gomersall and Bowen (2012) reporting on the ACTNow study, identify differences in the experiences of participants about the processes of SLT and visitor contact. The SLT contact was regarded as purposeful and its effects explicitly measurable. Contact with a visitor was regarded as something from which indirect benefits were discernible and measures of progress largely self-reflective. Participants did not perceive the SLTs and visitors to be fulfilling the same role, corresponding with the findings of this aphasia care pathways research that SLTs have an identified role in assessment, goal setting and intervention planning.

Goal setting, as part of the aphasia care pathway, generated a number of comments from PWA and carers. Both groups reported they wanted to be involved in the goal setting process but were reluctant to take the lead, feeling it was the responsibility of the professional (SLT) to do so. Power, Thomas et al. (2015) discuss that the age of clients may be influential, those who are older may expect to be directed in therapy rather than consulted. Goal setting needs to take into consideration a range of factors including the type of and severity of the stroke, the symptoms experienced and the individual’s personality. It is a key component of stroke rehabilitation and is recommended in the RCP stroke guidelines (2016). There is wide consensus within the literature that goal setting is beneficial for the rehabilitation process (Simmons-Mackie et al. (2017) and should always take place in collaboration with the individual and family members if appropriate. Goal setting can enhance patient confidence, motivation, and engagement with rehabilitation, as well as facilitating team communication, which, in turn, should impact upon timely and safe discharge (Rosewilliam et al. 2015) and (Plant, Tyson, Kirk and Parsons 2016).

The studies quoted above also reported difficulties in the goal setting process during the acute stages of recovery. The principal barriers were differences in staff and patients perspectives of goal-setting and unrealistic goals being identified by the patient and families, primarily due to an inability to accept the stroke related difficulties.
Rosewilliam et al. (2015) discuss the impact on goal setting, of the NHS focus on early supported discharge from hospital of stroke patients on the goal setting process, reporting that once at home, functional and meaningful goals are more likely to be set. Clinical experience supports this, as community stroke rehabilitation teams are in an excellent position to encourage patient centred goal setting in the home. Setting goals further along the aphasia care pathway or journey was seen as important to some of the participants, in order to remain focused. This is in line with other research findings. Grohn et al. (2014) discuss the timely delivery of aphasia services and the need to recognise that the acute stages of the journey may not be the most appropriate to focus on. Similarly, a study by Howe et al. (2012) exploring family members’ goals for aphasia rehabilitation revealed that participants found it easier and more effective to focus upon goals in the home and family environment. Mumby and Whitworth (2012) evaluated the experiences of PWA, living back at home, participating in a structured programme of real-life goal setting, individually or within a group. Real-life goals were set for each participant during the intervention and 80% were fully or partially achieved.

Worrall, Sherratt et al. (2011) debate reasons why goal setting can be challenging for PWA and those supporting them. It is likely that the aphasia related language impairment, results in difficulty expressing needs and discussion of experiences. In addition, there may be cognitive capacity issues, particularly in the early post-stroke period. Furthermore, the medical setting may reinforce a culture in which the focus is on being ill and the underlying impairment, with the medical team making the decisions.

Arguably, whilst goal setting is an important part of an aphasia care pathway, challenges remain about how it can most effectively be implemented. Shrubsole, Worrall, Power and O’Connor (2017) conducted a systematic review and evaluation of aphasia rehabilitation guidelines, which identified clinical recommendations for goal setting as a priority for further research.

There was consensus, from the SLTs surveyed, about the key stages of the aphasia care pathway, notably diagnosis, assessment, intervention, information giving, onward referral and discharge. These findings reflect those of Power et al. (2015) who identified eight domains of care, which should influence aphasia care pathways. These include setting goals and measuring outcomes, assessment, interventions, enhancing the communication
environment, enhancing personal factors and planning for transitions. HCPs were aware of the key elements of the aphasia care pathway, but did not comment specifically upon named stages. Keeping patients and carers well informed along the whole journey was their primary concern.

Participants in the qualitative arm of the study were asked to comment on the question “who should do what at which stage of the aphasia care pathway?” This topic generated considerable debate, with access to formal SLT led intervention being favoured by PWA and carers. Increasingly, SLTs working in the acute and post-acute stroke setting are asked by family members about the NICE stroke guidelines (2010), in particular the recommendation for 45 minutes of therapy each day. This guideline is measured by SSNAP. The on-going challenge for SLTs, along with other HCPs, in a resource limited NHS, is how to provide the frequency and intensity of intervention. The use of assistant practitioners (APs) is one possibility. The stages of an aphasia care pathway, which required a qualified professional, were agreed as being assessment and reassessment, goal setting, therapy planning, outcomes and discharge planning. Similarly, Bowen, Hesketh et al. (2012) conclude that SLTs have an important role in the assessment and diagnosis of the underlying speech or language impairment, a reorganisation of early communication therapy, to allow for a clear role for APs and trained volunteers, should be investigated. If this is achieved, rehabilitation assistants can and should facilitate rehabilitation and extend therapists' roles. Together with effective multidisciplinary team working, it can provide the impetus for a more consistent and goal-directed rehabilitative process (Rose et al 2014).

6.2.3 Aphasia related information
There is agreement across studies that PWA and their family members do not receive the information they would like, at the time they would like it and in a suitable format (Hinckley et al. 2013) (Foster, Worrall et al. 2016). This is reflected in the findings of this study. Participants in the qualitative arm of the study indicated that providing too much information in the early stages may not be beneficial as it was either too overwhelming or not retained. SLTs responding to the survey identified information giving as the most important feature of an aphasia care pathway. This point is reiterated by Power et al. (2015) who recommend that SLTS should identify the patient and family's needs and
readiness for information and that family or carers should be offered information about stroke and aphasia tailored to meet their needs, using relevant language and communication formats.

A study by Rose, Worrall, Hickson and Hoffmann (2010) identified that PWA found it beneficial to receive written information at several stages post stroke, particularly from one month onwards. Hinckley et al. (2013) discuss customized resources and the need to gain a greater understanding of how PWA and their families best access and use information. Howe et al. (2012) had similar findings. Participants in their study wanted information to be available in a variety of formats and to be given over time, not just on one occasion. Explaining the intricacy of aphasia, just once, is unlikely to be sufficient or acceptable; it is a complex disorder with many components and repetition of explanations is required. Findings from the aphasia care pathway study and published evidence indicate information given in the acute setting can be difficult for patients and carers to retain. It is recommended that there is a role for providing appropriate, comprehensive information to inpatients; however this needs to be revisited and adapted to the environment, change of situation, or status, as the PWA continues their rehabilitation journey. The timing of the provision of the information is a question frequently asked and whilst there is consensus between all groups interviewed that information giving is a key part of the aphasia care pathway, the timing of the information needs to be flexible. It is important to ensure that the information is available when it can best be used and when PWA and their families are ready to use it. The mode of information delivery requires consideration. Rotherham et al. (2015) conducted a qualitative study to explore the benefits of group interventions for PWA and concluded that one of the reported benefits was regarding the on-going provision and sharing of information provided by SLT and by peer support.

The role of technology in providing information was discussed by some of the participants in this study: whilst this can be a useful source for family members and other professionals, individuals with aphasia may have more difficulty accessing information, due to the nature of their communication difficulties. There is potential in the role of telemedicine, whether it is the development of apps, software or using video sharing
websites, for example YouTube. Future research may wish to consider the opportunities of modern technology to provide aphasia related information.

6.2.4 Psychosocial impact.

Aphasia can have a profound impact upon quality of life; individuals with aphasia have a significantly lower health related quality of life (HRQL), compared to non-aphasia stroke patients, (Hilari 2011). HRQL reflects the impact of a health state, incorporating an individual’s perception of and satisfaction with his or her physical, mental, emotional family and social functioning, (Patel, McKeivitt, Lawrence, Rudd and Wolfe 2007).

Remainig positive and maintaining healthy outlooks were identified by participants as being important components of the aphasia provision. A number of carers discussed the need for professional assistance when supporting the PWA during key stages of the care pathway, for example transition from hospital to home. A study by Howe, Davidson, Worrall, Hersh, Ferguson, Sherratt and Gilbert (2012) identified the rehabilitation needs of family members of PWA and conclude that the aphasia related needs of family members should always be considered. Caregivers of stroke survivors experience high rates of mental and physical morbidity. Stroke has sudden onset, the outcome is not immediately known and uncertainty surrounding the new caregiving role is likely to necessitate major changes in the lives of family caregivers, (Byun, Riegel, Sommers and Evans 2016). A review of studies exploring quality of life for carers of PWA, conducted by Rombouhg, Howse, Bagg and Bartfay, (2007), highlighted that they too suffer from reduced HRQL, increased levels of stress, anxiety and depression. Within the aphasia care pathway study, some carers identified a need for group focused support for themselves; others expressed a preference for one to one discussion.

The SLT has a role, as link person, to advocate for development of appropriate services and options. This may involve working closely with the voluntary sector, for example the Stroke Association and other similar organisations, to help incorporate communication rehabilitation and adaption into everyday activities and situations. Maintaining a sense of hope was considered important by carers, influencing how families adapt to the impact of aphasia and how the individual with aphasia engages in therapy.
A study by Bright, Kayes, McCann and McPherson (2016) aimed to explore how hope was experienced by people with aphasia following stroke, to identify factors influencing the experience of hope. In this study, five interviews with PWA, using supported conversation techniques, were used to gather data. The study by Bright et al. (2013) has contributed to developing knowledge of hope for PWA. There are some limitations however, which must be acknowledged. It is possible that those who consented to participate did so because they had experienced hope, which meant they were more willing to participate. Rose et al. (2014) conducted a study reporting on current aphasia rehabilitation practices of SLTs in Australia. A web-based survey targeted approaches to aphasia rehabilitation, education, discharge and follow-up practices. Providing PWA with a sense of hope was identified by respondents as a crucial role for SLTs. Priority should be given to the way in which information is provided, finding a balance between “telling them how it is” versus facilitating some hope with real information. The importance of an honest, yet optimistic approach is also discussed by Rose et al. (2014) who emphasise that protecting PWA and their families from the probability that their communication skills are unlikely to return to pre stroke levels, is not helpful.

6.3 Methodological observations

The main strengths of this programme of research are:

- Intervention and research methods were informed by careful consideration of findings from previous research.

- Research methods appropriate to the research question were used.

- The study met ethical requirements: annual reviews at the University of Portsmouth were successfully completed.

- Data collection and analysis was completed using suitable protocols and frameworks.
• Triangulation of data collection methods enhanced validity of findings, mixed methods analysis complimented and added insight to the stand alone results of the studies.

• Identified a need for further consultation with PWA regarding an accessible format of an aphasia care pathway.

• Initiated a debate within the SLT profession about the potential role of a national aphasia care pathway, in an accessible format.

• Results of this study are comparable to other recent aphasia care pathway research, notably by Power et al. (2015).

6.3.1 Methodological strengths
This was a mixed methods study, exploring experiences and beliefs and obtaining data about the use of an aphasia care pathway by SLTs. It involved a range of participants and a combination of data collection methods, this process of triangulation enhanced the validity of the findings (Ritchie, Lewis et al. 2014) by providing multiple methodological perspectives and observations to understand the research question.

The researcher was an SLT, experienced in the formal and informal assessment and management of an individual’s communication strengths and needs and of organising and facilitating groups for PWA. Supported conversation techniques (Kagan et al. 2011) were employed, with the aim of allowing the PWA to take an active role in the conversation and reduce the risk of researcher bias. These techniques provide language facilitation in the form of written key words, gestures and other conversational props, for example maps, photos, objects as points of reference. This strengthened the study by facilitating involvement of PWA in research, in which they are frequently excluded, allowing their valid opinions to be heard (Brady et al 2013).

In this study, measures were implemented to minimise the risk of bias, notably a web based survey was used to reduce participation burden and anonymity was assured. The survey was piloted, as discussed in chapter 4, raising the rigour of the data by ensuring unclear or ambiguous questions were revised.
The inclusion of PWA in research is a further strength of the qualitative arm of the study. They are frequently excluded from studies due to their assumed inability to give informed consent to participate (Brady et al. 2013), however their involvement is crucial to the relevance of the research, how it is organised and disseminated. The findings of this aphasia care pathway study support those findings of Shrubsole et al. (2016) further highlighting the importance of including PWA in trials, so that it could be more easily determined whether the results were applicable to those with aphasia. This was crucial to trustworthiness and transferability of the data.

This study included people with varying levels of aphasia, from mild word finding difficulties and mildly impaired language processing, to people with significant receptive and expressive language breakdown. This required careful facilitation and the experience and expertise of the SLT researcher allowed for this.

A mixed methodology approach has identified strengths (O'Cathain, Murphy and Nicholl, 2010). It can answer a broader and more complete range of research questions because the researcher is not confined to a single method or approach. It can also provide a greater explanation of the significant issues and add insights and understanding that might be missed when only a single method is used, increasing the generalizability of the results. Complexities associated with acquired communication difficulties such as aphasia, cannot always be investigated satisfactorily by using a single research method. Some issues require a more comprehensive understanding, which may be provided by combining the strengths of quantitative and qualitative methods in a mixed methods study (van Griensvena, Moore and Hall 2014). In the aphasia care pathway study, the qualitative information was used to inform the measurement instrument of the quantitative arm of the study (Creswell and Plano Clark 2011). A mixed method approach that uses both quantitative and qualitative analysis, as in this study, contributes to a more comprehensive picture of post-stroke aphasia rehabilitation. The qualitative data added information about participants’ perception of an aphasia care pathway, whereas the quantitative data provided statistical evidence about the use of this tool within clinical practice. The combination of the qualitative and quantitative data enabled a detailed exploration of an aphasia care pathway, identifying aspects for improvement and
development, notably the core components of a pathway, who should provide what at which stage of the pathway and the provision of information in an accessible format.

A mixed methods approach arguably introduces a client centred approach, qualitative and quantitative research being synthesised to produce a complete knowledge necessary to inform theory and practice (Glogowska 2011). The mixed methods analysis has yielded a number of valuable conclusions which are detailed above. It is suggested that the mixed methods analysis has supported the rationale for using mixed methods described in chapter 2, including corroboration of findings, offset of strengths and weaknesses, a greater understanding of process, greater credibility of findings, examples of context and illustration (Greene et al. 1989).

Generalisation of findings and recommendations, the process of drawing inferences from particular observations, is widely-acknowledged as a quality standard in quantitative research, but is more controversial in qualitative research. The goal of most qualitative studies is not to generalize, but rather to provide a rich, contextualized understanding of some aspect of human experience through the intensive study of particular cases (Ritchie, Lewis et al. 2014). However, as the evidence for this aphasia care pathway study was collected from a selection of service users, it is suggested that the findings can be transferred to a range of clinical settings, a further strength of the mixed methods approach. It is important to emphasise that findings are indicative, rather than representative, of the perceptions of PWA, carers and HCPs.

6.3.2 Methodological limitations
The findings discussed however, must be set within the methodological limitations of this study. Although these methodological limitations do not necessarily undermine the findings, interpretation and generalisation of the findings should be cautious as a consequence of them.

Participants were recruited from one health trust, therefore only one geographical area and one aphasia care pathway was explored. The views obtained were retrospective and relied upon individuals’ memories. It is therefore recommended that future research should explore pathways in two or more health trusts with differing demographics, for example, urban and rural settings.
It was not within the scope of this study to explore how the specific social care or voluntary sector can contribute to the aphasia care pathway; however these relationships should be examined in future research. Delivering integrated care is essential to improving outcomes for people who use health and social care services, reducing repetition, delay in service provision, duplication and gaps in service delivery, Glasby and Dickinson 2014).

Whilst the communication support co-ordinators played an important role as gatekeepers to the recruitment of PWA into the focus groups, it did limit the sample to participants who had attended or were currently attending a CSS group, arguably limiting the generalizability of the findings. Similarly, as 72% of SLTs responding to the survey worked within the NHS, questions need to be asked as to why those working in the independent sector chose not to respond, it may demonstrate that their behaviours, in respect of care pathways, are different to SLTs working within the public sector.

An inherent limitation of a survey collecting quantitative data is the potential for volunteer bias (Bowling 2014). Those who respond to a request to participate in a survey may not be representative of the whole population, in the case of this study, SLTs working with PWA. Therefore the responses received may not be reflective of practice within all clinical settings, (Archer et al. 2013). Non response has the potential to introduce bias if the SLTs who chose, for whatever reason, not to respond, differ in some way from the SLTs who replied to the survey. In this study, measures were implemented to minimise the risk of bias, as previously discussed, but it cannot be entirely removed.

Cognitive interviewing (Willis 2004) can help to identify potential problems that may be faced and any silent misunderstandings, with modifications to questions being made on the basis of the findings (Miller et al. 2014). This is a technique that could have been applied during the pilot phase of the survey, assisting the researcher to discover how well the questions were working, where they were failing, and determine what could have been done to improve the survey.

A "save and exit" feature should be accessible at any point in a survey, to allow a respondent to complete a portion of a survey and return later to finish the rest. This was not available in the aphasia care pathways survey; inclusion may have increased response
rate, as participants would have the option of finishing the survey over a period of time, potentially reflecting on the questions asked, rather than completing it in one go.

There has been some debate about the validity of using qualitative and quantitative methods within the same study, as each methodology is derived from opposing philosophical approaches to research, thus questioning the theoretical basis of mixed methods research. The argument, discussed by Ritchie, Lewis et al. (2014) that when a mixed methods approach is taken, either the qualitative or quantitative element will remain dominant and the other is seen as an exaggeration of the argument, rather than an essential component. Van Griensven et al (2014) debate the challenges of mixing methods, which includes the need for the researcher to learn about multiple methods and approaches and understand how to appropriately combine them. Within the research presented here, the qualitative strand was dominant; arguably the findings of the survey augmented those of the focus groups and interviews, rather than providing an equal value. The researchers also experienced some limitations regarding the use of the sequential data analysis design, notably the need for a wider range of researcher skills and flexibility. The risk, within mixed method analysis, of one strand influencing the other in a sequential study, requires careful consideration, (Creswell & Plano Clark 2007).

There is also some concern that the mixed methods approach is used to gain funding and credibility and that this may hinder the utility of this approach (O’Cathain et al. 2007). Creswell & Plano Clark (2007) report that increasingly research funders are looking more favourably upon research proposals applying a mixed methods approach, as each can provide a distinct form of evidence, which together, provide a powerful resource to inform and illuminate policy and clinical practice.

6.4 Recommendations
This section summarises the clinical implications and recommendations for future research.

6.4.1 Clinical recommendations
The study has expanded the evidence base for an aphasia care pathway, how it is perceived by those who need to access it and improvements that are needed. The
findings support the essential role of SLT in the assessment and direction of therapy with the support of assistants or volunteers. It provides further evidence that PWA and their families need timely, accessible information and a visual, accessible version of an aphasia care pathway. The importance of SLT beyond the acute phase and the long term value of intervention, as expressed by the key stakeholders, have been highlighted. It is important to be mindful of the national stroke guidelines and standards, notably NICE and SSNAP and how they impact upon the provision of aphasia interventions. There is currently no single high-quality guideline that summarises all of the available research knowledge into recommendations to guide decision-making (Shrubsole et al. 2016). Family members’ understanding and expectations of these guidelines should be taken into consideration when planning in-patient and community SLT aphasia services. Specific clinical recommendations therefore include:

- SLTs working with aphasia need to have a working knowledge of the core guidelines and best practice statements, for example RCP stroke guidelines (2016) RCSLT Resource guide for aphasia (2014).
- The development of an accessible version of an aphasia care pathway needs further exploration in terms of how it is developed, implemented and evaluated.
- Best practice statements addressing the timing of aphasia interventions, including the provision of aphasia related information, should be considered (Power et al. 2015).
- SLT services need to ensure there is sufficient clinical expertise and supervision for SLTs to manage the challenges of working with people following an aphasia care pathway.

6.4.2 Research recommendations
This programme of research has explored an aphasia care pathway using a mixed methods design. As stated by Glogowska (2011) given the increasing complexity of health and social intervention, mixed methods research can provide a more realistic and ultimately more useful picture of what is happening. In turn, given the multi factorial nature of human communication, a mixed methods approach should be considered more frequently by SLTs, as it can provide a more comprehensive in depth answer to clinical
research questions. In addition SLT research could contribute substantively to the future developments of mixed method research.

- Aphasia related research should include the PWA wherever possible
- Future research should explore the content and process of alternative aphasia care pathways, using participants from different health care organisations in order to compare the findings of this study.
- Future aphasia care pathway should further consider the value of a national aphasia care pathway, following the examples set by the Australian SLT service (Rose et al 2014). As debated by Foster, Worrall et al. (2016) the diversity of the aphasia management pathway raises significant concerns and questions about the equity of services to PWA and their families.

6.5 Review of the aphasia care pathway study aims and objectives.

This study met the research aim, to explore an aphasia care pathway from the perspective of the primary stakeholders, taking into consideration the limitations and areas for further research that have been identified. The study contributed to new knowledge regarding aphasia care pathways and identified areas for improvement, notably the development of an accessible version for PWA and their family members.

6.6 Reflections of the professional doctorate programme

Reflection can be defined as a learning process designed to gain insight into an individual’s own practice with the intention of improving it (Gibbs, 1988).

*Reflective practice helps to minimize adverse events in your practice. It supports recognizing when there is something ‘not quite right’ in your professional clinical practice and helps to 'make sense of it'. RCSLT CQ3 p64*

There is a requirement that Health Care Professionals demonstrate not only that they engage in the process of learning and continuing professional development but also in the application of reflective practice. When considering further study and research, I sought a doctoral programme which was clinically focused whilst also supporting my professional development. Professional Doctorates are rooted equally in the context of academic, the profession and the practice context of the student (Rolfe and Davies, 2009). During Part One of the programme, professional doctorate students came together for lectures and
seminars, working within this cohort brought advantages in the early days of the programme. The shared journey with peers from a range of professional backgrounds was positive and informative.

This Professional Doctorate programme has enabled me to further develop critical thinking, critical appraisal and reflective skills and challenge some of the traditions and boundaries within aphasia services, in order to deliver effective and cost-efficient evidence-based patient care. The professional doctorate, with its clinical focus, has enabled me to develop my research skills whilst still retaining a clinical perspective. I believe I am more knowledgeable about research methodology and increasingly able to understand statistical information. From the academic networks I now follow, including links to online publications, I receive up to date, clinically relevant evidence, which I disseminate to my SLT and MDT colleagues.

SLTs practising in today's rapidly changing National Health Service are increasingly responding to the need to evaluate and review services as well as considering the political, social and organisational issues affecting evidence. As change happens daily, it is important for therapists to be able to analyse and respond to new challenges proactively. The SLT profession needs clinicians with research and academic skills and experience, to further develop the evidence base and bring back that knowledge into the workplace. In addition, inspiring junior colleagues to pursue a clinical academic career is arguably a responsibility for more senior health care professionals.

The RCSLT, via its Research and Development strategy (2015-2018) supports members to critically evaluate, improve services and develop the research capacity of the profession. Also to reflect on individual areas of clinical provision in order to ensure that there are examples of evidence which are evaluated and concise, enabling SLTs to maintain high quality patient-centred care. Within my role as SLT community team lead, I can apply the skills I have gained as part of the Professional doctorate programme and thesis writing, within service evaluations, business planning and outcome measurement and importantly it encourages me to question my practice and ensure I can justify my clinical reasoning.

Completion of this thesis has enabled me to further develop my research knowledge and critical reflective thinking skills and as a result, progress as a clinician and clinical service
The development of this thesis has also enabled me to reflect upon how the experience in learning new skills such as the thematic framework analysis and statistics can work together in a mixed methods approach.

“Seeing much, suffering much, and studying much, are the three pillars of learning’
(Disraeli 1873)

This mixed methods study formed part of my Continuing Professional Development (CPD) programme and provided an opportunity for reflection which enabled me to improve and develop my clinical practice. The study provided a direct link between theory and clinical practice, an example of the researcher and practitioner in action. The study formed part of the developing process of professionalism, as is a requirement of the Professional Doctorate programme.

6.6.1 My personal journey

Frequent changes to my professional role have required determination and persistence in order to complete the Professional doctorate programme. The learning gained from whole experience has been multi-faceted: arguably the process I have undertaken to research and write this thesis has been as important as the research findings. I have had the pleasure of working with expert academics, notably my supervisor, Dr Chris Markham, who has continually encouraged and inspired me and experienced clinicians, in particular my SLT colleague, Dr Colin Barnes. I have attended a number of Graduate School teaching sessions and attended an annual review process, which has included a poster presentation with associate viva.

Undertaking the programme, alongside a busy and demanding professional life and, whilst always having as my top priority, my family life and role as a wife and mother to teenage and 20+ year old children, has been challenging, the journey had its highs and lows. My husband, Keith and children, Daniel and Katharine have been incredibly supportive and patient with me, not forgetting our dog, Meg, who has spent many hours sleeping on my desk chair as I have studied, talking away to myself!

“No one appreciates the very special genius of your conversation as the dog does”.
(Morley 1925).
I hope the example I have been able to set to my own children and my colleagues will inspire them to consider furthering their own professional and academic careers in due course.

A summary of the research, its findings and priorities for future research, are detailed in the following conclusion.
Chapter 7 CONCLUSION

The purpose of this chapter is to address the aims or research questions contained within the programme of research and the implications of the programme’s findings. This chapter also includes an overview of the primary recommendations for future research.

The findings suggest that whilst there is diversity amongst SLTs in the current use of an aphasia care pathways, there is validated evidence from the stakeholders receiving the care pathways that a unified, consistent service for PWA is required.

The literature review explored the evidence base for aphasia care pathway and whilst it summarised the existing knowledge base for the impact of aphasia and the generic use of care pathways within the NHS, minimal evidence for the specific aphasia care pathway was identified. The conclusion to the literature review stated that the overall aim of this programme of research was to evaluate an aphasia care pathways form the perspectives of the main stakeholders, identified as PWA, carers and HCPs. Objectives were then set to develop research activity to achieve this aim, using a mixed methods approach.

A qualitative study was undertaken to illuminate the experiences of these stakeholders, identifying four themes, the role of care pathways within the NHs, the role of an aphasia care pathway, the importance of consistent and relevant aphasia related information and the impact of psychosocial factors, on the response to an aphasia care pathway. These themes are defined and explored.

The findings of the qualitative arm of this study were used to develop the quantitative arm of the study, addressing the objective to describe the use of aphasia care pathways by SLTs. A survey was administered, which identified a diversity of use of an aphasia care pathways by practising SLTs, (48%) however an overwhelming support for an accessible version of a care pathways, that could be shared with PWA and their families (87.8%). The mixed methods analysis supported these findings, a shared understanding of the care pathway provision.

The programme of research has therefore provided evidence for improvement to aphasia care pathways, contributing to information about aphasia rehabilitation across the
continuum of care and helping to ensure SLTs are more informed about the current evidence and best care standards.

There is future potential for further research opportunities, focusing on the development of a national aphasia care pathway, including a version in an accessible format that can be shared with PWA and their families. The understanding of an aphasia care pathway, that this research provides, allows for a greater knowledge of current practice and arguably acts as a benchmark for future developments. The on-going involvement of PWA in future aphasia care pathway research is also paramount.
REFERENCES


NIHR Engaging with people who have aphasia: a set of resources for stroke researchers (2014).


Royal College of Speech and Language Therapists (RCSLT). Bulletin March 2015

Royal College of Speech and Language Therapists (RCSLT) (2006) Communicating Quality 3

Royal College of Speech and Language Therapists (RCSLT). Resource manual for commissioning and planning services for speech language and communication needs (SLCN). 182 Clinical Rehabilitation 27(2) London: Royal College of Speech and Language Therapists, 2010.


Rotheram, A., Howe T., & Tillard G. (2015). We just thought that this was Christmas: Perceived benefits of participating in aphasia, stroke and other groups. Aphasiology, 29(8), 965-982.

https://www.rcplondon.ac.uk/strokeguidelines.


URL:http://eprints-prod-05.library.pitt.edu/id/eprint/2442
## Table of evidence

<table>
<thead>
<tr>
<th>Author, Journal, type of study</th>
<th>Aim of study</th>
<th>Key findings and recommendations</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sulch, Evans, Melbourn &amp; Kalra (2002) Age and Ageing - RCT</td>
<td>To evaluate the effectiveness of ICP in improving processes of care in stroke rehabilitation</td>
<td>Stroke patients undergoing rehabilitation randomised to receive ICP management or conventional multidisciplinary care. ICP may improve assessment and communication in specialist stroke settings.</td>
</tr>
<tr>
<td>Kwan, Hand, Dennis &amp; Sandercock (2004) Age &amp; Ageing - Before and after study</td>
<td>To evaluate the effects of introducing an ICP for acute stroke</td>
<td>Control = 154 stroke patients admitted to acute stroke unit over 9 month period before IPC introduced. Intervention group = 197 patients admitted one year after introduction of ICP. Patient involvement in the ICP process not a high priority for HCP’s. ICP for stroke may improve quality of documentation and process of care and reduce the risk of some post stroke complications.</td>
</tr>
<tr>
<td>Kwan &amp; Sandercock 2005) Cochrane Review - Systematic review</td>
<td>To update Cochrane review authors conducted in 2003.</td>
<td>3 RCTs and 12 non randomised trials Use of stroke care pathways may be associated with positive and negative effects. The impact of stroke care pathway care on length of stay and hospitalization costs remains unclear, and more detailed research in this area is required.</td>
</tr>
<tr>
<td>Parker et al (2005) J. Integrated Care</td>
<td>To investigate the attitudes HCP’s about the</td>
<td>246 completed surveys returned (27%) Interviews / FG</td>
</tr>
<tr>
<td>Pathways</td>
<td>Mixed method</td>
<td>Use of ICP’s</td>
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<tr>
<td>Survey, interviews and focus groups</td>
<td>To survey the definitions used in describing the concept and to derive key characteristics of clinical pathways.</td>
<td>82/263 eligible articles included a CP definition A method of patient care for a well-defined group of patients during a well-defined period to time.</td>
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<tr>
<td>De Bleser, Depreitere, De Waele, Vanhaecht, Vlayen &amp; Sermeul, (2006) J Nurse Management- Systematic review</td>
<td>To present an overview of role of IPC within stroke, ICPs help to promote collaboration, coordination and team working. Can result in a less flexible approach, not able to always meet individual patient’s needs or community based issues.</td>
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<tr>
<td>Kalra, Langhorne (2007) J Rehabil Med - Synthesis of evidence</td>
<td>To explore experiences of patients, carers and staff about a hospital based stroke care pathway Focus groups for patients, carer and HCPS were completed Main themes identified were; information giving, staff attitudes, availability of care and holistic approach. Whilst a sound theory, implementation and effectiveness of ICP dependant on appropriate resources to provide the recommended service.</td>
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<tr>
<td>Morris, Payne, &amp; Lambert. (2007) J. Quality in Health Care Qualitative; focus groups</td>
<td>To systematically review high quality studies which have evaluated the impact of care pathways within stroke care Search strategy located 2123 papers, 39 were retrieved for detailed evaluation. 7 papers were included in systematic review. ICP’s can facilitate timely, appropriate clinical intervention, improved documentation of clinical goals, reduced length of stay. Clarification of role boundaries needed, Care pathways may not be flexible enough to identify and respond to higher level functioning impairments and carer</td>
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<tr>
<td>Reference</td>
<td>Study Type</td>
<td>Objectives</td>
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<tr>
<td>Kwan &amp; Sandercock (2005) Cochrane Review - Systematic review</td>
<td>To systematically review evidence relating to stroke care pathways</td>
<td>Use of stroke care pathways may be associated with positive and negative effects. Insufficient supporting evidence to justify the routine implementation of care pathways for acute stroke management or stroke rehabilitation</td>
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<tr>
<td>Ferguson et al (2010) Aphasiology - Qualitative study</td>
<td>To describe the experience of aphasia using metaphors</td>
<td>13 metaphors were identified “Journey” “product” and “battle” most frequently used terms</td>
</tr>
<tr>
<td>Panella, Marchiso, Brambilla, Vanhaecht and Di Stanislao (2012) BMC Medicine Cluster randomized trial</td>
<td>To investigate the effectiveness of stroke clinical care pathways</td>
<td>14 hospitals in Italy randomised to care pathways (CP) arm or non-intervention / usual arm of study Patients in CP arm had lower mortality rate and higher functional outcome. Authors concluded that CPs can significantly improve clinical outcomes for stroke patients as facilitate application of evidence based practice and up to date clinical guidelines</td>
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<tr>
<td>Constantini, Alquati, Di Leo (2014) Systematic review</td>
<td>To present and review the evidence relating to end of life care pathways</td>
<td>Systematic review of end of life care pathways. 2 Cochrane reviews included Limited evidence to support the effectiveness of end of life care pathways</td>
</tr>
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09 August 2013

Ms Lynn Dangerfield
Solent NHS Trust
Speech and Language Therapy Department,
Queen Alexandra Hospital, Cosham
Hants
PO6 3LY

Dear Ms Dangerfield

Study title: Aphasia care pathway for post stroke aphasia: People with aphasia, carers and Healthcare Practitioners points of view.

REC reference: 13/SC/0293
IRAS project ID: 113155

Thank you for your letter of 7 July 2013. I can confirm the REC has received the documents listed below and that these comply with the approval conditions detailed in our letter dated 25 June 2013

Documents received

The documents received were as follows:

<table>
<thead>
<tr>
<th>Document</th>
<th>Version</th>
<th>Date</th>
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<tr>
<td>Covering Letter</td>
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<td>07 July 2013</td>
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<tr>
<td>Participant Consent Form</td>
<td>5</td>
<td>30 June 2013</td>
</tr>
<tr>
<td>Participant Information Sheet: Professionals</td>
<td>5</td>
<td>30 June 2013</td>
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<tr>
<td>Participant Information Sheet: Carers of PWA</td>
<td>5</td>
<td>30 June 2013</td>
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<tr>
<td>Participant Information Sheet: PWA</td>
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<td>30 June 2013</td>
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Approved documents

The final list of approved documentation for the study is therefore as follows:

<table>
<thead>
<tr>
<th>Document</th>
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<tr>
<td>Covering Letter</td>
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<td>14 May 2013</td>
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<tr>
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A Research Ethics Committee established by the Health Research Authority
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<tr>
<th>Document Type</th>
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<td>Evidence of insurance or indemnity</td>
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<td>Municipal</td>
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<td>20 July 2012</td>
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<td>GP/Consultant Information Sheets - Guidelines for referrers (PWA)</td>
<td>4</td>
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<td>18 April 2013</td>
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<tr>
<td>GP/Consultant Information Sheets - Guidelines for referrers (SLTs)</td>
<td>3</td>
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<td>GP/Consultant Information Sheets - Guidelines for referrers (HPC)</td>
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<td>Investigator CV</td>
<td>Lynn</td>
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<td></td>
<td>Dangerfield</td>
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<td>30 April 2013</td>
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<tr>
<td>Investigator CV</td>
<td>Chris</td>
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<td>Markham</td>
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<td>Letter from Sponsor</td>
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<td>Participant Consent Form: Carers and Professionals</td>
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<td>Protocol</td>
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<td>REC application</td>
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<td>30 April 2013</td>
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<tr>
<td>Summary/Synopsis- Aphasia care pathway research flowchart</td>
<td>2</td>
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<td></td>
<td>30 April 2013</td>
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</tbody>
</table>

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

13/SC/0293 Please quote this number on all correspondence

Yours sincerely

Miss Kelly Pullin  
Assistant Committee Co-ordinator

E-mail: nrescommittee.southcentral-berkshireb@nhs.net
Copy to: Mrs Ann Rice, Dr Sarah Williams, Solent NHS Trust
School of Health Sciences and Social Work

Study title: AN IN-DEPTH EXPLORATION OF AN APHASIA CARE PATHWAY

Researcher = LYNN DANGERFIELD Speech and Language Therapist

Information sheet for people with aphasia

I would like to invite you to take part in my research. This information sheet will tell you about the study and why it is being carried out. Please take time to read this information sheet, with a friend or family member to help you if necessary. I will also talk through the information sheet with you. Please ask at any time if there is anything you do not understand or you would like more information about.

Part 1 of this information sheet explains why the study is being carried out and what will happen if you decide to take part.

Part 2 gives you some more detailed information about the study.

Part 1 About the study

Why is study taking place?

My name is Lynn Dangerfield. I am a Speech and Language Therapist [SLT] and have worked with people with stroke related communication difficulties for a number of years. The study is part of Professional Doctorate course I am taking at the University of Portsmouth. This study looks at the APHASIA CARE PATHWAY. Aphasia is the name given to the communication difficulties people may experience after a stroke. The aphasia care pathway is the care you should receive for the communication difficulties you have following your stroke. This is referred to as your APHASIA JOURNEY.

Why have I been invited?
You have been invited to take part in this study as you have personal experience of aphasia and will probably have ideas and opinions about the services you have received. The Stroke Association communication support Service Co-ordinator has suggested you may be happy to take part.

The study hopes to collect the views of people with aphasia about the journey they have experienced and how this could be improved.

Do I have to take part?

No, it is entirely up to you. You may say no if you do not wish to take part. If you decide would like to take part, you will be asked to sign a consent form.

If at any time before or during the group you do not feel comfortable about taking part, you are free to leave. This will not affect any Speech and Language therapy you are receiving.

What will happen if I do agree to take part?

If you agree to take part and sign the consent form, you will be invited to join a focus group. This is a small discussion group where people are asked to share their opinions and experiences of something specific. This group will be held at [exact venue to be confirmed]. Disabled facilities will be available.

During the group you will be asked to talk about your experience of aphasia and care you have been given, what has been good and what not so good. There will be pen and paper, pictures and written words to help you do this. All the others attending the group will have aphasia.

There will be 3 or 4 other people in the group; it will be run by Lynn. The group will be audio taped.
The group will last for approximately **one hour**; there will be a break half way through for **refreshments**. Thickened drinks and biscuits suitable for diabetics will be available for those that may need them.

You are very welcome to bring a **relative or friend** along to the centre, they will be able to wait in a nearby room. If at any point during the group you become upset or anxious, Lynn can take you to them so they can support or reassure you if necessary. If at any time you decide you no longer want to take part in the group, you can leave.

Your travel **expenses** to and from the group will be refunded.

**What will happen after the study?**

After the group has finished, Lynn will be in touch with you to **share with you the summary** of the discussion.

Taking part in this study **does not affect any Speech and Language Therapy** you may be receiving.

**Part 2**

**How will the information be stored?**

All the information and comments you provide will remain **confidential** and will only be read by Lynn and her research supervisor.

The information from the audio tapes of the groups will be stored **securely in a locked cabinet on Solent NHS premises and / or on a password protected computer.**

**What will happen if I cannot continue to take part in the study?**

If you are not able to continue to take part in the study for whatever reason, only data collected until this time will be used. Any **Speech and Language Therapy** you may be receiving can still continue.

**What will happen if I do not want to carry on with the study?**
You are free to leave the study at any time without giving a reason. If you do, all the **identifiable information** collected will be destroyed.

**What happens if I say something I regret later?**

If you decide you have said something you are not happy about, let us know within **two weeks** of the group, and Lynn will send you the script for you to find the comments and remove them.

**What are the benefits of me taking part?**

There is no specific benefit of you taking part, but your feedback and ideas may help to improve the services for other people with aphasia in the future.

**Are there any risks to me taking part in this study?**

There have been no identifiable **risks** to your health or welfare from taking part in this study.

If you decide to take part, it will not affect any Speech and Language Therapy you may still be receiving.

**What will happen to the results of this study?**

**Quotes** from the focus groups may be used in **scientific journals and conferences**, but will not include any details which could identify anyone personally. Any information you provide will be **confidential**. You will be able to ask for a copy of the research if you wish to.

**Who is organising this research?**

Lynn is an employee of **Solent NHS Trust** and a doctoral student at the **University of Portsmouth**.

**Who has reviewed the study?**

All research in the NHs is looked at by an independent group of people called a Research Ethics Committee to protect your safety, rights, wellbeing and dignity. This study has been reviewed and given favourable opinion by NRES Committee South Central – Berkshire B
The study will be closely checked by a group which will include health care professionals working in stroke care and a person with aphasia.

What do I do if there is a problem or concern?

If you have a concern about any aspect of this study you should speak to Lynn in the first instance. She will do her best to answer your questions.

If you do not wish to discuss your concerns with Lynn, you should contact;

**Ann Rice, Solent NHS Trust, Adelaide Health Centre, William Macleod Way**
**Southampton  SO16 4XE  02380 608894   Ann.rice@solent.nhs.uk**

If you remain unhappy and chose to make a complaint, you should use the **NHS complaints procedure.**

**NHS Complaints**

**Solent NHS Trust**

**Patient Experience and Engagement Service**

**Telephone : 0800 013 2319**

**Contact details**

For any further information about this study, please do contact;

**Lynn Dangerfield**

**Speech and Language Therapist**

**02392 286147 Lynn.dangerfield@solent.nhs.uk**

Revised in response to NRES Committee South Central – Berkshire B  30/06/13
Appendix 5 Information sheet for carers

School of Health Sciences and Social work

Study title: **AN IN-DEPTH EXPLORATION OF AN APHASIA CARE PATHWAY**

Researcher = **LYNN DANGERFIELD Speech and Language Therapist**

**Invitation to the carer/friend**

I would like to invite you to take part in a research study about the aphasia care pathway. Before you decide you need to understand why the research is taking place and what it would involve for you. Please take time to read this information sheet carefully and discuss it with a friend or family member if you wish. I will also talk through the information sheet with you, which will take about 15 minutes. Please ask at any time if there is anything you do not understand or you would like more information about. Do take your time to consider if you wish to take part or not.

Part 1 tells you about the purpose of the study and what will happen if you take part. Part 2 gives you more detailed information about the conduct of the study.

**PART 1 About the study**

**Why is the study taking place?**

My name is Lynn Dangerfield. I am a Speech and Language Therapist [SLT] and have worked with people with stroke related communication difficulties for a number of years. The study is part of Professional Doctorate course I am taking at the University of Portsmouth.

**Why have I been invited?**

You have been invited to take part in this study which looks at the APHASIA CARE PATHWAY. Aphasia is the name given to the communication difficulties your relative or
friend has experienced following their stroke. The aphasia care pathway is the planned care a person should receive. This is referred to as the APHASIA JOURNEY.

You have been chosen to take part as you have personal experience of aphasia and will probably have ideas and opinions about the services you have received. One of the SLT’s who has worked with your relative or friend has suggested you may wish to take part.

The study aims to collect views and opinions about the aphasia care pathway and how this could be improved.

Do I have to take part?

You may say no if you do not wish to take part in this study. It is entirely up to you. If you would like to take part, you will be asked to sign a consent form.

If at any time before or during the interview you do not feel comfortable about taking part, you are free to leave.

What will happen if I do agree to take part?

If you agree to take part and sign the consent form, I will contact you in due course to arrange a time to meet with you and conduct a short interview. This can take place in your own home. The interview will be audiotaped. These recordings and other information collected during the study will be used and stored in accordance with the Data Protection Act, as discussed in more details below. If at any time during the interview you become distressed or anxious about the questions being asked, the process will be halted. If you chose not to continue with the interview, your decision will be respected.

During the interview, which will last no longer than 45 minutes, you will be asked to talk about your experience of the aphasia care pathway, what has been good and what not so good.

What will happen next?

Following the interview, I will send you a written summary of the interview. If there is anything in the interview script that you wish to be removed or clarified, this can be done.
Taking part in this study does not affect any Speech and Language Therapy your relative or friend may be receiving.

**What are the benefits of me taking part?**

There is no intended clinical benefit of you taking part, but your feedback and ideas will help to improve the services for people with aphasia in the future.

**Are there any risks to me taking part in this study?**

There have been no identifiable risks to your health or welfare from taking part in this study.

**PART 2  More detailed information**

**What will happen if I cannot continue to take part in the study?**

If you are not able to continue to take part in the study for whatever reason, only data collected until this time will be used.

**What will happen if I do not want to carry on with the study?**

You are free to leave the study at any time without giving a reason. If you do, all the identifiable information collected will be destroyed.

**What do I do if there is a problem or concern?**

If you have a concern about any aspect of this study you should speak to me in the first instance. I will do her best to answer your questions.

If you do not wish to discuss your concerns with me, you can contact:-

**Ann Rice, Solent NHS Trust, Adelaide Health Centre, William Macleod Way**
**Southampton  SO16 4XE  02380 608894   Ann.rice@solent.nhs.uk**

If you remain unhappy and chose to make a complaint, you should use the NHS complaints procedure. Details of how to do this are provided at the end of this form

**How will the information from the focus groups be stored?**

All the information and comments you provide will remain confidential and will only be read by my research supervisor at and myself.
The scripts from the audio tapes of the focus groups will be stored securely in a locked in a cabinet on Solent NHS premises and / or on a password protected computer. All data will be destroyed after 5 years, this is in line with Solent NHS Trust policy.

What will happen to the results of this study?

I plan to publish the results of this when it is completed and also present the findings at local and national conferences. Any information you provide will remain totally confidential. You will be able to request a copy of the research if you wish to.

Who is organising this research?

I am an employee of Solent NHS Trust and a student at the University of Portsmouth.

Who has reviewed the study?

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

The study will be closely checked by a small group which will include healthcare professionals working in stroke care and a person with aphasia and a carer.

Contact details

For any further information about this study, please contact;-

Lynn Dangerfield
Speech and Language Therapy Department, Queen Alexandra Hospital, Southwick Hill Road, Cosham, Hants PO6 3LY
02392 286147
Lynn.dangerfield@solent.nhs.uk

NHS Complaints

Solent NHS Trust

Patient Experience and Engagement Service, 0800 013 2319
Appendix 6  Information sheet for HCPs

School of Health Sciences and Social work

Study title: AN IN-DEPTH EXPLORATION OF AN APHASIA CARE PATHWAY

Researcher = LYNN DANGERFIELD Speech and Language Therapist

Information sheet for Health Care Professionals

I would like to invite you to be interviewed as part of a research study about the aphasia care pathway. Before you decide you need to understand why the research is taking place and what it would involve for you. Please take time to read this information sheet carefully and consider if you wish to take part. I will also talk through the information sheet with you, which will take about ten minutes. Please ask at any time if there is anything you do not understand or you would like more information about.

PART 1   About the study

Why is the study taking place?

My name is Lynn Dangerfield. I am a Speech and Language Therapist [SLT] and have worked with people with stroke related communication difficulties for a number of years. The study is part of Professional Doctorate course I am taking at the University of Portsmouth.

Why have I been invited?

You have been invited to take part in this study which looks in detail at the aphasia care pathway. As you will know, aphasia is the name given to the communication difficulties an individual may experience following a stroke. The aphasia care pathway is the planned care a person should receive, alongside the stroke care pathway.

You have been chosen to take part as you have considerable experience working within the multi-disciplinary team with people with neurological impairments and will probably
have ideas and opinions about the services provided. Your service manager or clinical lead has suggested you may wish to take part.

The study aims to collect views and opinions about the aphasia care pathway and how this could be improved. People with aphasia and their carers have also been invited to take part in this study.

**Do I have to take part?**

You may say no if you do not wish to take part in this study. It is entirely up to you. If you would like to take part, you will be asked to sign a consent form.

If at any time before or during the interview you do not feel comfortable about taking part, you are free to leave.

**What will happen if I do agree to take part?**

If you agree to take part and sign the consent form, you will be asked to participate in an interview. This can take place at your clinical base or another venue convenient to you. It will last for approximately 45 minutes.

During the interview you will be asked to talk about your experience of the aphasia care pathway, what has been good and what not so good. The interview will be recorded using an audio recorder. These recordings and other information collected during the study will be used and stored in accordance with the Data Protection Act, as discussed in more details below. If at any time during the interview you become distressed or anxious about the questions being asked, the process will be halted. If you chose not to continue with the interview, your decision will be respected.

**What are the benefits of me taking part?**

There is no intended clinical benefit of you taking part, but your feedback and ideas will help to improve the services for people with aphasia.

**PART 2** More detailed information about the study

**Are there any risks to me taking part in this study?**
There have been no identifiable risks to your health or welfare from taking part in this study.

**What will happen if I cannot continue to take part in the study?**

If you are not able to continue to take part in the study for whatever reason, only data collected until this time will be used.

**What will happen if I do not want to carry on with the study?**

You are free to leave the study at any time without giving a reason. If you do, all the identifiable information collected will be destroyed.

**How will the information from the interviews be stored?**

All the information and comments you provide will remain confidential and will only be read by my research supervisor at and myself.

The scripts from the audio tapes of the interviews will be stored securely in a locked in a cabinet on Solent NHS premises and / or on a password protected computer. All data will be destroyed after 5 years, this is in line with Solent NHS Trust policy.

**What will happen to the results of this study?**

I plan to publish the results of this when it is completed and also present the findings at local and national conferences. Any information you provide will remain totally confidential. You will be able to request a copy of the research if you wish to.

**Who is organising this research?**

Lynn is an employee of Solent NHS Trust and a student at the University of Portsmouth.

**Who has reviewed the study?**

All research in the NHs is looked at by an independent group of people called a Research Ethics Committee to protect your safety, rights, wellbeing and dignity. This study has been reviewed and given favourable opinion by NRES Committee South Central – Berkshire B.
The study will be closely checked by a small group which will include healthcare professionals working in stroke care and a person with aphasia and a carer.

**What do I do if there is a problem or concern?**

If you have a concern about any aspect of this study you should speak to Lynn in the first instance. She will do her best to answer your questions.

If you do not wish to discuss your concerns with Lynn, you can contact;

**Ann Rice, Solent NHS Trust, Adelaide Health Centre, William Macleod Way**  
**Southampton SO16 4XE 02380 608894  Ann.rice@solent.nhs.uk**

If you remain unhappy and chose to make a complaint, you should use the NHS complaints procedure. Details of how to do this are provided at the end of this form.

**Contact details**

For any further information about this study, please do contact;-  

Lynn Dangerfield  
Speech and Language Therapist  
Queen Alexandra Hospital  
02392 286147  
Lynn.dangerfield@solent.nhs.uk

**NHS Complaints**

Solent NHS Trust  
Patient Experience and Engagement Service  
Telephone : 0800 013 2319

Revised in response to NRES comments 30/06/13
Appendix 7 Consent form for PWA

School of Health Sciences and Social Work

Consent form for people with aphasia

Title of Project: **An in-depth exploration of the aphasia care pathway**

Name of Researcher conducting focus group: **Lynn Dangerfield**

<table>
<thead>
<tr>
<th>Statement</th>
<th>Initials</th>
</tr>
</thead>
<tbody>
<tr>
<td>I confirm that I have read and understood the information sheet; version 5 dated 30\textsuperscript{th} June 2013, for this study. I have been given time to ask questions and these have been answered satisfactorily.</td>
<td></td>
</tr>
<tr>
<td>I understand that taking part in the study is voluntary. I am free to withdraw at any time if I choose to, without giving a reason.</td>
<td></td>
</tr>
<tr>
<td>I am aware that the focus group will be audio taped. I give my permission for this to happen.</td>
<td></td>
</tr>
<tr>
<td>I agree to anonymous direct quotes from the focus groups or interviews being published.</td>
<td></td>
</tr>
<tr>
<td>I agree to a written record of my participation in this study being securely stored for as long as the study lasts.</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Statement</th>
<th>Initials</th>
</tr>
</thead>
<tbody>
<tr>
<td>I understand that relevant sections of my medical notes and data collected during the study may be looked at by individuals from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in the research. I give my permission for these individuals to have access to my records</td>
<td></td>
</tr>
<tr>
<td>I agree to take part in this study.</td>
<td></td>
</tr>
</tbody>
</table>
Please put your initials in all boxes, if you agree, and then sign below.

<table>
<thead>
<tr>
<th>Name of participant</th>
<th>Date</th>
<th>Signature</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Name of person taking consent</th>
<th>Date</th>
<th>Signature</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Appendix 8 Referral form for SLTs to recruit carers

APHASIA CARE PATHWAY STUDY REFERRAL FORM

Thank you for helping with recruitment of participants to the Aphasia care pathway study. Please use this referral form to refer relatives/friends of people with aphasia who are interested in participating in an interview. Please ensure you are familiar with the inclusion/exclusion criteria for this study, as outlined in the information sheet for referrers. Participants should have been given a copy of the study information leaflet and asked if their details can be passed to Lynn Dangerfield.

Please PRINT all details

PARTICIPANTS NAME

GENDER

M       F

CONTACT DETAILS:

ANY SPECIAL INSTRUCTIONS REGARDING CONTACTING THIS PARTICIPANT?  Y / N

If yes – please specify ;-)

DO THEY MEET THE INCLUSION CRITERIAL FOR THIS STUDY? Y / N

HAVE THEY BEEN GIVEN A COPY OF THE STUDY INFORMATION LEAFLET?  Y / N

REFERRED BY

DATE OF REFERRAL

Thank you for making this referral

Please return the completed form internally, marked as private and confidential to Lynn Dangerfield, Speech and Language Therapist QAH

Office use ;-) Date received
Appendix 9  Referral form for HCPs into the study

APHASIA CARE PATHWAY STUDY REFERRAL FORM Draft 1 [Jan 13]

Thank you for helping with recruitment of participants to the Aphasia care pathway study. Please use this referral form to refer members of staff who are interested in participating in an interview. Please ensure you are familiar with the inclusion/exclusion criteria for this study, as outlined in the information sheet for referrers.

Participants should have been given a copy of the study information leaflet and asked if their details can be passed to Lynn Dangerfield

Please PRINT all details

PARTICIPANTS NAME
CONTACT DETAILS
BREIF DESCRIPTION OF CURRENT CLINICAL RESPONSIBILITY

ANY SPECIAL INSTRUCTIONS REGARDING CONTACTING THIS PERSON? Y / N
If yes – please specify ;-)

HAVE THEY BEEN GIVEN A COPY OF THE STUDY INFORMATION LEAFLET? Y / N

REFERRED BY DATE OF REFERRAL

Thank you for making this referral

Please return the completed form internally marked as private and confidential to

Lynn Dangerfield
Speech and Language Therapist

..................................................

Office use :-  Date received___________________
Appendix 10 Consent form for carers and HCPs

School of Health Sciences and Social work

CONSENT FORM

Title of study: AN IN-DEPTH EXPLORATION OF AN APHASIA CARE PATHWAY

Name of researcher: Lynn Dangerfield Speech and Language Therapist

PLEASE PUT YOUR INITIALS IN ALL BOXES IF YOU AGREE AND THEN SIGN AT THE BOTTOM OF THE PAGE

- I confirm that I have read and understood the information sheet [version 5 30th June 2013] for this study. I have been given time to ask questions and these have been answered satisfactorily.

- I understand that taking part in the study is voluntary and I am free to withdraw at any time if I choose to, without giving a reason.

- I am aware that the interviews will be audio taped. I give my permission for this to happen.

- I agree to anonymous direct quotes from the interviews being published.

- I agree to a written record of my participation in this study being stored securely for as long as the study lasts.

- I agree to take part in this study.

Name of participant Date Signature

------------------------- -------- ------------------------

Name of person Date Signature
taking consent

------------------------- -------- ------------------------

Name of person Date Signature
### Focus Group topic guide

<table>
<thead>
<tr>
<th><strong>Scene setting and ground rules</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>Introductions</td>
</tr>
<tr>
<td>Information about fire exits and toilets and refreshment break</td>
</tr>
<tr>
<td>Remind participants about the nature and purpose of research</td>
</tr>
<tr>
<td>Agree / Set ground rules for group</td>
</tr>
<tr>
<td>Assure confidentiality</td>
</tr>
<tr>
<td>Introduce tape recorder, one voice at a time press record.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Opening topic</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>Personal experiences / awareness of aphasia care pathway</td>
</tr>
<tr>
<td>Metaphors to describe impact of aphasia</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Discussion</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>Key stages of aphasia care pathway</td>
</tr>
<tr>
<td>Who should be involved and at what point?</td>
</tr>
<tr>
<td>Describe experience of aphasia care to date</td>
</tr>
<tr>
<td>Negative experiences of aphasia journey from the past or current experience.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Discussion</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>How would you like to see the aphasia care pathway represented so it would make sense to you – practical task / drawing pathways</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Conclusion / ending the discussion</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>- anything else you would like to add</td>
</tr>
<tr>
<td>- what happens to the data</td>
</tr>
<tr>
<td>- copies of the results</td>
</tr>
<tr>
<td>- Thank you for taking part</td>
</tr>
</tbody>
</table>
Appendix 12  Letter to PWA – focus group invitation

25th November 2013

Dear

I am writing to ask if you would be willing to help me with a piece of work I am doing at the moment.

This study looks at the APHASIA CARE PATHWAY. Aphasia is the name given to the communication difficulties people may experience after a stroke. The aphasia care pathway is the care you should receive for the communication difficulties you have following your stroke. This is referred to as your APHASIA JOURNEY.

I am very keen to hear YOUR views about the journey you have experienced so far and how this could be improved.

I would like to invite you to a “one off” small group meeting on

Tuesday 10th December 2013

10 – 11.30am

Speech and Language Therapy Department

Queen Alexandra Hospital, Cosham

02392 286147

Transport can be provided. Refreshments will be provided.
I do hope you are able to come along. Please say no if you do not wish to take part, it will not affect any further Speech and Language Therapy you may be having.

Please do contact me if you have any questions.

Thank you very much for your help, I look forward to seeing you on 10th December

With best wishes

Yours Sincerely

Lynn Dangerfield

Speech and Language Therapist

Queen Alexandra Hospital

02392 286147

Lynn.dangerfield@nhs.net
Appendix 13  Topic guide for interviews with carers

<table>
<thead>
<tr>
<th>Interview Schedule for carers</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>2. APHASIA CARE PATHWAYS</strong></td>
</tr>
<tr>
<td>• What do you know about / what are your experiences of the care pathway for people with aphasia [PWA]</td>
</tr>
<tr>
<td>• Key stages?</td>
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<tr>
<td>• Who should provide what and when?</td>
</tr>
<tr>
<td>• How could process be improved?</td>
</tr>
<tr>
<td><strong>3. THE IMPACT that aphasia / SLT had on their lives</strong></td>
</tr>
<tr>
<td><strong>4. FURTHER VIEWS about having aphasia / CPs that may not have been discussed in the interview</strong></td>
</tr>
</tbody>
</table>
Appendix 14 Topic guide for interviews with HCPs

<table>
<thead>
<tr>
<th>Interview topic guide for HCPs</th>
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</thead>
<tbody>
<tr>
<td><strong>Introduction</strong></td>
</tr>
<tr>
<td>• introduce self</td>
</tr>
<tr>
<td>• explain briefly the nature and purpose of research</td>
</tr>
<tr>
<td>• topics to be addressed</td>
</tr>
<tr>
<td>• assure confidentiality</td>
</tr>
<tr>
<td>• introduce tape recorder</td>
</tr>
<tr>
<td><strong>CARE PATHWAYS</strong></td>
</tr>
<tr>
<td>• Understanding of care pathways</td>
</tr>
<tr>
<td>• Advantages and limitations of care pathways</td>
</tr>
<tr>
<td><strong>APHASIA CARE PATHWAYS</strong></td>
</tr>
<tr>
<td>• What is HCPs experience of care pathway for people with aphasia [PWA]</td>
</tr>
<tr>
<td>• Who should provide what and when?</td>
</tr>
<tr>
<td>• How to communicate aphasia / care pathway to PWA and families</td>
</tr>
<tr>
<td>• Any suggested improvements</td>
</tr>
</tbody>
</table>

**Conclusion**

- anything else you would like to add
- what happens to the data
- copies of the results
- Thank you for taking part
### Framework of codes used to index data

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<th>Accessible format [AP]</th>
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<td>Acute care</td>
<td>Honesty</td>
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<td>Adaption</td>
<td>Independence</td>
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<tr>
<td>Alternative/ augmentative  communication [AAC]</td>
<td>Information giving [AP]</td>
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<td>Anxiety / fear [AP]</td>
<td>Informed choice</td>
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<td>Interventions</td>
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<td>Aromatherapy [D]</td>
<td>Intensity</td>
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<td>Assessment</td>
<td>Isolation</td>
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<td>Awareness</td>
<td>Limited knowledge</td>
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<td>Bureaucratic</td>
<td>Living with aphasia [AP]</td>
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<td>Capacity</td>
<td>Managing expectations [AP]</td>
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<tr>
<td>Challenges</td>
<td>Managing risk</td>
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<td>Commissioning</td>
<td>Map of care</td>
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<td>Communication</td>
<td>Motivation</td>
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<td>Co-ordinated care</td>
<td>Multi-agency</td>
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<td>Complexity</td>
<td>National drivers</td>
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<td>Computer based therapy</td>
<td>Onward referral</td>
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<td>Confidence</td>
<td>Outcomes</td>
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<td>Consent</td>
<td>Overload</td>
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<td>Discharge</td>
<td>Person centred</td>
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<td>Duty of care</td>
<td>Provision of communication aids / props</td>
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<td>Emotions</td>
<td>Prioritisation</td>
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<td>Category</td>
<td>Codes</td>
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<td>Experience</td>
<td>Recovery timescales [AP]</td>
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<td>Expertise</td>
<td>Rehabilitation</td>
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<td>Family involvement</td>
<td>Remaining positive</td>
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<td>Fatigue</td>
<td>Retaining information</td>
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<td>Financial implications</td>
<td>Review/follow up</td>
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<td>Flexibility</td>
<td>Roles</td>
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<td>Frameworks</td>
<td>Shock</td>
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<td>Stages of intervention</td>
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<td>Team involvement</td>
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<td>Therapy [P]</td>
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<td>Timing of intervention [AP]</td>
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<td>Group therapy</td>
<td>Websites</td>
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</table>

No of codes = 81
Appendix 16

Examples from interview and focus groups transcripts with initial labels identified

1. Excerpts from interview with JD (carer)

1.1

JD think someone talking to me and having something written, because at the time it was such a huge shock and when I was in the hospital I tried really hard to listen to what everyone was saying to me, but sometimes I realised afterwards I had missed something and wondered what they had said about that, so I think to be spoken to so I could ask questions but also something written that I could take away to look at later and even show my family.

LD Yes that’s important isn’t it, we hear this a lot, people say info may be given but some of it quite naturally is gone.

JD Well it is a very stressful time because the first 2 or 3 weeks I hardly slept

LD I bet, and you were in the hospital lot weren’t you

JD Every day for quite a few hours a day

LD Did you know what to expect?

JD No

LD do you think it would have been helpful if you had?

JD Yes, something written down to tell me what to expect, it would have been something we could be seen to be working towards

LD Were you given any written info in the early days around the aphasia.

JD Yes H gave me a leaflet, I can’t remember what is was called, it was very general and she also gave me a book about, talking and conversations

LD OH yes, was it called Better conversations

JD Yes

LD Was that helpful

JD [pause] I did not feel it directly, it didn’t seem very clear what I could do with J, it was helpful in general, but not specific

LD OK, so if I was to ask how you would change the info that was given to you, how could have that info have been better for you
JD  Pause... I can understand that everyone tells you that everyone who has had a stroke is different, I am not really sure. At the beginning when I first spoke to H it seemed very very dire J situation and [ pause] It was a huge concern, I did not even know if he could read or write, which we didn’t know for a few weeks, so perhaps if someone had explained to me that it is early days, this may happened, it may not happen, it may come that j can read and write

LD SO someone sitting down and explaining things, but not just giving you the info, there needed to be that discussion too

JD Some of the leaflets about aphasia seemed to be quite common sense, what to do and how to approach people, although I understand not everyone may be as sensitive. Because I tried everyday to put myself in J position. He was sitting on the settee at home at one moment, the next thing he knew he was in hospital, he didn’t know what had happened, he could not ask. I did tell him, every day I told him but I could see it was not going in. how frightening it must be, he had never been in hospital in his adult life, to ding himself somewhere and he didn’t know where and I wasn’t there at night. He could not ask for the toilet, for a drink, I just tried to think as he would have

LD So putting yourself in his shoes helped you think of strategies, ways to help J, that was more useful than the leaflet, we do say to people often the info is common sense, but seeing it written down may reassure people that what they are doing is the best thing.

JD And a pathway or map to say this is what j could or maybe, maybe not follow

LD And if, ...we do have this pathway but we are always looking o revise it and looking as ways we can improve what we provide at those very early stages, how do you think the passing on of information in those early days could be improved?

JD We have 3 sons but only one lives locally, he came in to see J everyday, he has been a huge support, he tried, we both tried to get involved as much as we could, so with family members in, if available and willing

JD Some family members found it overwhelming to see what had happened to J

LD So at least if you were there and maybe your son as well

JD Yes

LD SO that would be preferable to having a group meeting

JD Yes, if you had a family member there, the bits I forgot he would remember and vice versa

LD you went to family meetings on the rehab ward, did that cover much about J communication or was that very much more general?

JD They gave us an update of where J was, but because I was there so often I knew it all anyway, what he was doing in physio because I went to all the sessions, and I tried to attend all the speech sessions with H. So they only reported on what his progress was at that time and the d/c family
meeting to be frank we were very disappointed, they just said the same thing over again, yes j is still incontinent, he is still this ..., it was not very useful

LD I cannot comment specifically on anything like that today

JD It is just my opinion

LD Of course, I am asking for your opinion

LD So the pathway talks about info giving, that is kind of what we have just discussed, but it is how we given that info and in what format, that I am interested in finding out

JD It does depend on with people are able to absorb. I went toe the library and took out every book on stroke and aphasia, I still have two that I still refer to. my son looked things up on the internet because he is that generation

1.2

JD But no, everyone that I have spoken to says everyone is different, we cannot say

LD so you weren’t given 6 months as the time to expect the most progress

JD my son and I both talked about this, J was so unwell in the first month or so, he did not even react very well to me, he knew who I was but we felt he could not possible make progress because he was too ill, he had so much going on [some info given re physical status]. Every week it was back to square one. So although it has been 6 months, we do not feel he started on the pathway you talk about when he first had his stroke

LD And that is often the case, the first weeks or months can be an awful lot of uncertainty, a lot of change because there may be a lot of medical issues going on, a lot of instability. There reason I ask the question about timescales, some people are told that if they have not made progress after 6 months, that’s it

JD I have been supported by GN of the stroke association and she has said she has known people years down the line who have suddenly made progress, so she has made us think it is not a 6 months cut off, we are not thinking that

LD That’s good, what we are really keen is to get away from is what the traditional textbooks would say 6 months, but we know now, there is an awful lot of evidence, to say that people do, with aphasia, will make progress a year, 5 years down the line and it will happen at different stages

JD Yes we are certainly not thinking we have reached the end after 6 months

LD But that not specifically been said to you that the progress will not carry on

JD I think h did say she was treating a patient who was making progress 2 years after.

1.3
J finds it quite hard to put into words what his goals are, I think sometimes they have been suggested for him

LD How do you feel about that?

JD Pause I am not, J was always such a quiet reserved sort of person, he didn’t talk about his feelings or what he wanted, so for him even before his stroke to say, what. his goals were I think he would have found hard. He is still very positive, but I think I would feel like that if someone said they were going to finish with me now, that I am not going to get any better

2. Excerpts from interview with LG (HCP)

2.1

LG If I had to describe what a CP is, I think I would describe it as the journey a patient goes on and part of that journey is the contribution different MDT make in that process, so it is definitely something which occurs over a period of time, it has a beginning and an end, and there are various different people that feed into that pathway. So for us in stroke it would be the MDT but equally any other support teams. Does that answer your question?

LD Yes – so leading on from that, what do you see as the benefits or advantages of a CP?

LG I think there are probably several advantages of having a CP that is agreed on. I think it helps people to understand what their role and contribution is, what their responsibilities are within that, and it does allow you to have some way of measuring if it is working or not, so it is kind of a measurable process you can look into if you want to as well. So it about that ownership of role and it gives you a structure you can measure and be accountable to as well.

LD Then on the flip side, what do you see as the disadvantages or negative

LG I guess a negative thing would be if they were very prescriptive, you end up doing just what is essential to the CP, which may not necessarily meet that individual patient’s needs – so I think for me, an ideal pathway is something that has a formal structure but within that there is an element of freedom to make it adaptable to each individual patient, so they are not so rigid that you are just becoming really prescriptive in what you are trying to do

LD so they are flexible enough to meet individual’s needs, but also provide some sort of compliance or checklist

LG And a standard, I guess that you could argue that they provide some sort of baseline, a line in the sand to say that this is what in theory should happen, so there is a quality element in there as well

2.2.
LG I think for CP to be successful there does need to be someone who takes overall responsibility for it, so that is my first thought, there needs to be a role in there for somebody to lead, or as a co-ordinator and then within that, I think it needs to be the person who has the skills and the ability to complete the task, and within each profession, there will be different discussion about what that might look like whether it is appropriate for a qualified or an unqualified. The key thing is that the person is able to carry out, skilfully, the bit of the CP they are being asked to do.

LD That they are competent.

LG Yes, you either need some sort of level of qualification or some competency framework to work to, but I don’t think it needs to be set grades; it can be a local thing that is agreed with the professional groups that are doing it. The majority of the ax are completed by a qualified registered practitioner, so of our specific standardised ax you have to have a specific qualification or licence to use it.

LD Do you have any thoughts about how we share a CP with the patient and their family?

LG I think we should be doing that – the general basis for the way we treat people should be open and transparent to encourage involvement as much as is clinically possible for that individual – if it is something they can think about and process and manage, we should give them as much information as we can, and involve them in the decision, especially if there are choices within the CP, I think if patients can make choices themselves, then that is the way we should negotiate CP with patients, alongside them. It may not always be possible because of the nature of the client group we work with, but we should try and do that when we can.

LD How about the timing of info giving?

LG That’s quite an interesting one, I know that there is lots of evidence to say that when we give out information in the acute setting it is difficult for patients and carers to retain that info – it is a very busy environment, they are getting info for multiple people. There is definitely a role for giving good, clear info to I/P and we probably don’t do that as well as we should – but if we are able to follow people up in the community we need to be able to revisit it and do it again and adapt it to the environment or change of situation or status. There probably needs to be information at different points of the CP – and I guess that is the sort of thing we should involve patients more in – ask them when they would like to know bits and pieces, what is important at what point – and then work much harder to communicate that more clearly.

2. 3.

LD within a CP what key headings do you think there should be?

LG – interesting, I suppose there is a point of entry into the CP and what that might look like and then I guess there needs to be something about assessment or finding out the need, the clinical need for that person, setting goals, that can be a challenge especially if the person has aphasia and some sort of action plan and then the plan itself needs to be implemented, probably with some sort of time frame and then an evaluation or outcome, we call that the OT process, but I guess every profession has that kind of cycle that they go through and I guess within that there are time spans that are set externally by the hospital if they are trying to set d/c dates, those are
external bits that need to be within the CP as well. WE need to involve the family as much as possible but often they are in a state of shock, angry or distressed and they cannot take on the information about the pathways, progress ...

3. Excerpt from focus group

3.1

KB When I was first ... stroke I was very angry

DW Yes frustrated

KB Angry ... my wife.. read the television face and .. first hour is the ...

LD yes it is important to get help straight away

KB Yes ambulance arrived in 5 minutes, I was ¾ hour in an ambulance and when I got here I was 7 hours before I got ... and when I got here no one could give me an injection for clot thing and when I .. why, told no one here give it to you - 2 days later I had a scan, so no plan,

LD D what would your top word be to describe what has happened

DS points to nightmare

DW Yes

KB Yes yes

LD What would your next one be

KB The worst thing that has happened to me in my life Had heart attack but this is much worse

Ld why do think that was K

Kb Because heart attack you get over But stroke ... Can’t do the things I used to do Used to be able to hold screw driver and use the telephone. I used to be independent but I not now

LD Ok so it is not something you can see an end to

KB Oh yes I see an end, death

LD SO nightmare does sum it up What would your second word be D
DS time to think => points to experience But is not ...

KB A pleasant one

DS No

3.2

LD shows the aphasia care pathway / map (speakability format) - I am interested to find out from you what it as been like for you to go along this journey,

KB If in hospital, this would confuse you

DW Yes, too many things

KB you can’t think straight. I can’t speak, only swear, gradually I improved and I went home and the SLT came round for 2 weeks and the Physio 2 weeks or 3 weeks, I can’t remember and then I went to EL and I found I could improve the speech no end. But as I begun to understand how well I was getting they dumped me. Yes but, I know...1:1 is good but you cannot have it all the time, there are people out there having strokes all the time.

DW Segments, maybe you need to have it in segments, have a rest but do exercises and then pick it up again a few months later. Because you are overwhelmed and your concentration and everything else, its like so much effort goes into it, it literally knackers you

KB Yes...yes [evidence KB beginning to tire] Why not get a video to speak to you and practice words

KB [pointed to DS IPAD] I can’t use that

LD no not for everybody...

LD So when you have seen the SLT and done you therapy for a while, having something to carry on is important

KB Yes it stops

LD were you aware there was a plan to help you or a pathway to follow (Speakabiity plan and self drawn recovery road shown to group?)

KB No , not told, if I was ... not remember...

DW Me too

LD Would it have been helpful to have been told this plan

DS (scratched head – took time to think..) family yes – me ... don’t’ know
LD What our plan is, is to give you information, which is what we have been talking about, it may be information like this [brain map] we do some assessment, to work out what is difficult for you and what we need to help you with and then we give you some 1:1 therapy

KB Not enough .. too soon

LD Did you have just one block, one go at 1:1 or did you have a go and then a break

KB no just one

DW I cannot remember [brief discussion re who DW SLT was] I can’t remember how long it was or how long after the stroke it was, see I had no sense of time

LD How long did you have your 1:1 for DS

DS 2 or 3 in the hospital to assess me and then I was at home and E come along, give me some questions to answer myself. It didn’t work out. But I tried and tried and getting so annoyed, frustrated, the length of the question and I can’t read it

3.3

LD OK so nearly finished - to do the next section I have some more word written down [

Laminated cards shown to summarise aphasia care pathway headings, ax, intervention, therapy, information, support, goal setting placed on table – each participant given a number of counters

LD Can you each take a few minutes to look at these words... then put a counter on each word you think its important to include in a “pathway”

2-3 minutes when participants looked at words and placed counters Ax = 3 Therapy = 3 goal setting = 1 support = 3 Information =3

DS All are good

KB Whats goal setting ... don’t know about that

LD Did someone talk to you about goals or targets to work on

KB Don’t think so,

DB Did with me but only at home, hard to do though

KB Needed lots of help .. info... information
Appendix 17
Initial themes and sub themes from focus group and interview analysis

○ Aphasia care pathway
  ➢ Accessible format
  ➢ AAC (Alternative and augmentative communication)
  ➢ Assessment
  ➢ Intervention / Therapy
  ➢ Stages / sections
  ➢ Who does what when

○ Assessment
  ➢ Timing of assessment
  ➢ Keeping everyone informed

○ Care pathways
  ➢ Accessible formats
  ➢ Advantages and limitations
  ➢ Baselines
  ➢ How should they be used
  ➢ How should they be communicated
  ➢ How should they be organised / led
  ➢ Stages in the CP
  ➢ What do they mean

○ Communication difficulties
  ➢ Adaption
  ➢ Aphasia
  ➢ Impact of communication impairment
  ➢ Hope that improvements will be made
  ➢ Keeping motivated
  ➢ Progress
  ➢ Strategies to help communication
  ➢ Strengths

○ Family and friends
  ➢ Adaption
  ➢ Strategies to help communication

○ Information giving
  ➢ Accessible formats
  ➢ Format (paper, electronic, face to face
  ➢ Frequency of provision
  ➢ Individual needs led
o Intervention
  ➢ Assessment
  ➢ Computer based therapy
  ➢ Discharge from therapy
  ➢ Family involvement
  ➢ Functional communication
  ➢ Goal setting
  ➢ Group therapy
  ➢ Outcomes
  ➢ Qualified / registered staff vs therapy assistants
  ➢ Person centred
  ➢ Reviews / follow up
  ➢ Support from other organisations eg Stroke Association
  ➢ Timing of intervention / when to start and finish
  ➢ Who provides what when

o Multi-disciplinary team (MDT)
  ➢ Goal setting
  ➢ Information
  ➢ Motivation
  ➢ Prioritisation
  ➢ Shared learning

o Psychosocial impact
  ➢ Anger
  ➢ Anxiety
  ➢ Distress
  ➢ Confidence
  ➢ Expectation
  ➢ Hope / not giving up
  ➢ Mood
  ➢ Motivation
  ➢ Uncertainty

o Recovery process
  ➢ Care pathway, to provide structure / framework
  ➢ Discharge from therapy
  ➢ Expectation
  ➢ Goals
  ➢ Therapy provision
  ➢ Timescales

o Voluntary / third sector organisations
  ➢ Stroke Association
  ➢ Communication support service
## Emerging themes from peer validation

<table>
<thead>
<tr>
<th>Theme</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Awareness of the care pathway/pathway/lack of awareness about the process</td>
<td></td>
</tr>
<tr>
<td>Framework/guidelines for care pathway – having a process, but being able to be flexible</td>
<td></td>
</tr>
<tr>
<td>Experience &amp; expertise – amount that is necessary within team to create care pathway, coordinate/care pathway and carry out roles from the care pathway</td>
<td></td>
</tr>
<tr>
<td>Involvement in the care pathway: from team, family, patient</td>
<td></td>
</tr>
<tr>
<td>Aphasia care pathway – specific SLT interventions</td>
<td></td>
</tr>
<tr>
<td>Information: the type of information that people should be given e.g. about recovery timescales; a core set of information, when information should be given</td>
<td></td>
</tr>
<tr>
<td>Emotions – e.g. shock; stress; fear; frustration – links to difficulties retaining information &amp; therefore ? also to format of information giving</td>
<td></td>
</tr>
<tr>
<td>Long term support – from SLT, role of family, other HCPs, voluntary agencies</td>
<td></td>
</tr>
</tbody>
</table>

### Comments / questions

*1 Is there a code that describes the feeling that specific information is needed? It perhaps links to ‘person centred’

*2 Is there a code that encompasses the feeling of wanting to take action/ have direction/ have a goal to work towards?

*3 Is there a code about emotional support being provided – perhaps this links to the code ‘Emotions’?

*4 Is there a code that you are using to capture the feeling that there needs to be a core consensus/agreed pathway? Perhaps ‘Guidelines’ or ‘Frameworks’ means this?

*5 Is there a code for the patient being involved in the care pathway – I have put this under ‘person-centred’
APPHASIA CARE PATHWAYS - your opinions / experiences are needed.

As part of a Professional Doctorate research project entitled “An in-depth exploration of the aphasia care pathway”, I am conducting national survey of SLTs to scope their understanding and opinions of aphasia care pathways. The data collected from the survey will add to qualitative data collected from interviews and focus groups held for people with aphasia, carers, other health care professionals and commissioners.

If you currently work with people with aphasia and / or have done so in the last 5 years, I would be very grateful if you could complete the survey, accessed by the link below. It will only take a short time to complete.

Please do contact me directly if you have any questions or comments about this piece of work.

Thanking you in advance for your support

Lynn Dangerfield, SLT, Solent NHS Trust / University of Portsmouth

Lynn.dangerfield@nhs.net

Survey link: https://www.survey.bris.ac.uk/portsmouth/aphasia
Appendix 20 Survey pilot questions

Aphasia care pathway survey
Pilot phase

Thank you for agreeing to pilot this survey.

Please read through and complete the survey, as far as you are able and then answer the following questions;

1. How long did it take you to complete the survey?  
   Write down the number of minutes: ------mins

2. Were any of the questions ambiguous or difficult to understand?
   YES
   NO
   If yes, please state which questions

3. Did you object to answering any of the questions?
   YES
   NO
   If yes please state which questions

4. Did you think any questions were inappropriate?
   YES
   NO
   If yes, please state which and why

5. Do you think the questions have been placed in the best order?
   YES
   NO
   If no, please state which questions should be reordered

6. Are the instructions for respondents are clear/adequate?
   YES
   NO
If no. please state which instructions are not clear.

7. Do you have any comments about the overall layout of the survey?

Thank you very much for your help, it is very much appreciated

Lynn Dangerfield
Speech and Language Therapist
Aphasia care pathway survey: March 2015

I am conducting a survey as part of a study looking in detail at aphasia care pathways. The aim of the study is to explore the aphasia care pathway from the perspective of the key interested parties, person with aphasia, carers, health care professionals and commissioners. Interviews and focus groups have also been completed with these people, to obtain their opinions and suggestions.

I would be very grateful if you could assist with this study by completing the survey below.

It should take approximately 15 minutes to complete

Thank you

Aphasia care pathways

I am interested to find out your experiences and opinions about aphasia care pathways

A Care pathway is defined as:-

“a map of the patient’s journey, aiming to have the right people doing the right things in the right order, at the right time in the right place with the right outcome”.

1. Do you use an aphasia care pathway in your workplace?
   YES          NO          UNSURE

If Yes – please state for how long it has been used

If no, please give any reason why

2. Please rank in order of importance, the following the potential headings within an aphasia care pathway 1 = most important  7 = least important

- Information giving
- Goal setting
- Assessment
3. Which of the following best describe the value to you of an aphasia care pathway – please rank in order of importance 1 = most important 6 = least important

- Ensure all the key stakeholders are involved in the decision making process along the aphasia care pathway
- Discover client priorities
- A structured systematic tool to share with service users
- Break down the key stages of the aphasia journey into relevant sections
- A visual representation of the aphasia journey
- Facilitate a more consistent therapeutic approach to aphasia management

4. Suggest THREE ADVANTAGES of an aphasia care pathway

- 
- 
- 

5. Suggest THREE LIMITATIONS of an aphasia care pathway.

- 
- 
- 

6. Should the aphasia care pathway be in a format that can be shared with people with aphasia and their families?

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
<th>Unsure</th>
</tr>
</thead>
</table>

If Yes - please give suggestions how this could be done in box below
If No- please state why not in space below

7. Do you have any additional comments to make about care pathways?

8. Please use space below to add any further opinions of comments you have about the aphasia care pathway

9. How long have you been working with people with aphasia [PWA]?
   
   0-5 years [ ] 6-10 [ ] 11-15 [ ] 16-20 [ ]
   
   20 + [ ]

10. Which clinical setting do you PRIMARILY work in?
   
   Acute [ ] Community [ ]

11. What is your grade, according to Agenda for Change banding?
   
   BAND 4 [ ] 5 [ ] 6 [ ] 7 [ ] 8a [ ]
   
   8b [ ] 8c [ ]

12. Please indicate who your primary employer is, or if you work independently
   
   NHS [ ] Private health care provider [ ]
   
   Independent practice [ ] Other [ ]

Lynn.dangerfield@solent.nhs.uk

Lynn Dangerfield

Speech and Language Therapist
## Appendix 22 Summary of descriptive statistics

Description of the characteristics of the study population (N=82)

<table>
<thead>
<tr>
<th>Variable</th>
<th>Number / %</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>CP used – n (%)</strong></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>48 (58.5%)</td>
</tr>
<tr>
<td>Yes</td>
<td>34 (41.5%)</td>
</tr>
<tr>
<td><strong>Accessible format – n [%]</strong></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>3 (3.7%)</td>
</tr>
<tr>
<td>Yes</td>
<td>72 (87.8)</td>
</tr>
<tr>
<td>Unsure</td>
<td>7 (8.5)</td>
</tr>
<tr>
<td><strong>Work setting</strong></td>
<td></td>
</tr>
<tr>
<td>Acute</td>
<td>22 [26.8%]</td>
</tr>
<tr>
<td>Community</td>
<td>34 [41.5%]</td>
</tr>
<tr>
<td>Both</td>
<td>26 [31.7%]</td>
</tr>
<tr>
<td><strong>Years working</strong></td>
<td></td>
</tr>
<tr>
<td>0-5 years</td>
<td>23 [28%]</td>
</tr>
<tr>
<td>6-10 years</td>
<td>26 [31.7%]</td>
</tr>
<tr>
<td>11-15 years</td>
<td>17 [20.7%]</td>
</tr>
<tr>
<td>16-20 years</td>
<td>3 [3.7%]</td>
</tr>
<tr>
<td>20 + years</td>
<td>13 [15.9%]</td>
</tr>
<tr>
<td><strong>Grade</strong></td>
<td></td>
</tr>
<tr>
<td>Band 5</td>
<td>5 (3.7%)</td>
</tr>
<tr>
<td>Band 6</td>
<td>39 (47.6%)</td>
</tr>
<tr>
<td>Band 7</td>
<td>30 (36.6%)</td>
</tr>
<tr>
<td>Band 8a</td>
<td>8 (9.8%)</td>
</tr>
<tr>
<td>Band 8b</td>
<td>1 (1.2%)</td>
</tr>
<tr>
<td>Band 8c</td>
<td>1 (1.2%)</td>
</tr>
<tr>
<td><strong>Employer</strong></td>
<td></td>
</tr>
<tr>
<td>NHS</td>
<td>72 (87.7%)</td>
</tr>
<tr>
<td>Independent</td>
<td>6 (7.3%)</td>
</tr>
<tr>
<td>Other</td>
<td>4 (4.9%)</td>
</tr>
<tr>
<td><strong>CP info giving [Median (IQR)]</strong></td>
<td>6.0 (4.0- 7.0)</td>
</tr>
<tr>
<td><strong>CP goal setting [Median (IQR)]</strong></td>
<td>6.0 (4.0 – 6.0)</td>
</tr>
<tr>
<td><strong>CP assessment Median ( IQR)</strong></td>
<td>5.0 (4.0 – 6.0)</td>
</tr>
<tr>
<td><strong>CP refer on [Mean (SD)]</strong></td>
<td>4.0 (2.04)</td>
</tr>
<tr>
<td>Variable</td>
<td>Number / %</td>
</tr>
<tr>
<td>---------------------------</td>
<td>----------------</td>
</tr>
<tr>
<td>CP d/c planning [Mean (SD)]</td>
<td>3.78 (2.22)</td>
</tr>
<tr>
<td>CP therapy planning [Median (IQR)]</td>
<td>5.0 (4.0 – 6.0)</td>
</tr>
<tr>
<td>CP liaison [Mean (SD)]</td>
<td>5.09 (2.02)</td>
</tr>
<tr>
<td>CP Stakeholders [Mean (SD)]</td>
<td>3.61 (1.74)</td>
</tr>
<tr>
<td>CP Client priorities [Mean (SD)]</td>
<td>4.24 (1.718)</td>
</tr>
<tr>
<td>CP Tool Mean (SD)</td>
<td>3.8 (1.356)</td>
</tr>
<tr>
<td>CP Key stages [Mean (SD)]</td>
<td>3.54 (1.398)</td>
</tr>
<tr>
<td>CP Visual rep Mean (SD)</td>
<td>3.59 (1.506)</td>
</tr>
<tr>
<td>CP Consistency Mean (SD)</td>
<td>4.46 (1.565)</td>
</tr>
</tbody>
</table>