Health care services for multiple sclerosis: The experiences of people with multiple sclerosis and health care professionals

A thesis submitted to The University of Manchester for the degree of Doctor of Philosophy (PhD) in the Faculty of Medical and Human Sciences

2015
Abigail Methley

School of Medicine, Institute of Population Health, Faculty of Medical and Human Sciences
## Contents

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Contents</td>
<td>2</td>
</tr>
<tr>
<td>List of appendices</td>
<td>6</td>
</tr>
<tr>
<td>List of tables</td>
<td>7</td>
</tr>
<tr>
<td>List of figures</td>
<td>8</td>
</tr>
<tr>
<td>List of boxes</td>
<td>9</td>
</tr>
<tr>
<td>List of abbreviations</td>
<td>10</td>
</tr>
<tr>
<td>Abstract</td>
<td>11</td>
</tr>
<tr>
<td>Declaration</td>
<td>12</td>
</tr>
<tr>
<td>Copyright statement</td>
<td>13</td>
</tr>
<tr>
<td>Acknowledgements</td>
<td>14</td>
</tr>
<tr>
<td>Chapter 1: Introduction</td>
<td>15</td>
</tr>
<tr>
<td>1.1 The scope of the thesis</td>
<td>15</td>
</tr>
<tr>
<td>1.2 The importance of this topic</td>
<td>15</td>
</tr>
<tr>
<td>1.3 Current knowledge on this topic</td>
<td>15</td>
</tr>
<tr>
<td>1.4 Gaps in current knowledge on this topic</td>
<td>15</td>
</tr>
<tr>
<td>1.5 Research questions</td>
<td>16</td>
</tr>
<tr>
<td>1.6 The structure of the thesis</td>
<td>16</td>
</tr>
<tr>
<td>1.7 The author</td>
<td>17</td>
</tr>
<tr>
<td>Chapter 2: Context</td>
<td>19</td>
</tr>
<tr>
<td>2.1 Introduction to the chapter</td>
<td>19</td>
</tr>
<tr>
<td>2.2 Multiple Sclerosis</td>
<td>19</td>
</tr>
<tr>
<td>2.2.1 Aetiology, prevalence and presentation</td>
<td>19</td>
</tr>
<tr>
<td>2.2.2 Diagnostic labelling of MS</td>
<td>20</td>
</tr>
<tr>
<td>2.2.3 Diagnosis and management</td>
<td>23</td>
</tr>
<tr>
<td>2.3 Symptom management</td>
<td>24</td>
</tr>
<tr>
<td>2.3.1 Mental health services for people with Multiple Sclerosis</td>
<td>24</td>
</tr>
<tr>
<td>2.3.1.1 Stepped care model</td>
<td>25</td>
</tr>
<tr>
<td>2.3.1.2 Improving Access to Psychological Therapies services for people with MH problems</td>
<td>27</td>
</tr>
<tr>
<td>2.4 Service delivery and health care policy relevant to the care of people with MS</td>
<td>27</td>
</tr>
<tr>
<td>2.4.1 NHS General Medical Services Contract</td>
<td>27</td>
</tr>
<tr>
<td>2.4.2 Service Commissioning</td>
<td>28</td>
</tr>
<tr>
<td>2.4.3 Patient and Public involvement in the NHS</td>
<td>29</td>
</tr>
<tr>
<td>2.4.4 The move to self-management</td>
<td>29</td>
</tr>
<tr>
<td>2.4.5 Policy for MS and long-term conditions</td>
<td>31</td>
</tr>
<tr>
<td>2.4.5.1 MS Clinical Guideline CG8- (National Institute of Health and Clinical Excellence, 2003)</td>
<td>32</td>
</tr>
<tr>
<td>2.4.5.2 National Service Framework for long term conditions (Department of Health, 2005a)</td>
<td>33</td>
</tr>
<tr>
<td>2.4.5.3 National audit of services</td>
<td>34</td>
</tr>
<tr>
<td>2.5 Experiences of health care services and living with illness: MS and the wider literature</td>
<td>35</td>
</tr>
<tr>
<td>2.5.1 Theories of illness experience and help-seeking</td>
<td>35</td>
</tr>
<tr>
<td>2.5.1.1 Symptom experience</td>
<td>36</td>
</tr>
<tr>
<td>2.5.1.2 Identification of illness as ‘difference’</td>
<td>36</td>
</tr>
<tr>
<td>2.5.1.3 Medical care contact</td>
<td>37</td>
</tr>
<tr>
<td>2.5.1.4 ‘Dependent’ patient role, recovery and rehabilitation</td>
<td>38</td>
</tr>
</tbody>
</table>
2.5.1.5 Summary of how these apply to candidacy and wider thesis .......................... 39
2.5.2 Health care experiences of people with MS ..................................................... 39
2.5.3 MS health care experiences of health care professionals ............................... 46
2.5.3.1 General Practitioners’ role and experiences of MS care ............................... 46
2.5.3.2 Practice Nurses’ role and experiences of MS care .................................. 50
2.5.3.3 MS Specialist Nurses’ role and experiences of MS care ............................. 50
2.5.3.4 The role of wider allied health professionals ........................................ 52
2.6 Addressing both patient and professional experiences ..................................... 53
2.7 Chapter summary ................................................................................................. 54

Chapter 3. A systematic review exploring the health care experiences of people with MS ................................................................................................................. 56
3.1 Introduction to the chapter .................................................................................. 56
3.2 Introduction to the review ................................................................................... 56
3.3 Objectives ............................................................................................................ 56
3.4 Systematic review methods ................................................................................ 57
3.4.1 Inclusion and exclusion criteria ................................................................. 58
3.4.2 Search strategy ............................................................................................... 59
3.4.3 Data management and quality appraisal ....................................................... 60
3.5 Findings ............................................................................................................... 64
3.5.1 Quality appraisals ......................................................................................... 65
3.5.2 Data analysis .................................................................................................. 65
3.5.2.1 Diagnosis .................................................................................................. 65
3.5.2.2 Palliative care ......................................................................................... 68
3.5.3 Further analysis .............................................................................................. 69
3.6 Discussion ............................................................................................................ 70
3.6.1 Summary of review findings ......................................................................... 70
3.6.2 Implications for practice and research ......................................................... 70
3.6.3 Implications for commissioning .................................................................... 71
3.6.4 Strengths and limitations of the study .......................................................... 72

Chapter 4: Methodology and methods ........................................................................ 74
4.1 Background to this study/Introduction ............................................................... 74
4.2 Justification for qualitative methodology ......................................................... 74
4.3 Epistemological considerations .......................................................................... 76
4.4 Research design .................................................................................................. 79
4.4.1 Semi-structured interviews as a method ...................................................... 79
4.4.2 Ethical considerations and research governance ......................................... 81
4.5 Data collection technique/process ..................................................................... 81
4.5.1 Sampling of participants .............................................................................. 81
4.5.2 Modes of interviewing .................................................................................. 82
4.5.3 Confidentiality and anonymity ..................................................................... 83
4.6 Eligibility and recruitment strategies .................................................................. 84
4.6.1 Recruitment strategies for people with MS .................................................... 84
4.6.2 Recruitment strategies for General Practitioners and Practice Nurses ........ 85
4.6.3 Recruitment strategies for MS Specialist Nurses ........................................... 87
4.7 The interview process ......................................................................................... 87
4.7.1 The interview process for people with MS .................................................... 87
4.7.2 The interview process with professionals ..................................................... 88
4.8 Topic guide for people with MS ........................................................................ 89
4.9 Analysis .............................................................................................................. 92
4.9.1 Constant comparison approach ................................................. 92
4.9.2 Coding process ........................................................................ 96
4.9.2.1 Coding ............................................................................. 96
4.9.2.2 Categorising .................................................................... 96
4.10 Theoretical framework- the concepts of candidacy and recursivity .......... 102
4.10.1 Candidacy............................................................................. 102
4.10.2 Recursivity ........................................................................ 106
4.11 Quality and rigour in qualitative methods ........................................... 107
4.12 Service user involvement/PPI ....................................................... 111
4.13 Chapter summary ...................................................................... 112

Chapter 5: Results-The health care experiences of people with Multiple Sclerosis ....113
5.1 Introduction .............................................................................. 113
5.1.1 Sample characteristics ............................................................... 113
5.1.1.1 People with MS ................................................................. 113
5.1.1.2 Demographic commentary .................................................. 114
5.1.1.3 Recruitment commentary .................................................... 116
5.2 Experience of MS ..................................................................... 121
5.2.1 Impact of symptoms ................................................................ 121
5.2.2 Uncertain progression ............................................................... 122
5.2.3 Identity and labels .................................................................. 123
5.3 Self-management of symptoms ...................................................... 125
5.3.1 Expert patients .................................................................... 125
5.3.2 Management strategies ............................................................. 127
5.4 Access ...................................................................................... 129
5.4.1 Navigation .......................................................................... 129
5.4.2 Timeliness and availability ....................................................... 130
5.4.3 Staying “in the loop/system” .................................................... 135
5.5 Interactions with health care professionals ....................................... 136
5.5.1 Loss of personhood: Attitude of professionals ............................. 136
5.5.2 Professional judgements ............................................................ 139
5.5.3 Responsiveness .................................................................... 140
5.6 Continuity of care ..................................................................... 143
5.6.1 Relational continuity with health care professionals ................... 143
5.6.2 Variation of follow up ............................................................... 146
5.6.3 Coordination and communication ............................................ 147
5.7 Chapter summary ...................................................................... 151

Chapter 6: Results- The perspectives of health care professionals on providing care for people with MS ................................................................. 152
6.1 Introduction .............................................................................. 152
6.1.1 Sample characteristics ............................................................... 155
6.1.1.1 Sample characteristics of Practice Nurses ............................ 155
6.1.1.2 Sample characteristics of General Practitioners .................. 156
6.1.1.3 Sample characteristics of Specialist Nurses ....................... 158
6.2 Primary care role and role in MS care ............................................ 161
6.2.1 Co-ordination of care ............................................................... 167
6.3 Patient-centred care .................................................................. 171
6.3.1 Holism ................................................................................. 171
6.3.2 Time .................................................................................... 178
6.3.3 Continuity of care and the professional-patient relationship .......... 180
Chapter 7: Discussion .................................................................................. 205

7.1 Introduction ......................................................................................... 205

7.2 Summary of main findings ................................................................... 206

7.2.1 Summary of findings from people with MS .................................... 206

7.2.2 Summary of findings from health care professionals ....................... 207

7.2.3 Similarities and differences between people with MS and professionals’
     experiences of care for MS ................................................................. 208

7.3 Comparison with the literature ............................................................ 211

7.3.1 Identification of candidacy ............................................................. 211

7.3.1.1 Identification of candidacy for physical symptoms .................... 211

7.3.1.2 Identification of candidacy for psychological symptoms .............. 214

7.3.2 Navigation ....................................................................................... 217

7.3.2.1 Information as a tool for navigation: the rise of the expert patient .. 217

7.3.2.2 The choice between continuity of care, access and specialist knowledge
     ........................................................................................................... 219

7.3.3 Permeability (access) and operating conditions ............................... 222

7.3.4 Appearances at health care ............................................................. 227

7.3.5 Adjudication .................................................................................... 227

7.3.5.1 Referral thresholds ..................................................................... 229

7.3.5.2 Medically unexplained symptoms and legitimacy ....................... 232

7.3.5.3 Adjudication of psychological needs .......................................... 235

7.3.6 Offers and resistance ....................................................................... 237

7.4 Beyond candidacy ................................................................................ 238

7.4.1. Self-management and multimorbidity .......................................... 238

7.4.2 Patient centredness ........................................................................ 239

7.5 Strengths and limitations of my study ............................................... 240

7.5.1 Critique of recruitment ................................................................... 240

7.5.2 Critique of methods ....................................................................... 243

7.6 Reflections on the study ..................................................................... 245

7.7 The role of the researcher and reflexivity .......................................... 246

7.8 Wider implications for research, education, policy and practice .......... 232

7.8.1 Psychological needs of people with MS ....................................... 232

7.8.2 Education of both people with MS and professionals .................... 233

7.8.3 Implications for policy: commissioning new models of care ......... 250

7.8.4 Implications for practice: MS Specialist Nurses .......................... 252

7.8.5 Implications for practice: GPs ......................................................... 253

7.8.6 Implications for practice: Practice Nurses .................................... 254

7.9 Chapter summary .............................................................................. 255

References ............................................................................................. 256
List of appendices
A. Health Expectations research article ............................................................. 295
B. BMC Health Services research article ......................................................... 307
C. Way Ahead MS Trust review article ............................................................ 338
D. Systematic review search strategy ............................................................... 341
E. Qualitative assessment tool- CASP ............................................................... 343
F. NHS Research Ethics approval .................................................................... 346
G. University Ethics Committee approval ......................................................... 350
H. NHS Research and Development approval .................................................. 351
I. Study documents .......................................................................................... 352
   l-i GP Practice letter of invitation ................................................................. 352
   l-ii Participant Information Sheet for GPs ....................................................... 353
   l-iii Invitation letter to participants from their GP surgery .............................. 356
   l-iv Participant Information Sheet for participants with MS ........................... 357
   l-v Topic guide for GPs v1 ............................................................................ 360
   l-vi Demographic questionnaire for GPs ...................................................... 361
   l-vii Letter of invitation to Practice Nurse .................................................. 363
   l-viii Participant Information Sheet for Practice Nurses ............................... 364
   l-ix Letter of invitation to Multiple Sclerosis Specialist Nurses ........................ 366
   l-x Topic guide for Practice Nurse v2 .......................................................... 367
   l-xi Topic guide for MS Specialist Nurse v2 ............................................... 368
   l-xii Demographic questionnaire for Practice Nurses ................................. 369
   l-xiii Demographic questionnaire for MS Specialist Nurses .......................... 370
   l-xiv Invitation letter to the MS Society ......................................................... 371
   l-xv Publicity poster/flyer .............................................................................. 372
   l-xvi Recruitment advertisement for University intranet .............................. 373
   l-xvii Topic guide for people with MS v1 ...................................................... 374
   l-xviii Topic guide for people with MS v4 .................................................... 375
   l-xix Demographic questionnaire for people with MS .................................. 377
   l-xx Consent form for GPs ............................................................................ 380
   l-xxi Consent form for Practice Nurses ....................................................... 381
   l-xxii Consent form for MS Specialist Nurses .............................................. 382
   l-xxiii Consent form for participants with MS .............................................. 383
J. Coding framework for interviews with people with MS .............................. 384
K. Conferences at which I have presented/been accepted to present ............... 402
L. Dissemination plan and future outputs ....................................................... 403
List of tables

Table 1. Diagnostic labelling of MS ................................................................. 21
Table 2. Recommendations from the MS NICE guideline CG8 (National Institute of Health and Clinical Excellence, 2003) ................................................................. 32
Table 3. National Service Framework for long term conditions, quality requirements ..... 33
Table 4. Reported themes from the free text boxes of the 2011 National Audit .................. 35
Table 5. Key themes from the literature investigating health care experiences of people with MS .................................................................................................................. 45
Table 6. Key gaps in the literature and how my PhD addressed them ............................... 55
Table 7. Stages of completing a systematic narrative review ....................................... 57
Table 8. Characteristics of included systematic review studies (n = 5) ............................. 62
Table 9. Epistemological stances and their relevance to this research ............................. 77
Table 10. Interview types and their relevance to this research ..................................... 80
Table 11. The overall process of constant comparison analysis followed the systematic process outlined in Boeije (2002) ........................................................................................................... 94
Table 12. An example constant comparison table of ‘access’ categories for people with MS .......................................................................................................................... 98
Table 13. An example constant comparison table of inter-professional categories of ‘patient-centred care’ ................................................................................................. 100
Table 14. Quality criteria for qualitative research ..................................................... 108
Table 15. Demographic characteristics of people with MS ......................................... 114
Table 16. Clinical characteristics of people with MS ................................................. 116
Table 17. Differences in findings between health care professional groups .................. 153
Table 18. Demographic characteristics of Practice Nurses ......................................... 155
Table 19. Demographic characteristics of General Practitioners ................................. 156
Table 20. Demographic characteristics of Specialist Nurses ....................................... 158
Table 21. Key points presented in the discussion chapter ............................................ 205
List of figures

**Figure 1.** The stepped care model ................................................................. 26
**Figure 2.** PRISMA diagram detailing the process of searching and identifying relevant papers ................................................................................................. 60
**Figure 3.** Presentation of themes from diagnosis and palliative care studies ............ 69
**Figure 4.** The concept of candidacy (Dixon-Woods *et al.*, 2006) .............................. 104
**Figure 5.** A thematic map showing the themes and categories of people with MS’ experiences of health care .............................................................................. 117
**Figure 6.** The pathway of participant 13: Secondary progressive MS ......................... 119
**Figure 7.** The pathway of participant 1: Relapsing-remitting MS ............................. 120
**Figure 8.** A thematic map showing the themes and categories of professionals’ experiences of MS care ......................................................................................... 160
**Figure 9.** The extended concept of candidacy .......................................................... 210
List of boxes

Box 1. Symptoms of MS................................................................................................................19
Box 2. Recruitment strategies.....................................................................................................85
Box 3. Examples of memos.........................................................................................................91
Box 4. Example of data...............................................................................................................106
**List of abbreviations**

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>CCG</td>
<td>Clinical Commissioning Group</td>
</tr>
<tr>
<td>DMT</td>
<td>Disease Modifying Treatment</td>
</tr>
<tr>
<td>GP</td>
<td>General Practitioner</td>
</tr>
<tr>
<td>IAPT</td>
<td>Improving Access to Psychological Therapies</td>
</tr>
<tr>
<td>MS</td>
<td>Multiple Sclerosis</td>
</tr>
<tr>
<td>NHS</td>
<td>National Health Service</td>
</tr>
<tr>
<td>NICE</td>
<td>National Institute for Health and Clinical Excellence</td>
</tr>
<tr>
<td>NSF</td>
<td>National Service Framework</td>
</tr>
<tr>
<td>PCT</td>
<td>Primary Care Trust</td>
</tr>
<tr>
<td>PN</td>
<td>Practice Nurse</td>
</tr>
<tr>
<td>SN</td>
<td>Specialist Nurse</td>
</tr>
</tbody>
</table>
Abstract
The University of Manchester
Abstract for thesis by Abigail Methley
For the degree of PhD titled: Health care services for multiple sclerosis: The experiences of people with multiple sclerosis and health care professionals.
Submitted date: 15\textsuperscript{th} June 2015
Background: Multiple Sclerosis (MS) is a chronic degenerative condition. It presents with highly varied physical and psychological symptoms and an unpredictable prognosis, causing difficulties for both professionals and patients. A high prevalence of comorbid psychological symptoms are reported in MS research, yet these may be underreported and underdiagnosed clinically in people with MS. Previous research has taken a dualistic approach, focussing on physical and psychological symptoms separately, resulting in a lack of knowledge on how MS is managed holistically. The aim of this research was to explore the experiences of both people with MS and professionals in the management of physical and psychological symptoms throughout the care pathway for people with MS.
Methods: A qualitative approach was used. A systematic review was conducted to investigate existing qualitative literature exploring United Kingdom (UK) health care experiences of people with MS. A qualitative study using semi-structured interviews to explore the experiences of receiving or providing care for people with MS (n =24), general practitioners (n = 13), practice nurses (n = 13) and MS specialist nurses (n = 9). People with MS were purposively sampled from primary care and community settings in North West England. Primary care professionals were purposively sampled from across the North West. Specialist Nurses were purposively sampled from four NHS Foundation Trusts across the North of England. Transcripts formed the data and these were analysed using constant comparison analysis. Once themes had been derived from the data, this data was then interrogated using the concepts of candidacy and recursivity as a theoretical framework (Dixon Woods \textit{et al.}, 2006; Rogers, Hassell & Nicolaas, 1999).
Results: Five studies meeting the review criteria were identified from the systematic review. The findings showed that previous UK research had focussed on the beginning (diagnosis) and the end (palliative care) of the care pathway for MS, resulting in a paucity of information regarding experiences of care between these points, for both people with MS and professionals. The subsequent qualitative study addressed this and identified central themes for people with MS: experiences of MS, managing self-care, access to services, interactions with health care professionals and continuity of care. For professionals the central themes identified were: the role of primary care for MS, patient-centred care for MS, access for MS care and management of people with MS.
Conclusion: This study provides a unique contribution to the literature on the health care experiences of both people with MS and health care professionals responsible for their care. It has addressed the gaps in knowledge regarding the ongoing health care experiences of people with MS and the holistic management of psychological and physical symptoms. This study showed that candidacy is an appropriate theoretical framework to explain help-seeking and access to health care for MS: use of health services is based on both patient and professionals’ interpretation of symptoms, perceptions of services and previous experiences. To improve identification of candidacy there is a need for greater education for patients and professionals on symptoms of MS and information on availability of local services.
**Declaration:** No portion of the work referred to in the thesis has been submitted in support of an application for another degree or qualification of this or any other university or other institute of learning.
Copyright statement

i. The author of this thesis (including any appendices and/or schedules to this thesis) owns certain copyright or related rights in it (the “Copyright”) and s/he has given The University of Manchester certain rights to use such Copyright, including for administrative purposes.

ii. Copies of this thesis, either in full or in extracts and whether in hard or electronic copy, may be made only in accordance with the Copyright, Designs and Patents Act 1988 (as amended) and regulations issued under it or, where appropriate, in accordance with licensing agreements which the University has from time to time. This page must form part of any such copies made.

iii. The ownership of certain Copyright, patents, designs, trade marks and other intellectual property (the “Intellectual Property”) and any reproductions of copyright works in the thesis, for example graphs and tables (“Reproductions”), which may be described in this thesis, may not be owned by the author and may be owned by third parties. Such Intellectual Property and Reproductions cannot and must not be made available for use without the prior written permission of the owner(s) of the relevant Intellectual Property and/or Reproductions.

iv. Further information on the conditions under which disclosure, publication and commercialisation of this thesis, the Copyright and any Intellectual Property and/or Reproductions described in it may take place is available in the University IP Policy (see http://documents.manchester.ac.uk/DoculInfo.aspx?DocID=487), in any relevant Thesis restriction declarations deposited in the University Library, The University Library’s regulations (see http://www.manchester.ac.uk/library/aboutus/regulations) and in The University’s policy on Presentation of Theses.
Acknowledgements

My thanks go to all my participants for giving their time and for sharing their deeply personal stories and experiences; this research would not have been possible without them.

I have been incredibly lucky over the last three years to experience the support, dedication and enthusiasm of an inspiring supervisory team, Professor Campbell, Professor Chew-Graham and Dr Cheraghi-Sohi, who all went far above and beyond their remit. I would also like to gratefully acknowledge the support and guidance provided by my advisor and centre lead Professor Peter Bower, in helping me see the greater context of my work and take full advantage of many great opportunities.

The support and funding provided by the National Institute for Health Research School for Primary Care Research made this PhD possible. In particular, I am grateful to Dr Georgina Fletcher and Kate Farrington for supporting me in my career development through their first class training opportunities and ongoing publicity.

This research was substantially improved by the ongoing involvement and support provided by Carole Bennett, who has given her time and expertise so graciously in her role as service user consultant on this project. I am also grateful to the PRIMER team and Claire Planner for their time in providing feedback on the design of my study.

The recruitment for this study would not have been possible without the enthusiasm and support of key individuals. I would like to thank Janice Howard for sharing her knowledge, expertise and time on this project. I would like to express my thanks to the three branches of the MS Society who assisted me with my recruitment and I thank the MS Society, the MS Trust and MS-UK for their support publicising my study. I am very grateful to Karen Vernon and Dr Jessica Drinkwater for their support with recruitment.

For the completion and publication of my systematic review I would like to thank Rosalind McNally for volunteering her time and expertise. For my knowledge of qualitative methodology I am very grateful to Dr Gavin Daker-White for sharing his expertise and skills, and I express my thanks to my colleagues at the Centre for Primary Care more widely for their support, especially Dr Neesha Patel and Dr Nic Small.

My knowledge of the clinical practice of MS is due to my role as an assistant psychologist within the specialist NMO team at the Walton Centre NHS FT in Liverpool; therefore I wish to thank Kerry Mutch, Dr Perry Moore and Dr Anu Jacob for their support and expertise.

My thanks go to my fellow PhD students and friends. My final and greatest thanks go to my extended family for their support over the last three years.
Chapter 1: Introduction

1.1 The scope of the thesis

In this thesis I present a qualitative investigation of the experiences of health care services for Multiple Sclerosis (MS) in the UK, from the perspectives of both people with MS and health care professionals (General Practitioners [GPs], Practice Nurses [PNs] and MS Specialist Nurses [SNs]). In this introductory chapter I outline the scope and structure of this thesis.

1.2 The importance of this topic

The global prevalence of MS is estimated to be 2.5 million people, with a UK prevalence of 285.8 per 100,000 for women and 113.1 per 100,000 in men (Mackenzie et al., 2013). It is an incurable condition of unknown aetiology, resulting in a variety of symptoms which may cause severe and long lasting disability (Compston et al., 2006). Symptom exacerbations or relapses are unpredictable and the disease trajectory is uncertain, this can cause difficulties in care planning for both people with MS and professionals (Golla et al., 2014).

1.3 Current knowledge on this topic

People with MS are frequent users of a variety of health care services (Marrie, Yu et al., 2012a) and may experience difficulties accessing services (Edmonds et al., 2007a). Some health care professionals may find MS a challenging condition to manage, due to the unpredictable nature and complexity of the condition, and the need for specialist knowledge (Golla et al., 2014). UK research on the health care experiences of people with MS has primarily focussed on experiences of diagnostic procedures and palliative care (Edmonds et al., 2007a; Methley et al., 2014). The reported prevalence of psychological symptoms such as depression is high in MS (up to 50% of community samples; Feinstein, 2011). However, most research on MS has focussed solely on physical symptoms, and consequently the experiences of health care use for psychological problems are poorly researched (Minden et al., 2007; Minden et al., 2013).

1.4 Gaps in current knowledge on this topic

People with MS’ experiences of UK health care services other than specialist MS services are currently understudied, especially through ‘in-depth’ methods, such as qualitative interviews (MacLurg et al., 2005; Somerset et al., 2001).
Few research studies have investigated professionals’ experiences of providing health care services for MS, including the experiences of primary care professionals (Golla et al., 2012; While et al., 2009) or professionals providing care for psychological problems (While et al., 2009).

I developed the research questions for this thesis based on observations in clinical practice. I later refined these research questions based on findings from a systematic review of the literature (Methley et al., 2014), to address these gaps in the literature. The below research questions are designed to provide a unique contribution to knowledge in MS research by addressing novel issues, and providing a previously unseen level of depth on understudied topics (such as people with MS and professionals’ experiences of UK health care services for MS) through the use of in-depth qualitative methods.

1.5 Research questions

1. What are the physical and psychological health care experiences of people with MS?

2. What are the experiences of primary care professionals (GPs and PNs) providing services to people with MS?

3. What are the experiences of SNs in providing services for people with MS, including services for the psychological symptoms of MS?

I investigated these research questions by using the qualitative research method of semi-structured interviews with all participants. These were undertaken using phenomenological and interactionism epistemologies. Data were analysed initially using constant comparison analysis (Lincoln & Guba, 1985). The theoretical framework of candidacy was chosen to underpin the analysis after preliminary interviews with people with MS.

1.6 The structure of the thesis

In chapter 2, I provide context for this research, by outlining key information regarding MS (e.g. aetiology, manifestation), its management and an overview of the health care policies and guidelines pertinent to MS. I then conclude with a brief review of literature on patient experiences, and the role and experiences of GPs, PNs and SNs in relation to care for people with MS.

In chapter 3, I present the methods and findings of a systematic narrative review investigating people with MS’ experiences of UK health care for MS.
In chapter 4, I describe the methods used in this research, with a critique of the theory and method. I discuss definitions of quality to explain how the methods utilised met suggested standards of high quality qualitative research, and I present and justify the sampling method and recruitment strategies.

In chapter 5, I present the findings of a qualitative study investigating experiences of health care for people with MS.

In chapter 6, I present the findings of a qualitative study exploring the perceptions and experiences of GPs, PNs and SNs, who provide health care services to people with MS.

In chapter 7, I present a discussion of findings in relation to the existing literature and the chosen theoretical framework of candidacy. I then critique the strengths and limitations of this study and present the implications for clinical practice and research.

1.7 The author

My professional background is in applied psychology, working specifically with people experiencing lifelong conditions and disability (including intellectual/developmental disabilities, dementia, acquired brain injury and neurological conditions). The conditions I have focussed on in my BSc, MRes, PhD and clinical research (autism, learning/intellectual disabilities, MS and Neuromyelitis Optica) all share commonalities. These include an often unclear diagnosis and referral pathway, a lack of public (and often health care professional) knowledge and awareness, and in many cases invisible symptoms with no known cure and an uncertain prognosis.

In 2009, whilst completing my BSc in Psychology, I volunteered at an MS Society Respite Centre, to gain insight into peoples’ experience of living with a neurological condition and experience of the provision of health care services for a chronic condition. The centre was widely acknowledged for the broad range of physical therapies and activities it provided and attracted clients from a wide geographical radius. Whilst talking to residents I heard about many experiences of health care and the variety in the quality of care received across the UK. I was interested in the inequity described, both nationally and locally, and the apparent disparity between care for physical and psychological symptoms. To investigate this topic further I shadowed a consultant neurologist and MS specialist nurse and saw the restrictions and possibilities available to health care professionals providing care to people with MS. From these experiences I designed a research proposal to investigate patient and professionals' experiences of MS care; this proposal was later funded by the National Institute for
Health Research School for Primary Care Research and accepted for study at the University of Manchester.

Throughout my PhD I have been employed for two days a month as an Assistant Psychologist in a national Neuromyelitis Optica (NMO) National Health Service specialist team, based at the Walton Centre for Neurology and Neurosurgery in Liverpool. In this role I participated in a qualitative study investigating lived experience and quality of life in families with NMO, and I conducted qualitative interviews with children and adults with NMO and family members including spouses, parents and children. Completing these interviews improved my interviewing skills and confidence. It also enabled me to develop an increased holistic understanding of the lived experience and management of acute and chronic disability. Most importantly I viewed this from both the perspective of people with Long Term Conditions (LTC), and my own perspective as an NHS member of staff in a rapidly changing health care system (during the change of Primary Care Trusts [PCTs] to Clinical Commissioning Groups [CCGs]).

This experience, and the networking it provided, has proved invaluable in ensuring that my PhD research was developed to be relevant to both clinical practice and commissioning, whilst the themes from the research were still participant led. Therefore, my experience and knowledge of this population acted as the basis of both my PhD research and this thesis.
Chapter 2: Context

2.1 Introduction to the chapter
In this chapter I provide an introduction to the condition Multiple Sclerosis (MS) and outline the policy pertaining to MS, and the health services available for people living with MS in the UK. I then briefly review the available literature on people with MS and health care professionals’ experiences of health care services for MS, provide the context and justification for the research topic and finally present the aims of the research.

2.2 Multiple Sclerosis
MS is a neurological condition in which the nerves in the brain and spinal cord are attacked by the body’s own immune system (Compston & Coles, 2008). The definitive marker of MS is the presence of plaques or lesions of sclerosis (hardened scar tissue) around the brain and spinal cord. Damage caused by lesions can occur anywhere in the central nervous system. Consequently, people with MS can present with a wide variety of symptoms, of which incidence and presentation varies by individual (as displayed in Box 1; Compston et al., 2006).

Box 1. Symptoms of MS.
- Vision problems
- Paralysis
- Pain
- Fatigue
- Spasms and stiffness
- Problems with balance, mobility and coordination
- Incontinence (bladder and bowel)
- Cognitive dysfunction
- Sexual dysfunction
- Headaches
- Tingling/numbness
- Speech/swallowing problems
- Depression

2.2.1 Aetiology, prevalence and presentation
MS primarily affects young adults, mainly occurring in people aged between 20 and 40 years (Compston & Coles, 2008), which is a younger age of onset than many other chronic conditions. It is currently the most prevalent cause of neurological disability in young adults in Europe and North America (Alonso et al., 2007), with a UK prevalence of 285.8 per 100,000 in women and 113.1 per 100,000 in men (Mackenzie et al., 2013).
The National Institute for Health and Care Excellence (NICE) guideline on MS (NICE, 2003, CG8) estimated a prevalence of 52,000 to 62,000 people with MS in England and Wales; however this estimated figure has since been increased to 127,000 (Mackenzie et al., 2013). In comparison, 341,332 people in the UK live with epilepsy (a common neurological condition) (Health and Social Care Information Centre; HSCIC, 2012) and 2,566,436 people live with diabetes mellitus (Health and Social Care Information Centre, 2012), highlighting the rarity of MS.

Large geographical differences are found in the worldwide distribution of MS, although research suggests that prevalence rates of MS are increasing worldwide (Koch-Henriksen & Sorenson, 2011). It has been suggested that this is due to an increased incidence of MS, with only a minimal increase as a result of improved diagnostic testing (Sellner et al., 2011).

Currently the aetiology of MS is unknown. It has been suggested that vulnerability to MS may differ by ethnicity, with Caucasian and African American individuals in the United States more likely to develop MS than Hispanic or Asian individuals (Langer-Gould et al., 2013). Gene-environment interaction is suggested as the most common pathway to development (Handunnetthi et al., 2010) and the Epstein-Barr virus is clinically linked to MS (Levin et al., 2010), potentially interacting with vitamin D to increase risk of MS (Disanto et al., 2011). Epidemiological studies have demonstrated a positive association between latitudinal gradient and MS prevalence, most likely explained by ultraviolet radiation, which is essential for the production of vitamin D (Simpson et al., 2011). Lifestyle factors such as smoking and obesity have been also suggested as potential risk factors (Sellner et al., 2011). However, despite numerous theories, the lack of conclusive aetiology results in uncertainty for both people with MS and professionals.

2.2.2 Diagnostic labelling of MS

MS is categorised into several subtypes with different prognoses. These are presented in Table 1.
<table>
<thead>
<tr>
<th>Table 1. Diagnostic labelling of MS.</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Relapsing-remitting MS</strong></td>
</tr>
</tbody>
</table>
| • This is the most prevalent form of MS, diagnosed in 85% of cases*. People with this subtype experience symptom exacerbations (relapses) which later remit, but may potentially leave residual damage if left untreated. A relapse is defined as a period of neurological impairment with new symptoms or a worsening of previously established symptoms, for at least 24 hours (Confavreux, Vukusic & Adeleine, 2003).
| • Symptoms usually progress very quickly over a matter of hours or days and on average remain for a period of weeks. The impact of relapses is variable, and whilst most can be treated in the home by a Multi-Disciplinary Team (MDT), more severe relapses may require hospitalisation (NICE, 2003, CG8).
| • Currently the cause of relapses is not known; however there is an established link of increased risk in the first three months post-partum, especially in women with high disease activity before and during pregnancy (Portaccio et al., 2014). Urinary tract infections and upper respiratory tract infections may induce or exacerbate relapses (Correale, Fiol & Gilmore; 2006; Edwards et al., 1998). Although anecdotally stress is often reported by people with MS as a cause of relapses, research evidence is currently inconclusive (Artemiadis, Anagnostouli & Alexopoulos, 2011; Riise et al., 2011).
| • Recovery from relapse is possible over time; however for some people with MS, each subsequent relapse may cause increasing levels of disability (Bennetto et al., 2011). |
| **Progressive MS** (divided into two forms: primary and secondary progressive MS). |
| • Primary progressive MS is rarer (10-15% of all MS cases*) and is diagnosed when symptoms progress over time without noticeable relapses. It affects equal numbers of men and women and is usually diagnosed at a later age of 40-50 years (Miller & Leary, 2007). |
- Secondary progressive MS is commonly developed after a period of relapsing-remitting MS (65% of people with relapsing-remitting MS develop secondary progressive MS within 15 years post diagnosis*; Compston et al., 2008). For a diagnosis of this subtype, disability is needed to be clearly evident for at least 6 months. As these changes may progress slowly, it may be an extended period of time before a diagnosis of secondary progression can be confirmed.

**Progressive relapsing MS**
- A less commonly used diagnosis is that of progressive relapsing MS which features both relapses and ongoing progression of symptoms, affecting 10-15% of people with MS* (Leary, Porter & Thompson, 2005).

**Benign MS**
- Benign MS can only be diagnosed retrospectively after 10-15 years with minimal MS progression or relapses. It can be difficult to define as potentially symptoms may have been present in this period but not interpreted as MS. Also, it cannot predict that the individual will continue to stay relapse free, as relapses may occur after many years of symptom inactivity (Sayao, Devonshire & Tremlett, 2007).

*Percentages do not add to 100% due to the necessary use of multiple references*
2.2.3 Diagnosis and management

Given the variety in both the type and severity of symptoms and various subtypes of MS, MS is a complex and difficult condition to manage. The aetiology of MS is unknown and therefore it can be difficult to predict progression and outcome in an individual patient, although increasing and progressive disability is common (Compston & Coles, 2008). Lack of prognostic certainty may cause difficulties in managing the disease for both health professionals and people with MS. Lack of knowledge about future levels of disability may prevent the implementation of long term treatment and rehabilitation plans (Golla et al., 2014).

Due to the complexity of presentation, the diagnosis of MS is a multifaceted process. Commonly people with MS will present to a GP with initial sensory symptoms including loss of mobility or optic neuritis (Palace, 2001). The GP will then conduct a full history and neurological examination. If the GP and person with MS recognise the symptoms as suggestive of MS, the GP will then make the initial referral to specialist care, where diagnostic services will be coordinated by a consultant neurologist. A number of tests are required before a diagnosis of MS is reached (Polman et al., 2011). These include Cerebrospinal Fluid (CSF) examination and a CT or MRI scan of the brain which may be organised by the GP or consultant neurologist. A diagnosis of MS will be given by the GP or consultant neurologist if results are suggestive of MS. As some of these tests will have a time delay, and others may be inconclusive, there can sometimes be a lengthy wait between onset of symptoms and confirmation of diagnosis; however diagnostic criteria introduced in 2005 (and later updated in 2010) have been credited with increasing the timeliness and accuracy of diagnosis (Polman et al., 2011). These complex ‘2010 McDonald criteria’ (developed from McDonald et al., 2001) state that relapsing-remitting MS should be diagnosed after a minimum of two patient reported relapses where there is clinical evidence of lesions which are disseminated in time and space (Polman et al., 2011). They further state that primary progressive MS should be diagnosed after one year of neurological decline, in addition to lesions and evidence of oligoclonal bands in cerebrospinal fluid (a marker of MS) (Polman et al., 2011).

Once a diagnosis of MS is made a variety of treatments may be advised by a specialist neurologist, for both the treatment of symptom exacerbations (relapses) and the daily management of chronic symptoms such as pain and continence issues (NICE, 2003, CG8). Disease Modifying Treatments (DMTs) have been found to lessen the number of
relapses experienced, potentially preventing disability from occurring. However, these treatments are of variable effectiveness with strict eligibility criteria and, and there is still no identified cure for MS (Comi, 2013). In addition, there is currently no successful treatment to delay the progression of primary or secondary progressive MS.

2.3 Symptom management
As treatments for MS may not be effective or available, symptom management is key to the long term management of people with MS (Ziemssen, 2011). Primary care acts as the gateway to health care services, and accounts for 90% of all patient contact in the National Health Service (NHS) (HSCIC, 2014). It is likely that GPs in primary care will provide the first contact for people with initial neurological symptoms and will coordinate services and referrals (Royal College of General Practitioners [RCGP] 2010). People with MS are also eligible for specialist neurology services and are commonly registered with a neurologist and SN (NICE, 2003, CG8). Daily symptom management may involve frequent contact with both primary and specialist health care services and for some people it may also involve active self-management (NICE, 2003, CG8). Strategies reported by people with MS for managing symptoms were investigated in my research and results are presented in chapters five and six.

2.3.1 Mental health services for people with Multiple Sclerosis
Psychological conditions are common in all LTCs (Naylor et al., 2012). Research has suggested that psychological conditions such as depression are common in people with MS; for example, a prevalence rate of 50% (in a sample taken from both community and tertiary care clinics) was found for symptoms of depression indicative of Major Depressive Disorder (Feinstein, 2011). Clinically significant levels of anxiety are also found frequently in samples of people with MS, with a prevalence of approximately 19.3%-25% (Beiske et al., 2008; Feinstein et al., 1999), and these figures may be higher still for subclinical symptoms.

In the UK there are various health care services to manage people with psychological conditions. The Improving Access to Psychological Therapies (IAPT) service will be outlined in the next section explaining health care policy and service delivery for people with MS.

In 2009 a National Institute for Health and Clinical Excellence (NICE) guideline was published for depression in adults with a chronic physical health problem (NICE, 2009, CG91). This guideline advocates patient-centred care and outlines the stepped care
model (NICE, 2004; explained below). Principles of care relevant to MS include: being aware of cognitive impairments, working with people whose management is shared between primary and secondary care, and working with people whose physical health problems may prevent them from engaging in face to face psychosocial or psychological treatment (NICE, 2009, CG91).

The guideline encourages the involvement of both the patient and their carer or family in shared decision making about treatment and care, and close collaboration between mental and physical health services, in keeping with later policy advocating equity between mental and physical health care support (Department of Health [DH], 2011a). These suggestions mirror recommendations for physical health services, such as the National Service Framework for LTCs (NSF)(DH, 2005a).

2.3.1.1 Stepped care model

The stepped care model of mental health care provides a framework to ensure the most effective use of services, by tailoring interventions to the severity of symptoms (NICE, 2004, CG23). It comprises four steps, starting with the most effective intervention for mild symptoms and through referral to the next step ascends in intensity as the severity of symptoms increases. A presentation of the stepped care model is presented in Figure 1.
**Figure 1.** The stepped care model (taken from CG23, National Institute for Health and Clinical Excellence, 2004).

<table>
<thead>
<tr>
<th>Step</th>
<th>Who is responsible for care</th>
<th>What is the focus</th>
<th>What do they do</th>
</tr>
</thead>
<tbody>
<tr>
<td>Step 5</td>
<td>Inpatient care, crisis teams</td>
<td>Risk to life, severe self-neglect</td>
<td>Medication, combined treatments, ECT</td>
</tr>
<tr>
<td>Step 4</td>
<td>Mental health specialists, including crisis teams</td>
<td>Treatment-resistant, recurrent, atypical and psychotic depression, and those at significant risk</td>
<td>Medication, complex psychological interventions, combined treatments</td>
</tr>
<tr>
<td>Step 3</td>
<td>Primary care team, primary care mental health worker</td>
<td>Moderate or severe depression</td>
<td>Medication, psychological interventions, social support</td>
</tr>
<tr>
<td>Step 2</td>
<td>Primary care team, primary care mental health worker</td>
<td>Mild depression</td>
<td>Watchful waiting, guided self-help, computerised CBT, exercise, brief psychological interventions</td>
</tr>
<tr>
<td>Step 1</td>
<td>GP, practice nurse</td>
<td>Recognition</td>
<td>Assessment</td>
</tr>
</tbody>
</table>
2.3.1.2 Improving Access to Psychological Therapies services for people with psychological needs

Improving Access to Psychological Therapies (IAPT) (DH, 2007a) was introduced in 2006 in acknowledgement of the economic impact of mental health related work absenteeism. The original aim of IAPT was to provide low and high intensity psychological therapies for people of working age (DH, 2007a) as outlined in the service model of stepped care for adults with depression (NICE, 2004, CG23).

IAPT services are commissioned by CCGs to provide services to people with psychological conditions (particularly depression) (DH, 2008). Since then the scheme has been extended and they are now responsible for mental health services for people of a working age experiencing depression and anxiety associated with long-term conditions (DH, 2011b), including neurological conditions. As MS is a long-term neurological condition, people with MS should be eligible for IAPT services. However no research has previously been conducted to investigate the experiences of people with MS of IAPT services, similarly to the lack of research investigating experiences of IAPT for people with other long-term conditions. This research explored health care professionals’ perspectives of referring people with MS to IAPT services and asked people with MS if they had experienced IAPT services. Findings are presented in chapters 5 and 6.

2.4 Service delivery and health care policy relevant to the care of people with MS

Aspects of national health care policy and service delivery relevant to people with MS will now be discussed, as the variety and availability of services may facilitate or prohibit the frequency with which people with MS’ contact both primary and secondary care.

2.4.1 NHS General Medical Services Contract

The NHS General Medical Services Contract (DH, 2005b) provides a contract between General Practices and Primary Care Organisations (PCO) to provide primary care services to the community. This contract focuses on three main areas; the financial cost of running a GP Surgery, the Quality and Outcomes Framework (QOF), and Directed Enhanced Services (DES) which are services that practices can chose to provide in addition to their regular services.

The QOF offers financial incentives for the diagnosis and treatment of certain conditions (Campbell & Lester, 2010). These tend to be high prevalence conditions such
as diabetes, and targets are based on recommendations made by NICE (Campbell, McDonald & Lester, 2011).

MS is not included as a QOF condition as it is a low prevalence condition, which does not have the evidence-base and processes of care for treatment in primary care that make it amenable to targets, and as such would not be included under the prioritisation criteria used (Campbell & Lester, 2010). This may mean that if practices choose to prioritise care only for the conditions for which they are financially incentivised (Campbell, McDonald & Lester, 2008), then the overall quality of care for people with non-incentivised conditions such as MS may decrease, although the evidence base for the effect on non-incentivised conditions is not conclusive (Dixon et al., 2011; Doran et al., 2010).

### 2.4.2 Service Commissioning

Commissioning of services at a local level now plays a much larger role in primary care, due to changes outlined in The Health and Social Care Act 2012 (House of Commons, 2012). The Act outlines the role of commissioning services in the NHS, whereby CCGs and local and national strategic partners are responsible for commissioning local services, overseen by NHS England on a national level. This is relevant for UK services for people with MS, as research suggests people with MS in the UK may struggle to access the MS specific services they need (Edmonds et al., 2007a). To improve this aspect of care, GPs and PCOs could choose to commission specialised services for people with MS. This would improve the specificity, responsiveness and therefore potentially the quality of care provided to people with MS, by addressing their needs locally and more directly. It has been suggested that the GP contract 2003 (now GP contract 2014) was a good opportunity to improve services for people with neurological conditions more broadly, through redesigning services and increasing multi-disciplinary working (Smithson, Hukins & Jones, 2006).

However, changes for people with MS rely on local commissioners making MS services a priority for funding, and the MS Society and The Neurological Alliance charities have raised concerns that CCGs may not have the necessary knowledge to identify where neurological services are below standard (The Neurological Alliance, 2012). The impact of clinical commissioning on people with MS will depend on the priorities and knowledge of neurological services in both local Clinical Commissioning Groups and those who report to NHS England.
2.4.3 Patient and Public involvement in the NHS

A parallel policy priority is patient and public involvement in local services. Patient involvement in health care services has been increasingly advocated since the publication of the NHS and Community Care Act (House of Commons, 1990), which required local authorities to involve both patients and their carers. Patient and public involvement in health care services at a strategic level was previously achieved through the initiation of Local Involvement Networks (LINks) (DH, 2006), designed to improve local health and social care services. It is hoped that the role of patient input in commissioning and improving health care services will be expanded through the development of HealthWatch England and HealthWatch local (which replaced LINks in April 2013 under the Health and Social Care Act 2012), as a voice for patients and the public at both a local and national level. HealthWatch England advises NHS England and local authorities and acts as a statutory committee for the Care Quality Commission. This reflects the NHS’s increasing focus on patient and public involvement in the design and commissioning of services and shows that at a policy level the experiences of patients and views of the public are important to shaping the NHS. This suggests an increased role for research investigating patient experiences to ensure that relevant issues are represented at both local and national levels.

2.4.4 The move to self-management

There has been an increasing move to view patients as autonomous individuals, responsible for personal preferences and decisions regarding initiating and maintaining their own health networks, incorporating both professionals and informal support (Cheong, Armour & Bosnic-Anticevich, 2013).

The increased appreciation of patient experience and preferences has coincided with an increased NHS focus on personalised care planning (DH, 2012), where it is the norm for individuals to make decisions about their care, including a written record of decided actions. In the document “Liberating the NHS: No decision about me without me” (DH, 2012) plans were outlined for increasing patient choice and providing a more sensitive, flexible health care system where service users have greater control and involvement in their health care. Given the variation in symptoms both between and within people with MS, it may be that this flexibility and control could be beneficial in tailoring services to individual service users’ needs and preferences; however investigations of
service users’ experiences are necessary to confirm this. They were therefore investigated in this PhD and are presented in chapter 5.

The current approach to increasing patient autonomy is to offer greater choice in management of health (as outlined in the white paper “Equity and Excellence: Liberating the NHS” (DH, 2010a), and also to improve self-management and self-care. In 2009 (DH, 2009a) the Department of Health published “Your health, your way- A guide to long term conditions and self-care”. This guide was designed to improve the way health care professionals and people with LTCs discuss self-care and self-management options, and highlights the increased focus on self-management for LTCs. The terms self-care and self-management are often utilised concurrently in literature on LTCs, but are conceptually distinct (Jones et al., 2011).

Self-care is defined as “care taken by individuals towards their own health and wellbeing: it comprises the actions they take to lead a healthy lifestyle, to meet their social, emotional and psychological needs; to care for their long-term condition and to prevent further illness and accidents” (Barlow et al., 2002). Opinions differ as to whether self-care incorporates support from health care professionals or is independent of professional support (Jones et al., 2011). Self-management however, is defined more specifically as a collaborative approach between a patient and professionals, to not simply maximise health but also to enhance diagnosis and treatment of a given medical condition (Eales & Stewart, 2001).

Research into proactive patient management of MS has primarily described collaborative management of MS symptoms and treatment, in keeping with the concept of self-management rather than self-care, including formal interventions for fatigue, stress and medication management (Plow, Finlayson & Rezac, 2011). The move to self-management was related to the concept of the expert patient (DH, 2001). Expert patients were defined by the Chief Medical Officer in 2001 as “people who have the confidence, skills, information and knowledge to play a central role in the management of life with chronic diseases (DH, 2001, p.9)”. In the report “The Expert Patient: A New Approach to Chronic Disease Management for the 21st Century” (DH, 2001) peer support for self-management in MS was used as a case example, suggesting that the concept of expert patients is applicable to MS. Expert patient programmes have been described as central to primary care (Kennedy, Rogers & Bower, 2007; Rogers et al., 2008) and people with MS are eligible for expert patient programmes for
chronic diseases available on the NHS (NHS, 2014). Certainly the goals of the expert patient programme match reported needs of people with MS, including improving knowledge and empowerment regarding their LTC and improving appropriate access to services (Rogers et al., 2008). However, it is less clear how expert patient programmes could achieve their aim of preventing physical deterioration in MS when this is currently reliant on medical management through disease-modifying treatments, not self-management. There is a dearth of research evidence investigating the impact of expert patient programmes on the wellbeing of people with MS.

In addition, there are both advantages and disadvantages in viewing MS as a long term or chronic condition, similar to conditions such as diabetes, asthma and coronary heart disease (NHS, 2014). The assumption that all LTCs share a common set of challenges is in some ways applicable; people with MS must make physical and psychological adjustments to disability and become familiar with their condition and use of appropriate services (Dennison et al., 2011), similarly to all people with LTCs. MS does, however, differ from other LTCs in its younger age of onset, variable disease progression and unknown aetiology (Compston & Coles, 2008). The low prevalence of the condition and severity of disability caused by relapses (Compston & Coles, 2008), may require differences in the use of specialist care than for other conditions. It is therefore unclear as to whether the increasing focus on self-management for LTCs in the NHS can be fully applied to MS and whether the benefits will be the same. My thesis has addressed this topic by investigating how people with MS manage their symptoms, and exploring self-management where it emerged in interviews (shown in chapters 5 and 6). However, the focus of this thesis was on experiences of health care services, not on self-management specifically.

2.4.5 Policy for MS and long term conditions
The NICE guideline for Multiple Sclerosis (NICE, 2003, CG8) and NSF (DH, 2005a) had both been in place for over 6 years when this research project began. I present these policies, followed by a brief overview of the findings of audits conducted by the Royal College of General Practitioners and the Multiple Sclerosis Trust to investigate their impact.
2.4.5.1 MS Clinical Guideline CG8 (National Institute of Health and Clinical Excellence, 2003)

In 2003 the National Institute for Health and Clinical Excellence (NICE) guideline for the management of Multiple Sclerosis in primary and secondary care was published.

<table>
<thead>
<tr>
<th>Table 2. Recommendations from the MS NICE guideline CG8 (National Institute of Health and Clinical Excellence, 2003).</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Specialised services</td>
</tr>
<tr>
<td>2. Rapid diagnosis</td>
</tr>
<tr>
<td>3. Seamless services</td>
</tr>
<tr>
<td>4. A responsive service</td>
</tr>
<tr>
<td>5. Sensitive but thorough problem assessment</td>
</tr>
<tr>
<td>6. Self-referral after discharge</td>
</tr>
</tbody>
</table>

This guideline had six areas for priority action (Table 2) designed to improve the quality of care provided for people with MS.

Although a revised guideline of this review (created by the National Clinical Guideline Centre) is due for publication in October 2014, the 2003 guideline was the relevant guide to best practice at the time this research was undertaken. However, this guideline has been widely acknowledged to be out of date, as it was implemented before the NSF (DH, 2005a) and the Health and Social Care Act 2012 (House of Commons, 2012).

The proposed 2014 NICE guideline for MS (NICE, 2014) has been heavily criticised by people with MS and MS organisations. A major criticism has been that it does not state that people with MS should be regularly reviewed by MS Specialists. The MS Society highlight the fears of some people with MS by stating that “this could be left to GPs who are not specialists in this condition, are already overstretched and are not likely to be aware of new medicines and treatments due to the ‘general’ nature of their role” (Brown, 2014, no pagination). A further criticism has been that this draft guideline rejects two licensed MS treatments, Sativex and Fampyra, which aim to manage spasticity, pain and mobility impairments which can be currently difficult to manage. In response this has led to the initiation of the “Treat me right” campaign by the MS Society, aiming to ensure fair and equal access to MS treatments nationally. Finally the measure has been criticised for a lack of transparency and stakeholder involvement, by only accepting feedback from organisations not individuals, and refusing to arrange a
meeting between the MS Society and the national guideline group (Brown, 2014). This has led the MS Society to state that they feel they have been “silenced”.

Outside of the MS Society the drafts have been criticised by professionals for being too prescriptive, without utilising appropriate evidence (Giovannoni, 2014). Also it has been suggested that the guidelines do not fully describe the multi-disciplinary nature of services for MS and underappreciate the role of therapists (Association of Chartered Physiotherapists in Neurology, 2014).

**2.4.5.2 National Service Framework for long term conditions (DH, 2005a)**

The quality of UK care for people with neurological conditions has previously been questioned (Clinical Standards Advisory Group, 2000). In 2005 the Department of Health published the NSF for LTCs, aimed to improve the way services are planned and delivered for people with LTCs, including neurological conditions such as Multiple Sclerosis (DH, 2005a). This framework identified 11 quality requirements designed to provide high quality services from initial diagnosis through to palliative care (Table 3) due to be fully completed by 2015 (DH, 2005a). The recommendations from the above NICE guideline and NSF cover all areas of health care for MS and require a multi-disciplinary professional focus.

A mid-term review of the NSF conducted by Thomas, Davies and Peel (2010) found that from a representative sample of 11 PCTs (differing by performance, rurality, population size and integration with health and social care) none had fully met a single NSF quality requirement. In particular, they identified deficits in access to treatment, rehabilitation and emergency services, paucity of information provision, poor coordination of services and insufficient numbers of staff with specialist training in neurology, suggesting the need for health care improvement. A review of the NSF conducted by Sixsmith et al. in 2014 identified the same issues in services suggesting that the implementation of the NSF had not improved the health care experiences of people living with neurological conditions in the North West of England, where my research was conducted.

**Table 3. National Service Framework for long term conditions, quality requirements.**

1. A person-centred service
2. Early recognition, prompt diagnosis and treatment
3. Emergency and acute management
4. Early and specialist rehabilitation
5. Community rehabilitation and support
6. Vocational rehabilitation
7. Providing equipment and accommodation
8. Providing personal care and support
9. Palliative care
10. Supporting family and carers
11. Caring for people with neurological conditions in hospital or other health and social care settings
A summary of information from audits and research studies, designed to investigate the progress made on the NICE guideline and National Service Framework priorities will now be presented.

2.4.5.3 National audit of services

The national audit of services for people with Multiple Sclerosis has been completed three times (Royal College of Physicians & The MS Trust, 2006; 2008; 2011). They were designed to measure health care authorities’ adherence to the six priorities identified in the 2003 NICE guideline (NICE, 2003, CG8) and in the 2011 audit to investigate adherence to the 11 requirements of the NSF.

In 2011, 704 people with MS were recruited from a wide variety of sources including the MS Trust, MS therapy centres, care homes, online discussion groups and regional newspapers. Participants were also recruited through SNs, neurologists and therapists. The average age of respondents was 48 years and 72% were female. Table 4 below displays the key qualitative findings from the 2011 Audit. They show that people with MS can have different experiences of the same aspects of health care services and highlight the large number of aspects of care that are viewed as negative experiences in UK NHS services.

The report states that there have been no improvements in any audit areas since audits were started in 2006. Similarly, the themes identified in Table 4 above include many areas that were identified as priorities for change in the 2003 NICE guideline (NICE, 2003, CG8) and the 2005 NSF, suggesting that these are still major areas for change, as identified by people with MS in the UK.

The reliance on secondary care services and convenience samples without recruiting through primary care however, may mean that participants were missed if they lived independently, were not involved with the MS Trust and were not in contact with secondary care services. Also, given the younger age of onset in MS (as compared to many other chronic conditions) it is possible that this survey does not representatively portray the views of younger people with MS.
Table 4. Reported themes from the free text boxes of the 2011 National Audit.

<table>
<thead>
<tr>
<th>Themes of negative experiences of health care services</th>
<th>Themes of positive experiences of health care services</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Quality of care</td>
<td>1. Quality of care</td>
</tr>
<tr>
<td>2. Responsiveness</td>
<td>2. Responsiveness</td>
</tr>
<tr>
<td>3. Information provided</td>
<td>3. Information provided</td>
</tr>
<tr>
<td>4. Support including respite</td>
<td>4. Support including respite</td>
</tr>
<tr>
<td>5. Administrative errors</td>
<td>5. Specialist MS Nurses and Therapists</td>
</tr>
<tr>
<td>6. Availability of resources</td>
<td></td>
</tr>
<tr>
<td>7. Communication and integration between staff and organisations</td>
<td></td>
</tr>
<tr>
<td>8. Level of knowledge of GPs about MS</td>
<td></td>
</tr>
<tr>
<td>9. Attitude of doctors and nurses</td>
<td></td>
</tr>
<tr>
<td>10. Fear of future about availability of services</td>
<td></td>
</tr>
<tr>
<td>11. Clinical issues such as diagnosis and treatment</td>
<td></td>
</tr>
</tbody>
</table>

While informative, this report only offered participants the opportunity to discuss their experiences through short open-ended questions or quantitative questions. By using a more detailed qualitative approach in a study focussing specifically on health care experiences these experiences could be explored in greater depth, to not simply highlight relevant areas of change for service provision but also investigate why these are important to people with MS. This would provide a better understanding of health care services for MS that may suggest opportunities to increase the quality and relevance of health care services provided and identify the areas of greatest importance. My research addresses this need and the findings are presented in chapter 5.

2.5 Experiences of health care services and living with illness: MS and the wider literature

2.5.1 Theories of illness experience and help-seeking

Previous research has recognised the variation in experiences of illness and help-seeking behaviour, between individuals with objectively similar symptoms and signs. Indeed, it has been suggested that the highest quality of care is achieved when the concept of ‘quality of care’ is applied at a personal level (based on the accessibility and effectiveness for an individual), rather than at a societal level (Campbell, Roland & Buetow, 2000). This has led to sociological, psychological and health services research
investigating these differences and debating the optimum access and use of health services (with different stakeholders holding different, and sometimes conflicting, views). It is established that experiencing illness and using health care services involves a much greater variety of factors than simply health care availability; theories postulated to explain this will now be discussed, in the order outlined by Suchman’s five key stages of illness experience (Suchman, 1965): symptom experience, identification of illness as difference, medical care contact, dependent-patient role, and recovery and rehabilitation.

2.5.1.1 Symptom experience

It is established that individuals may self-monitor their symptoms for a long time before choosing to seek formal intervention (e.g. Smith et al., 2008). There are several theories explaining why this may be the case, including David Mechanic’s (1968) theory of help-seeking behaviour. Mechanic explained variation in help-seeking due to how individuals’ define illness and appraise their ability to cope (both of which are determined and constructed within wider community and social norms). He identified 10 factors determining illness response: visibility, recognisability or salience of symptoms, perceived seriousness of symptoms, extent to which symptoms disrupt family, work or social activities, frequency and persistence of symptoms, tolerance threshold of symptoms, available information, knowledge and cultural understanding of symptoms, perceptual needs i.e. anxiety or fear, competing needs e.g. where health is a lesser priority, competing interpretations of symptoms, availability and physical proximity to treatment resources and the psychological and monetary costs of acting on symptoms. Given the potential variation in all of these factors based on idiosyncratic and cultural norms, it is clear how experiences of illness and help-seeking can be so varied. This directly corresponds to the section of identification of candidacy described on pages 103 and 107 of the thesis, as how an individual appraises their symptoms, influences their identification of candidacy and further help-seeking.

2.5.1.2 Identification of illness as ‘difference’

Assuming the social role of the sick role (Parsons, 1951), involves identifying when an individual’s symptoms reach a threshold which differs from those experienced by the majority of society, causing the individual to be in the deviant sick minority. Labelling theory suggests that this definition of illness is not an objective phenomenon but a subjective construction between a doctor and patient within a specific cultural context.
(Friedson, 1970a). As labelling is commonly attributed by the majority to the minority, there is potentially the opportunity for stigma (either felt or enacted; Goffman, 1963), and perceived stigma from health care professionals is related to decreased use of health care services (Earnshaw & Quinn, 2012).

2.5.1.3 Medical care contact

Psychological theories of motivation suggest that health care use is related to factors which increase or decrease the drive to seek care. The Health Behaviour Model developed in the 1950s to explain poor uptake of tuberculosis screening (and later expanded to address poor HIV screening; Rosenstock, Strecher & Becker, 1994), states that for behaviour change (i.e. preventative health care use) to occur, an individual must perceive a threat from their current behaviour, believe in a benefit (at an acceptable cost) from changing this behaviour and perceive themselves as competent to implement change. Severity of the threat caused by behaviour is central to this theory, and for people with MS the severity of potential risks from not acting on symptoms may be a motivator for health care use. In comparison, changing their behaviour (e.g. to use disease modifying treatments) may not be seen as an acceptable cost, due to extensive side effects. This model incorporates subjective viewpoints about susceptibility, and the factual, or lay beliefs people use to judge their individual level of risk from a behaviour.

Later models began to incorporate both patient and service or system related characteristics, relevant to health care use.

DiMatteo and Friedman described individual characteristics relevant to health care use as: the background of the patient (including age, gender, ethnicity, social class etc.), the patient’s perception of the illness (incorporating Zola’s, 1973 work and Mechanic’s theory of help seeking [1968]) and the individual’s situational factors (e.g. whether the onset of symptoms is outside of routine medical support or on a non-working day, whether the individual is pressurised to seek medical care by others).

The Anderson General Model of Total Patient Delay (developed by Anderson et al., 1995, building on Safer et al., 1979) explains potential reasons for patient delay in seeking a medical diagnosis as: appraisal delay (inferring illness), illness delay (deciding to seek medical attention), behavioural delay (acting on decision by making an appointment), scheduling delay (first receiving medical attention) and treatment delay (beginning treatment). This model begins to incorporate health care service related
factors (such as operational factors delaying the onset of medical attention and treatment) but disproportionately so, in comparison to the emphasis on patient related factors.

System or services factors influential to health care use include resources and institutional norms, procedures, regulations and structures (Shengelia, Murray, & Adams, 2003). However, models which discuss system factors typically present the role of the professional as constrained within service related variables, whilst research shows that professionals show subjectivity in their interpersonal communication styles and treatment decisions (e.g. idiosyncratic referral thresholds; Cummins, Jarman & White, 1981), suggesting that these factors are essential to address too. This is very relevant to candidacy as how individuals appraise their symptoms affects how they interpret their identification for candidacy and may explain their help seeking.

2.5.1.4 ‘Dependent’ patient role, recovery and rehabilitation

The concept of dependent patients may not be applicable to expert patients with chronic or long term conditions. The Chronic Care Model (Wagner; 1998, 2001) aims to improve the outcomes of patient care for chronic illness by implementing a new style of health care. This model uses the interactions between community resources (including self-management) and the organisation and delivery of health care systems to increase patients’ knowledge and involvement in their health care and to allow health care teams to become proactive, not reactive, in their provision of care. The six core components comprise: community resources, self-management support (discussed on page 29), delivery system design, decision support, clinical information and health care system, focussing on use of services from a service-driven viewpoint (such as the WISE study, Rogers et al., 2011). Care for people with MS may need to vary between traditional secondary hospital-focussed care for acute relapses, and a more chronic care model style of care for ongoing residual health care needs.

All experiences of health care must also function within the wider sociological and psychological processes of adaptation to illness, including the physical and biographical ‘comebacks’ discussed by Corbin and Strauss (1991), where in addition to physical recovery, individuals must integrate their perceptions of their past, present and future. As discussed by Bury (1997) this means that health care services for chronic care must move away from the concept of deviant and nondeviant identities, to instead focus on individual’s efforts and strategies to cope with their condition and their preferred
management style (Bury, 1991), in line with the negotiation model of adaptation (Gerhardt, 1989). How individuals chose to view their long term condition, and their preferences for management may influence their identification of candidacy and further help-seeking and use of services.

2.5.1.5 Summary of how these apply to candidacy and wider thesis
Throughout the above models there is a strong focus on the subjectivity of appraisals of health, illness and medical decision-making by patients. However, the subjective appraisals of professionals are less prominent within these models, where instead health care service influences are presented as dependent on objective and systematic factors. Research clearly suggests that utilisation of health care services relies on both patient and system related factors, yet few theoretical frameworks incorporate both aspects proportionately. Candidacy (discussed further in the methods section) can address patient factors, individual professional factors and system characteristics, thus potentially providing a more realistic appraisal of relevant factors for health care use and decision-making by people with MS and their health care professionals. The appropriateness of the candidacy model for MS will be considered within this thesis, whilst the wider psychological and sociological theories will also addressed where relevant to the findings.

2.5.2 Health experiences of people with MS
Many previous studies investigating health care experiences of MS utilised a quantitative design such as highly structured questionnaires or surveys (Buchanan et al., 2008, Freeman & Thompson, 2000; MacLurg et al., 2005; Minden et al., 2007; Minden et al., 2008; While et al., 2009). The themes of importance identified in these studies (e.g. access to services, satisfaction with services, continuity of care) are mirrored in qualitative investigations of this topic. However, the reductionist nature of quantitative research methods has limited the depth to which these important issues can be investigated, (for example, presenting the percentage of people with MS who have accessed a service, but unable to expand on this experience and its significance for that individual). This has prevented exploration of the perceptions’ of people with MS and professionals regarding these issues in their wider context.

As qualitative methods may be more effective at allowing an understanding of experiences (Holloway, 2005) I opted for a qualitative research design in this PhD (outlined in chapter 4). I identified the need to conduct a systematic review to
comprehensively identify the available literature on my chosen topic. I therefore conducted a systematic review of the qualitative literature pertaining to the UK health care experiences of people with MS and this is presented in chapter 3. As this review only investigated qualitative UK studies with a clear focus on health care experiences (thus limiting included papers), a broader overview of the empirical international literature quantitatively and qualitatively investigating health care experiences for people with MS will now be presented. These studies were identified from Medline, CINHAL, psychINFO and EMBASE databases, alongside the MS Society library, using key words corresponding to Multiple Sclerosis patients or service user experiences and perceptions of health care services. I used Zetoc alerts, electronic journal content alerts and ResearchGate to stay aware of current literature on this topic.

Many research studies utilise mixed samples including people with different neurological conditions (Kristjanson, Aoun, & Yates, 2006; Peters et al., 2013; Sixsmith et al., 2014), and/or mixed samples of people with neurological conditions and their carers or health care professionals (Edmonds et al., 2007a; Golla et al., 2014; Preston, Haslam & Lamont, 2012; Sixsmith et al., 2014). This can make it difficult to identify the experiences specifically of people with MS.

Smithson, Hukins and Jones (2006) investigated the role of general practice in the care of people with neurological conditions in the UK in a mixed sample of people with epilepsy, MS and Parkinson's Disease. They found that participants wanted a good working relationship with professionals, timely access to information and tailored support, access to specialist information and care, and better coordination between primary and secondary care. Peters and colleagues (2013) identified that for a sample of people with MS, Motor Neurone Disease and Parkinson's Disease, many of these problems still existed (Peters et al., 2013). The main issues identified were: poor planning and integration of care, information about medication side effects, and delays in diagnosis, suggesting that these issues were still in need of improvement in 2013. Delays in diagnosis and problems in communicating diagnosis (lack of sympathy, follow up and information) were worse for people with MS than those with Motor Neurone Disease or Parkinson’s Disease, highlighting the need to investigate these issues differently by diagnostic group.

It is currently unclear how long it takes to receive a diagnosis of MS in the UK, as although Peters et al. (2013) reported that it took 43% (n = 448) of their sample over 12 months from their initial GP appointment to diagnosis, data were collected between
2008 and 2009: it is not clear as to when participants were diagnosed, and how technology may have advanced since then. A 2011 audit conducted in Dublin reported that it was not possible to meet the NICE guideline recommendation of an MS diagnosis made for everyone within six weeks of being seen by a neurologist, due to poor availability of imaging and lumbar punctures, in addition to administrative issues (Kelly et al., 2011). As this study was conducted within the Irish health care system however, it is still unclear as to how this may translate to UK health care settings.

UK research suggests that a lack of MS specific advice from health care professionals is a problem for people with MS (Defriez et al., 2003; Hepworth & Harrison, 2004; Somerset et al., 2001; While et al., 2009). However, due to the time elapsed since these studies were published (>5 years) they cannot account for the increased availability of MS related information freely available on the internet, or the increased number of SN posts, of which information giving is a key duty (De Broe, Christopher & Waugh, 2001). More recent research in South Australia (Matti et al., 2010a) suggests that SNs address this gap, resulting in people with MS receiving relevant MS information. It remains to be seen whether the situation has improved in the UK and data regarding this will be presented in chapters 5 and 6.

Access to health care for neurological conditions differs nationally (Janca et al., 2006). Studies investigating access for MS care in the United States found that even when the majority of their nationally representative sample had health care insurance, many had insurance that would not cover the costs of prescription medication, provided limited access to specialists and restricted their choice of treatment centre or provider (Minden et al., 2007). Some American studies have suggested that people with MS who receive care from a neurologist have an increased likelihood of diagnostic and treatment related tests and immunotherapeutic treatments (Schwartz et al., 1998).

Vickrey et al. (1999) investigated people with MS’ primary physician for MS symptoms and found that 94% of 532 participants used a neurologist, leaving only 6% using a family physician or other physician (not specified). Both these American studies compared service users who utilised either a neurologist or primary care professional as their sole point of MS care. It is therefore unclear whether these findings are applicable to the UK, where patients have free access to both primary and specialist (via the GP gatekeeper route unless in an emergency or private provision) services and the concept of either GP or neurologist led care may be a false dichotomy.
Comorbidities (defined as a condition experienced in addition the index condition; Feinstein, 1970) in MS have risen over the last 20 years (potentially due to improved coding in medical records Marrie et al., 2012b) to the point where they now mirror the general population on conditions such as diabetes and hypertension (Marrie et al., 2012b). The most common comorbidities in MS have been reported to be hypercholesterolemia, hypertension and arthritis, which are all manageable in primary care (Marrie et al., 2008a). This suggests a large role for primary care to play in both the routine management of these conditions, and in managing potential interactions, for example, vascular comorbidities in MS have been found to substantially increase the risk of disability progression in MS, suggesting that they should be a key target for intervention (Marrie et al., 2010b). However as most research investigating comorbidity in MS has been led by one team in Canada (Marrie et al. 2008, 2009a, 2009b, 2010, 2012a, 2012b), it is currently unclear what the role of primary care in the UK is in managing comorbidity in MS.

People with MS, like people with physical disabilities more generally (Becker & Stuifbergen, 2004), have been found to experience difficulties in accessing preventative care such as lifestyle management and disease prevention including weight management, access to exercise and screening (Becker & Stuifbergen, 2004; Bombardier, Wadhwni & LaRotonda, 2005). It is well recognised that people with disabilities may have a greater risk than people without disabilities of developing poorer health outcomes and preventable comorbidity (Coyle & Santiago, 2002). The primary barriers to preventative care experienced by people with MS have been suggested to be fatigue, impairment and lack of time (Becker & Stuifbergen, 2004). These barriers to care, especially when combined with increasing awareness of comorbidity in MS also suggest a role for primary care intervention.

There are few papers which specifically focus on a qualitative investigation of experiences of health care services for multiple sclerosis. However, of the many papers that investigate the experience of living with MS in general, most contain experiences of health care and diagnosis as an emergent theme (e.g. Barker-Collo, Cartwright & Read, 2006; Koopman & Schweitzer, 1999). Themes identified through research on this topic correspond to those identified in the 2011 National Audit described above (Royal College of Physicians & The MS Trust, 2011). Negative experiences of encounters with services are commonly described, for
example, Koopman & Schweitzer (1999), found encounters with health care professionals were “challenging and diverse” and responses from health care professionals were often “futile or empty, no answers or clarification of symptoms (p.20)”. They reported that the manner in which their participants were given a diagnosis of MS was “trauma-filled, unexpected, stunned (Koopman & Schweitzer, 1999, p.21)”, highlighting the emotive responses experienced in reaction to health care services interactions.

Qualitative studies have also highlighted issues identified by the three National Audits of MS care. Edmonds et al. (2007a) conducted a qualitative study on health care experiences with people with MS who were mainly bed bound. This study identified different themes to previous research involving people with greater physical mobility: a lack of continuity and coordination, difficulty accessing information on services and end of life care and a sense that their participants were “fighting for everything” (p. 5). This suggests that the health care experiences and needs of people with MS may be dependent on their level of MS progression and disability and it may therefore be necessary to consider disability status in the analysis of results. As the Edmonds et al. (2007a) study used a mixed sample of patients and carers it is not possible to know if the themes are the priorities of just people with MS or joint carer/patient priorities as it has been suggested that findings may differ if people are interviewed separately from their carers (Smithson, Hukins & Jones, 2006) and that carers and people with MS may have similar but different priorities (Mullan, Achesen & Coates, 2011). As the priorities of my PhD were to investigate people with MS and professionals’ experiences, the experiences of carers were not investigated in my research.

Research into clinical and community samples suggests a high prevalence of mental health symptoms in people with MS, which it is suggested are both underdiagnosed and undertreated (Marrie et al., 2009b). These are commonly linked to negative aspects of living with a chronic condition, such as unemployment, and a loss of, or altered nature of social relationships with family and friends (Reynolds & Prior, 2003). Depression is a common focus and finding of quantitative studies investigating wellbeing in people with MS (Feinstein, 2011) but less frequently investigated in qualitative studies of the lived experience of MS. Ploughman et al. (2012) identified the management of psychological conditions such as depression as a central theme in their research into ageing healthily with MS; however, this was simply one of the findings
and not the specific focus of the research. This suggests that a more holistic approach is needed in future research, to investigate both physical and mental symptoms equally and simultaneously. Only one study (Rintell et al., 2012) was identified specifically investigating access to, and provision of, psychological/mental health services for people with MS using qualitative methods. This study, conducted in America, identified novel findings for MS research including people with MS’ desired characteristics of a mental health care provider and their preferred style of therapist-client relationship. It also identified findings similar to those in American studies on general health care for people with MS, such as physical and financial difficulties accessing care (Beatty et al., 2003; Minden et al., 2007). Given the high prevalence and detrimental impact of psychological conditions in MS there is a need for more research to focus on people with MS’ experiences of the treatment of emotional and psychological issues in health care services. As care systems in the United States differ from the UK NHS and as cost has been cited as the major obstacle to accessing psychiatry services (Minden et al., 2007), then data cannot be transferable to a UK health care setting. It is therefore necessary to investigate the experiences of mental health care with participants in the UK to address this gap in knowledge. This was explored in my study and findings are presented in chapter 5.

Key themes relating to people with MS’ experiences of health care are summarised in Table 5. In conclusion, research suggests that a myriad of factors may contribute to positive and negative experiences of care for people with MS. Key themes for dissatisfaction of care appear to be access, continuity, and responsiveness in terms of both communication and relevant specialist knowledge and services. It is possible that results may differ by the disability status of the sample and this must be recorded during data collection and accounted for in analysis. My thesis builds on this by utilising subtype of MS and disability status in the analysis of findings of experiences of health care, presented in chapter 5. The experience of living with depression or other comorbid psychological problems has not been investigated in MS, and is unclear how UK centric systems such as IAPT and stepped-care apply to people with MS as this research has yet to be conducted. My research investigated psychological problems in MS and findings are presented in chapters 5 and 6.
<table>
<thead>
<tr>
<th>Key theme</th>
<th>Sources</th>
</tr>
</thead>
<tbody>
<tr>
<td>Rapid diagnosis and treatment</td>
<td>DH, 2005a; Edwards, Barlow &amp; Turner, 2007; Johnson, 2003; Malcomson,</td>
</tr>
<tr>
<td></td>
<td>Lowe-Strong &amp; Dunwoody, 2008; NICE, 2003, CG8; Peters et al., 2013;</td>
</tr>
<tr>
<td></td>
<td>Royal College of Physicians, 2011; Sixsmith et al., 2014; Thomas,</td>
</tr>
<tr>
<td></td>
<td>Davies and Peel, 2010</td>
</tr>
<tr>
<td>Access to specialist services</td>
<td>Johnson, 2003; NICE, 2003, CG8; Royal College of Physicians, 2011</td>
</tr>
<tr>
<td>Responsiveness of care including person-</td>
<td>Edwards, Barlow &amp; Turner 2007; Laidlaw &amp; Henwood, 2003; Malcomson,</td>
</tr>
<tr>
<td>centred care and interpersonal skills</td>
<td>Lowe-Strong &amp; Dunwoody, 2008; Peters et al., 2013; Smithson, Hukins &amp;</td>
</tr>
<tr>
<td></td>
<td>Jones, 2006; Royal College of Physicians, 2011</td>
</tr>
<tr>
<td>Need for ongoing rehabilitative care</td>
<td>Sixsmith et al., 2014; Thomas, Davies and Peel, 2010; Royal College</td>
</tr>
<tr>
<td></td>
<td>of Physicians, 2011</td>
</tr>
<tr>
<td>Palliative care needs</td>
<td>Edmonds et al., 2007b; Embrey 2009a/b; Golla et al., 2014; Royal</td>
</tr>
<tr>
<td></td>
<td>College of Physicians, 2011</td>
</tr>
<tr>
<td>Information provided</td>
<td>Edmonds et al., 2007a; Johnson, 2003; Smithson, Hukins &amp; Jones,</td>
</tr>
<tr>
<td></td>
<td>2006; Somerset et al., 2001; Royal College of Physicians, 2011;</td>
</tr>
<tr>
<td></td>
<td>Thomas, Davies and Peel, 2010</td>
</tr>
<tr>
<td>Family and carer support including access</td>
<td>NICE, 2003, CG8; Royal College of Physicians, 2011</td>
</tr>
<tr>
<td>to respite care</td>
<td></td>
</tr>
<tr>
<td>Administrative errors</td>
<td>Royal College of Physicians, 2011</td>
</tr>
<tr>
<td>Availability of resources</td>
<td>Royal College of Physicians, 2011; Sixsmith et al., 2014</td>
</tr>
<tr>
<td>Communication, integration and continuity of</td>
<td>Edmonds et al., 2007a; Johnson, 2003; NICE, 2003, CG8; Peters et al.</td>
</tr>
<tr>
<td>care</td>
<td>2013; Royal College of Physicians, 2011; Sixsmith et al., 2014;</td>
</tr>
<tr>
<td></td>
<td>Smithson, Hukins &amp; Jones, 2006; Thomas, Davies and Peel, 2010</td>
</tr>
<tr>
<td>Level of knowledge of primary care staff</td>
<td>Edwards, Barlow &amp; Turner, 2007; Johnson, 2003; Royal College of</td>
</tr>
<tr>
<td>about MS</td>
<td>Physicians, 2011; Sixsmith et al., 2014; Thomas, Davies and Peel, 2010</td>
</tr>
</tbody>
</table>
2.5.3 MS health care experiences of health care professionals
As outlined in the literature on experiences of people with MS, health care may be of significant importance in the life of someone with MS. Although all health care professionals are trained to a minimum standard in their various disciplines they may not be specifically trained and experienced in dealing with relatively rare neurological conditions such as MS. This may be especially pertinent for those working in more generalist settings, such as primary care. It has been reported that health care professionals working with people with MS may feel they need support, mentoring, training and better interdisciplinary networking to provide good quality care (Holland et al., 2011). In particular previous research suggests communicating bad news (such as an MS diagnosis) is a challenging and distressing task for professionals, and one in which they may need additional or specific training (Amiel et al., 2006). It is therefore important to not neglect the experiences that health care professionals may have in providing health care services to people with MS and the potential challenges that they may face. This was addressed in my thesis and is presented in chapter 6. The role and experiences of PNs, GPs and SNs will now be outlined, with the justification and context to explain their selection as participants in this research.

2.5.3.1 General Practitioners’ role and experiences of MS care
General Practitioners (GPs) are the first point of contact for most service users in the NHS (HSCIC, 2014); however, as outlined below, a recent evidence base for their role in MS care is severely lacking, relying on evidence predominantly from the 1990s and 2000s. My research addresses this gap in knowledge in chapter 6.
GPs are frequently involved from the onset of MS symptoms, as people with MS have a higher than average number of consultations at their general practice both before and after diagnosis (Marrie et al., 2012a). GPs are often responsible for the initial referral to specialist neurology services and primary care professionals such as GPs are in a key position to improve the overall wellbeing of people with MS (Swain, 1996). Whilst neurologists may see people with MS at the point of diagnosis and relapse, GPs are responsible for the generalist holistic care and support of people with MS during periods of stability (Swain, 1996). In addition, GPs diagnose and manage co-morbid illnesses as well as, initiating and monitoring medication and offering health promotion advice (e.g. smoking).
A questionnaire study (Somerset et al., 2001) of 318 people with MS recruited through GP practices suggested that 78% of people with MS had visited their GP in the previous year, making GPs the most commonly accessed health care professional. In addition, GPs play a key role in signposting and referring people with MS to available information and other services (Swain, 1996) and prescribing medications to manage MS symptoms (Tremlett, Luscombe & Wiles, 2001). However, the role of the GP for people with MS may differ depending on location and access to other services. Buchanan et al., (2006) found that in the United States, people who lived in rural areas were significantly more likely to have a GP as their primary physician, compared to those who lived in urban areas who were more likely to utilise specialist neurology services. However, in the UK there is a lack of community based neurology services (The Neurological Alliance, 2013) and the majority of neurology services are based in major cities, limiting their access for rural populations (Neurological Commissioning Support, 2012).

It has been suggested that most GPs do not have more than 2 or 3 people with MS under their care at any given time (Burgess, 2001) However, as incidence rates of MS have increased, in addition to GP practice size increases, since 2001 (HSCIC, 2014) it may be that this is now higher. Where the estimated prevalence of MS is 285.8/100,000 for women and 113.1/100,000 for men (Mackenzie et al., 2013), a practice with the North West average list size of 5,000 (2012 data from HSCIC, 2013) could expect to have 17 women and 6 men with MS registered with their practice. This in an increase on Smithson, Hukins & Jones’s 2006 estimate that per practice of 8000 patients a GP may have one new case of MS every two to three years and five to eight established cases at any given time.

There is relatively little research investigating the experiences of GPs with regards to providing care for MS. While et al., (2009), investigated health care professional perceptions of services for MS, and found that a multi-disciplinary group of health care professionals (including community nurses, SNs, speech therapists, physiotherapists, occupational therapists and neurologists) voted GPs as the most appropriate person to manage depression in people with MS, suggesting that health care professionals value the significance of the GP role for MS.

Golla et al. (2012, 2014) conducted a programme of work exploring patient and professional experiences of care for people with MS in Germany. In a group of mixed physicians (including neurologists, physicians and 2 GPs) participants explained how
they were aware of unmet needs in health care services, but it was not possible to improve these due to rigid financial and time constraints. They highlighted the complexity of MS and the need for time in consultations to ensure a positive doctor-patient interaction. Also, they were aware of the need for specialist MS knowledge. They reported experiencing burden when patients expected too much of professionals, expecting a continuing relationship with one professional outside of their area of expertise. From this data it is not possible to identify which of these themes are relevant to GPs specifically, as opposed to the sample overall. Further research is needed to investigate their experiences specifically, as it may be that the organisational structures such as consultation length and funding differ between primary and specialist care. This was addressed in this PhD and is presented in chapter 6.

Evidence from early 2000s suggested that GPs may require greater education on MS. Mackowiak (2003) investigated 177 French GPs’ knowledge on managing relapsing MS and found that only 2.8% of GPs were able to define an MS relapse, despite 55.9% of GPs routinely diagnosing relapses without input from other services. This suggested that there was a need for improving MS education for GPs and improving coordination with specialist services. They also highlighted a lack of expertise regarding pharmacological treatments for MS, which has also been highlighted in UK settings (Defriez et al., 2003; Tremlett, Luscombe & Wiles, 2001). Potentially this may be because these studies were completed before the introduction of the 2003 NICE guideline for MS (NICE, 2003, CG8). However, as this has not been investigated more recently, it is not possible to comment on whether lack of knowledge is still a problem in UK general practice.

Defriez et al. (2003) present findings from a focus group study investigating professionals’ experiences of MS care. They present the findings of six GPs who participated as part of a multidisciplinary focus group, and also present findings from an additional 14 GPs who responded to a questionnaire measure investigating the same topic. From this data collection they identified two main themes: concerns that they could not do anything for people with MS and their carers, and the need for somebody with additional time and knowledge to coordinate care for people with MS. For their specific area of Hillingdon they also identified the need for access to counselling and the provision of a SN. However, as this study presented very limited data collected as part of a wider multidisciplinary team focus group, it is currently...
difficult to identify the experiences of GPs specifically. In addition, there have been several primary care reforms since 2003 and these may have impacted on GPs’ experiences. Altogether these studies suggest educational and support needs for GPs. These needs may therefore be necessary issues for research investigating GPs’ experiences of MS care. However, there are several factors that require critical appraisal in these studies. Firstly, the majority were conducted over a decade ago. The NICE clinical guideline for MS was introduced in 2003 (NICE, 2003, CG8), with the NSF introduced in 2005, which may potentially have impacted upon clinical practice and experiences of providing services. It is also possible that the increase in SNs across the UK may have partially addressed issues regarding access to specialist knowledge and care coordination. However, as no recent studies in the UK have been conducted it is not possible to confirm this.

The increase of SNs has been particularly relevant due to the increase in rare and complex disease-modifying treatments for MS (including interferon beta, glatiramer acetate, fingolimod and nataluzamab), requiring specialist knowledge and increased coordination with specialist services. It is currently unclear as to GPs’ confidence in managing people with MS taking these new treatments, as they see a small number of people with MS, not all of whom may be taking disease-modifying treatments, and therefore they may have a limited exposure to specialist issues and limited need for specialist knowledge. As the prevalence of MS is increasing, MS may become a more frequent part of GPs’ caseloads allowing for greater experience of management. However, given the low frequency with which GPs encounter a person with MS it is necessary to investigate how GPs perceive their ability and confidence in managing psychological needs such as depression in people with MS.

Several qualitative studies investigating MS state that although GPs were invited to participate, they declined due to a lack of involvement with people with MS, lack of financial remuneration or a lack of time (Golla et al., 2012; While et al., 2009). However, given that GPs are rated as important professionals by people with MS (While et al., 2009) it is important to investigate where these discrepancies in opinion arise from and the potential implications they may have on patient care. This was investigated in my research and is presented in chapter 6.
2.5.3.2 Practice Nurses’ role and experiences of MS care

Practice Nurses (PNs) are key members of the primary care health care team in the UK and play a key role in the management of service users with chronic conditions (McDonald, Campbell & Lester, 2009), as they are also integral to delivering the Quality Outcomes Framework (QOF) (Campbell et al., 2008; DH, 2004). In 2009 there were 13582 full time PNs in the UK (HSCIC, 2010). Data from Scotland suggests they make up approximately 17.39% of all primary care consultations for people with MS, with approximately 2770 consultations with people with MS in 2012-2013 (Information Services Division Scotland, 2014). They have opportunities for intervention with people with MS, including providing emotional support and information on MS and relevant local services to both people with MS and their families (Burgess, 2001) and assisting people with MS with managing their symptoms (Litchfield & Thomas, 2010). Past research suggests that people with MS may show potentially negative health behaviours that would traditionally fall within the remit of PNs, including smoking, alcohol abuse, obesity and lowered exercise levels (Marrie et al., 2009a). Somerset et al., (2001) investigated the health care needs of people with MS and identified that exercise and diet were the primary and secondary concerns, which would suggest the potential for practice nurse intervention as they commonly deliver brief preventative interventions (Kemppainen, Tossavainen & Turunen, 2013).

PNs have recognised the need for further training and education when working with chronic illnesses such as musculoskeletal conditions (Fletcher et al., 2011). However, few studies were identified on PNs’ experiences of providing services to people with MS; this may be because the role of PNs is not comparable in international contexts. Studies were found that reported the findings of “nurses” more generically or “generalist nurses”, and one study included PNs as part of multi-disciplinary focus groups (Defriez et al., 2003) but made no reference to them in the results section of their article. Therefore, as no studies have addressed the PNs voice (as opposed to the wider health care team), it is not clear how PNs perceive their role for MS, any training or educational needs required and any wider challenges they may experience in this role. Their role and experiences were investigated in my PhD research and presented in chapter 6.

2.5.3.3 MS Specialist Nurses’ role and experiences of MS care

MS Specialist Nurses (SNs) are registered nurses with specialised knowledge, skills and experience of caring for people with MS and their families. Since the 1970s there have
been an increasing number of SNs posts for a wide variety of conditions, both in the UK and internationally (Storr, 1988). The role of SN comprises: clinical expert, resource consultant, educator, change agent, researcher and advocate (Miller, 1995). In the UK there are a diverse range of specialisms including epilepsy, diabetes and MS. Cost-benefits demonstrated by the employment of SNs include reduced waiting times, avoidance of unnecessary hospital admissions, services delivered at the point of need, increased adherence to medication, improved education of professionals, service users and families (Royal College of Nursing [RCN], 2010). However, there is an increasing risk of the loss of posts, combined with an increasing need due to increasing prevalence rates of many long-term conditions (RCN, 2014).

De Broe, Christopher and Waugh (2001) reported 77 SN posts in the UK in 2001, and in 2012 there were 235 whole time posts reported in the UK (The MS Trust, 2012). It has been suggested that the increase in posts was as a result of the increase in disease modifying treatments and the need for ensuring adherence, providing education, managing side-effects and monitoring outcomes (The MS Trust, 2012) although employment of SN varies geographically, with poorer access in rural areas (De Broe, Christopher & Waugh, 2001). Primarily SNs are funded within secondary care to work in hospital, community, care home and hospice settings. One example has been reported of a SN employed by a PCT, which (through treating people with MS in their homes and increased liaison with GPs) was reported to save the PCT £60,000 in unnecessary admissions and increased patient satisfaction with services (Quinn, 2011).

SNs can be key health care professionals for people with MS (De Broe, Christopher & Waugh, 2001). They often play a central role in the coordination of, and access to, services for people with MS as well as providing support and information (Johnson, Smith & Goldstone, 2001). A recent research study to define the role and value of SNs was commissioned by the MS Trust (2010-2011). This focussed on their role within current NHS guidelines, the caseloads they managed and their economic value. Although this project investigated the experiences of 12 MS Nurses through qualitative interviews, the findings are presented as part of a wider multi-disciplinary data set, with a strong focus on economic value. It is therefore not possible to tease out the experiences of SNs, or any challenges or support needs they experience. In response to this study the MS Trust commissioned the Generating Evidence in Multiple Sclerosis Study (GEMSS) in 2012. This study is currently ongoing and aims to generate further evidence of the value of SNs, by
training nurses to measure their clinical impact and demonstrate the economic value of their work. Outside of this body of work focussing on economic value, there is limited research focussing on the experiences of MS nurses, leaving a large gap in the literature, as alongside GPs, SNs deal holistically with people with MS, taking into account their wider lifestyle and family factors, and assessing their physical and psychological adaptation and coping states and strategies. SNs do not have to have formal training in counselling or mental health. Yet, given their regular contact with people with MS they may be in the best position to detect psychological conditions in people with MS and to refer to psychological services (Askey-Jones, Shaw & Silber, 2012). Problems arise when the waiting lists for psychological services are so lengthy that support is needed in the meantime which SNs may not be trained to provide. In addition, there may be access barriers to services (e.g. IAPT services do not provide home visits) that may be prohibitive for people with MS, resulting in increased responsibility being deferred to SNs.

While et al. (2009) found that SNs were viewed by a multi-disciplinary sample of health care professionals (including neurologists, community nurses, physiotherapists and occupational therapists) as the most appropriate professional group to manage emotional, psychological and mental health needs. This suggests that they may be expected by other professionals to deal with issues that are outside their remit. Askey-Jones, Shaw and Silber (2012) showed that by adding a mental health nurse to the MS nursing team the need for community mental health teams decreased and the perceived ability to manage mental health symptoms after discharge from psychological services increased. This suggests that there may be areas of psychological/mental health care where SNs feel they require support or advanced knowledge. Despite this a research study has not yet been identified investigating SNs’ experiences of providing support for mental health issues with people with MS or their opinions and experiences of referring to services for these problems. This was addressed in my research and findings are presented in chapter 6.

2.5.3.4 The role of wider allied health professionals

The NICE guideline for MS (NICE, 2003, CG8) recommends that a wide variety of professionals should be available to people with MS, including district nurses, physiotherapists, occupational therapists, psychologists, social workers, speech and language therapists.

There is a literature on the role of physiotherapists and occupational therapists due to the rehabilitative needs of people with MS, and they have been rated with a high
degree of satisfaction in studies of people with MS due to positive interpersonal interactions involving positive communication skills and a good sense of rapport (Normann et al., 2012), although difficulties in access to regular physiotherapy have been reported in UK studies (Forbes, While & Mathes, 2007). Given the available knowledge in previous literature, in addition to the time restraints of this PhD, only a certain group of professionals could be studied, therefore the major gaps identified from the literature were addressed; namely the role and experiences of GPs and PNs, in order to provide knowledge on primary care services for MS, and the experiences of SNs, particularly with regards to providing support for psychological problems.

2.6 Addressing both patient and professional experiences

Previous research that has investigated health care from the perspective of both people with MS and health care professionals has identified differences in opinion on the priorities needed for care. Heesen et al. (2003) identified that there were differences in when people with MS and professionals believed was the best time to disclose diagnosis; patients favoured as early a diagnosis as possible, whilst professionals were more cautious, preferring to diagnose later on when symptoms were more pronounced. Kremenchutzy & Walt (2013) quantitatively investigated congruence in opinions of neurologists and people with MS and found significant disagreement on which aspects of health were most important. Their findings suggest that people with MS rated their mental health as more important, and their physical disability as less important, than did their clinicians. Whilst this study was valuable in highlighting the discrepancies in opinion between people with MS and neurologists, their findings were constrained by the quality of life questionnaire measure utilised; whilst they could state what the differences in opinion were there was no potential for participants to explain and expand on the reasons why. A qualitative approach to this topic could offer more in-depth information on discrepancies in opinion and communication between professionals and people with MS, and this may assist in exploring the reasons behind conflicting priorities in health care services. For example, Finlayson, Denend & Shevil (2003) conducted focus groups with people with MS, family members and health care professionals, and using content analysis, identified that differences in priorities between people with MS/family members and professionals was due to differing perceptions of what constituted health care services. Whilst
people with MS believed services included social wellbeing and community accessibility, health care professionals focussed on medical needs. This level of detail and nuance is crucial to investigate why differences in opinion exist and how they may act as barriers or enablers to care.

2.7 Chapter summary

People with MS struggle to access relevant and well-coordinated services in a timely manner. This is imperative in managing both relapses and symptoms, across primary and specialist care services. Whilst there is a large body of literature on unmet patient needs, there is little evidence on people with MS ‘experiences of physical and psychological health care services for MS, particularly through research undertaken using qualitative methodology.

In addition to the gaps in the literature on patient experiences, there is little recent evidence on how GPs and PNs view their role in MS care and their experiences of providing this care, even though they may be heavily involved in providing services to people with MS. Although there is a current evidence base available on the role of SNs, what remains unclear are their experiences of providing services, and any support needs, particularly for managing psychological symptoms in MS.

Therefore, in my PhD research I addressed three research questions:

1. What are the physical and psychological health care experiences of people with MS?
2. What are the experiences of primary care professionals (GPs and PNs) providing services to people with MS?
3. What are the experiences of SNs in providing services for people with MS, including services for the psychological symptoms of MS?

In Table 6 I outline where these questions were derived from and the chapters in which they are addressed.

Findings of these research questions are presented in chapters 5 and 6. I identified the need to conduct a systematic review to comprehensively identify the available literature on my chosen topic. I therefore conducted a systematic review of the qualitative literature pertaining to the UK health care experiences of people with MS. The next chapter (chapter 3) will present this systematic systematic review on patient experiences of health care services for MS.
Table 6. Key gaps in the literature and how my PhD addressed them.

<table>
<thead>
<tr>
<th>Gap in literature</th>
<th>Key source</th>
<th>Derived research question</th>
<th>Addressed in chapter(s)</th>
</tr>
</thead>
<tbody>
<tr>
<td>An up to date understanding of experiences of UK health care for MS post the 2003 NICE guideline and the 2005 NSF. Previous research has investigated mixed samples of varied neurological conditions and combinations of people with MS and carers/professionals.</td>
<td>Methley et al. (2014); Peters et al. (2013); Royal College of Physicians (2011); Sixsmith et al. (2014)</td>
<td>RQ1</td>
<td>3 &amp; 5</td>
</tr>
<tr>
<td>The experiences of younger people with MS, men with MS and people with MS from minority ethnic backgrounds.</td>
<td>Methley et al. (2014); Royal College of Physicians (2011)</td>
<td>RQ1</td>
<td>3, 4 &amp; 5</td>
</tr>
<tr>
<td>Experiences of people with MS analysed by level of disability.</td>
<td>Edmonds et al. (2007b); Golla et al. (2014); Moriya &amp; Suzuki (2011)</td>
<td>RQ1</td>
<td>3 &amp; 5</td>
</tr>
<tr>
<td>A holistic investigation of the UK management of both physical and psychological needs in people with MS.</td>
<td>Marrie et al. (2009b); Minden et al. (2007); Rintell et al. (2012)</td>
<td>RQ1</td>
<td>5</td>
</tr>
<tr>
<td>An understanding of the experiences of depression, help seeking and UK service use in people with MS.</td>
<td>Feinstein (2011); Marrie et al. (2009b); Minden et al. (2007); Rintell et al. (2012)</td>
<td>RQ1</td>
<td>5</td>
</tr>
<tr>
<td>An investigation into the role of Practice Nurses in MS care and their experiences.</td>
<td>Defriez et al. (2003)</td>
<td>RQ2</td>
<td>6</td>
</tr>
<tr>
<td>An understanding of professionals’ experiences managing MS holistically (including psychological needs).</td>
<td>Askey-Jones, Shaw and Silber (2012); While et al. (2009)</td>
<td>RQ 2 &amp; RQ 3</td>
<td>6</td>
</tr>
</tbody>
</table>
Chapter 3. A systematic review exploring the health care experiences of people with MS

3.1 Introduction to the chapter

Whilst undertaking the literature review on patient experiences (presented in Chapter 2) it became evident that no systematic reviews had previously been conducted on patient experiences of health care services for MS and therefore there was a gap in the literature needed to address my primary research question. To investigate the state of literature on the research topic a systematic search of major research databases was conducted and a systematic narrative review published in Health Expectations on this topic (appendix A). Whilst undertaking this search it became clear that there were well-established difficulties in conducting a systematic search for qualitative literature. To contribute further original knowledge to the field I (in collaboration with supervisor SCS) conducted a systematic search contrasting different qualitative literature search tools to test their specificity and sensitivity. This study is under review at BMC Health Services Research and is presented in appendix B.

3.2 Introduction to the review

A systematic narrative review was used to address research question 1 “What are the health care experiences of people with MS?” As the planned empirical research method was to use purely qualitative methods then only qualitative studies were included to present the current state of the literature on this topic. Although a number of systematic reviews exist on pharmacological treatments and physical rehabilitation for MS (Rice et al., 2009; Rosti-Otajarv & Hämäläinen, 2011) no systematic review exists of the literature reporting experiences of UK health care by people with MS. In this chapter I present the methods used in this review and the findings of the review which addressed my first empirical research question pertaining to the UK health care experiences of people with MS.

3.3 Objectives

The review objectives were to:

- Identify and present studies using qualitative methods to investigate the experiences of people with MS using health care services in the UK.
- Appraise the quality of the studies to inform the development of the research methods for this PhD research.
3.4 Systematic review methods

Systematic reviews are a crucial method, underpinning evidence based practice and informing health care decisions (Higgins & Green, 2013; Stephens, 2001). Traditionally systematic reviews are completed using an objective and primarily quantitative approach (Dixon-Woods et al., 2006) whereby a comprehensive search is conducted, attempting to identify all relevant articles which are then integrated and assimilated through statistical analysis. The comprehensiveness of the search process has been viewed as a key factor in preventing bias and providing a true representation of available research (Centre for Reviews and Dissemination, 2008). Conducting comprehensive searches also forms the bedrock of qualitative or narrative reviews, now commonly referred to as qualitative evidence syntheses (Noyes, 2010). Qualitative evidence syntheses are now seen as a necessary and valuable type of information to answer health services research questions (Noyes et al., 2011). Table 7 outlines the necessary stages of completing a systematic narrative review which were adhered to for this review.

<table>
<thead>
<tr>
<th>Table 7. Stages of completing a systematic narrative review.</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Identifying a suitable area for the review</strong></td>
</tr>
<tr>
<td><strong>Formulating a question</strong></td>
</tr>
<tr>
<td><strong>Conducting searches</strong></td>
</tr>
<tr>
<td><strong>Inclusion/exclusion criteria</strong></td>
</tr>
<tr>
<td>Data extraction</td>
</tr>
<tr>
<td>-----------------</td>
</tr>
<tr>
<td>Narrative summary</td>
</tr>
<tr>
<td>Critical appraisal</td>
</tr>
<tr>
<td>Protocol</td>
</tr>
<tr>
<td>Updating reviews</td>
</tr>
<tr>
<td>Publication and dissemination</td>
</tr>
</tbody>
</table>

**3.4.1 Inclusion and exclusion criteria**

Studies eligible for inclusion were those that qualitatively investigated the experiences of people with MS, and their views, attitudes to and perceptions of health care services for MS in the UK. No date restriction was imposed on searches as this was an original review.

Qualitative research, for this purpose, was defined by the Cochrane qualitative methods group (Noyes et al., 2011), as using both a qualitative data collection method and qualitative analysis. Both quantitative and mixed method studies were therefore excluded.

The definition of a patient for this study was adults (aged 18 years old and over) with a diagnosis of MS, who had experience of utilising health care services at any time point. We chose to specify adults as there are differences in paediatric and adult health care
for MS in the UK which may have made comparisons difficult. Also, paediatric MS cases are estimated to make up less than 5% of the total population of people with MS (Yeh et al. 2009). There were no restrictions on subtype of MS, gender, ethnicity or frequency of use of health care.

We defined experience using a definition from a narrative review investigating experiences of health care for another chronic condition (Sinfield et al., 2009, p.301) as “patients’ reports of how care was organised and delivered to meet their needs”. Patients’ reports could refer to either experience of health care services delivery and organisation overall, or their experiences of care by specific health care personnel. Due to the focus on MS, studies were excluded if they used: a mixed sample of various conditions (e.g. a mixed sample of people with neurological conditions or a mixed sample of people with MS and people with Huntington’s disease) or if they used a sample of mixed respondents (i.e. people with MS and their carers) where results of people with MS could not be clearly separated. Finally, studies investigating quality of life were excluded. Additional exclusion criteria were non-English language papers, papers that only described carer or health care professional experiences not patient experiences, editorials and commentaries.

3.4.2 Search strategy

I created a list of search terms in collaboration with a Specialist Librarian at the University of Manchester, an Information Scientist and the wider supervisory team. Terms were grouped within the categories: i) MS, ii) health care services, iii) patients/service-users, iv) experience/opinions/perspectives and v) qualitative research.

The search strategy comprised groups of free text and MeSH headings divided into the categories of terms described above, which were then searched together using the AND function. A separate search strategy was used for each database to ensure that the terms and MeSH headings used were relevant for each particular database. The full search strategy is presented in appendix D.

I completed a systematic search of the databases psycINFO, Medline, EMBASE, CINAHL, and the MS Society library. Reference lists of included papers were searched for additional relevant references. The Multiple Sclerosis Journal was hand searched from inception in 1995 until August 2012. A further search was also conducted in the British Journal of Neuroscience Nursing using the words “Multiple Sclerosis” and “Qualitative”.

59
Grey literature outside that contained within the MS society library was not searched due to resource constraints. The search was not limited by geographical area to ensure that studies were not missed due to incorrect labelling. However, only studies that reported on UK services were included. An updated search was run on 22nd August 2013 (see Figure 2); however no new papers were identified.

**Figure 2. PRISMA diagram detailing the process of searching and identifying relevant papers.**

- 454 records identified through database searching
- 8 records identified through other methods
- Updated search 22nd August 2013 identified 60 new records from databases and 0 from other methods
- With duplicates removed 459 records screened
- 56 full text articles assessed for eligibility
- 6 articles (5 studies) included in review
- 403 records excluded
  - Not a research article
  - Not in English
  - Not an adult sample
  - Not a qualitative study
  - Not just people with MS
  - No data on health care experiences
- 50 records excluded
  - Not a qualitative study
  - Not just people with MS
  - No data on health care experiences

### 3.4.3 Data management and quality appraisal

I judged titles and abstracts against the inclusion criteria. If a title and abstract met the inclusion criteria then full text copies of all articles were retrieved for further investigation. Together with supervisor SCS I then independently assessed these articles against the inclusion and exclusion criteria. Any disagreements were resolved
via discussion. We extracted data from included studies independently to ensure accuracy and then stored data on a Microsoft Excel spread sheet.

We then appraised extracted data for quality using an expanded version of the Critical Appraisal Skills Programme (CASP) criteria (Solutions for Public Health, 2011) modified for thematic syntheses with qualitative literature. (Campbell et al., 2011). Quality was independently appraised by SCS and myself, and we met to decide a consensus. As some questions in this modified CASP tool could be subjective and difficult to grade (e.g. “what is your overall view of this study?” graded from 1 = Excellent to 6 = Very poor) we followed the process detailed in Masood et al. (2011), where the percentage of CASP criteria met by each paper was taken as an indicator of quality (see Table 8). We therefore removed all questions that required grading and marked remaining questions in terms of whether evidence was present (1 = Yes) or absent (2 = No) (see appendix E for more information). Studies were not excluded on grounds of quality, instead this information was used to present the quality of evidence available on this topic for discussion.
<table>
<thead>
<tr>
<th>Source article</th>
<th>Setting (hospital/community)</th>
<th>Sample</th>
<th>Research design</th>
<th>Aims</th>
<th>Word count</th>
<th>Overall quality assessment (% of CASP criteria met)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Edwards, Barlow &amp; Turner (2007)</td>
<td>England, Birmingham. (Recruited through MS Society and local newspaper)</td>
<td>N = 24. Age range 35-72 years. 17 f and 7 m. Disease duration 1-37 years. 23 Caucasian</td>
<td>Semi-structured telephone interviews with thematic content analysis</td>
<td>To examine service users’ experiences of being diagnosed with MS, information given at the time, treatment and the impact on their lives</td>
<td>3183 words</td>
<td>59.5%</td>
</tr>
</tbody>
</table>
| Embrey (2009a, 2009b)                | England, Staffordshire. (Recruited through hospice day care)           | N= 9                                                                   | Interviewed using an open ended question approach and analysed using Giorgi’s (1985) framework analysis | To explore the experiences and views of people with moderate and severe MS participating in a palliative day care programme offered at a hospice in North Staffordshire                                          | Paper 1: 3664 words  
  Paper 2: 4180 words | 40.5%                                             |
<p>| Johnson (2003)                       | England, Southeast. (Recruited through hospital database)               | N = 24. Interviewed in 2 cohorts. Cohort 1: Age range 37-67. Cohort 2: Age range 34-66 years. Cohort 1: 6 m, 6 f Cohort 2: 4 m, 8 f. Cohort 1: Age of onset 24-59. Illness duration 0.4-26 years. Cohort 2: Age of onset 21-51 years. Illness duration 0.4-33 years | Interviewed one cohort before and one after the implementation of an SN. Analysed with thematic analysis | To investigate service users’ experiences of receiving a diagnosis of MS                                                                                                                                  | 3923 words | 48.6%                                             |</p>
<table>
<thead>
<tr>
<th>Study</th>
<th>Location</th>
<th>Sample Size</th>
<th>Methodology</th>
<th>Research Question</th>
<th>Word Count</th>
<th>% of Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Laidlaw and Henwood (2003)</td>
<td>England, London. (Recruited through MS Society)</td>
<td>N = 8. 2 m, 6 f.</td>
<td>Unstructured interviews and open thematic analysis</td>
<td>To investigate service users' holistic experience of Magnetic Resonance Imaging (MRI)</td>
<td>3604</td>
<td>51.4%</td>
</tr>
<tr>
<td>Malcomson, Lowe-Strong &amp; Dunwoody (2008)</td>
<td>Newtownabbey, Northern Ireland (Recruited through MS Society)</td>
<td>N = 13. Aged 40 -67 years.1 part time, 3 unemployed, 5 homemakers, 4 retired. Group 1: 5 f, 1 m. Group 2: 4 f, 3 m. 6-30 years since diagnosis. 6 relapsing-remitting, 6 secondary progressive, 1 primary progressive. Ambulant with aids (n = 8), wheelchair user (n = 2), independently mobile (n = 3)</td>
<td>Two focus groups and thematic analysis</td>
<td>To explore personal accounts and experiences of individuals with MS who felt able to cope with the disease in day-to-day life</td>
<td>7997</td>
<td>59.5%</td>
</tr>
</tbody>
</table>
3.5 Findings

The majority of papers were excluded because they did not report qualitative methods, yet contained words that were relevant search terms, such as “patient”, “knowledge”, “experience”, which were frequently key words for questionnaire studies on patient experience and satisfaction. Papers that were excluded at the full text stage contained samples of both people with MS and another group e.g. carers, that was not explicit in the title and abstract.

The search identified 5 studies that fitted the inclusion criteria (2 publications reported different results from the same study (Embrey 2009a, Embrey 2009b). Information about these studies is presented in Table 8. Although no date restrictions were set, all studies found were published between 2003 and 2008. The majority of the studies were conducted in England (n = 4), (Edwards, Barlow & Turner, 2007; Embrey, 2009; Johnson, 2003; Laidlaw & Henwood, 2003) with one in Northern Ireland (Malcomson, Lowe-Strong & Dunwoody, 2008). Levels of demographic reporting varied widely. Discussion of ethnicity was virtually absent with only one study reporting this information (Edwards, Barlow & Turner, 2007). Embrey (2009) only provided information on the number of participants. Similarly Laidlaw and Henwood (2003) only provided the sample size and gender of participants. In the other three studies (Edwards, Barlow & Turner, 2007; Johnson, 2003; Malcomson, Lowe-Strong & Dunwoody, 2008) participants were aged from 34 to 72 years, with a disease duration of between 0.4-37 years. Only one study (Malcomson, Lowe-Strong & Dunwoody, 2008) provided an in-depth profile of disease progression, reporting that the majority of their sample was ambulant with aids, an equal number of participants with relapsing-remitting and secondary progressive MS were included and the majority of participants were homemakers or retired. Four studies (Edwards, Barlow & Turner, 2007; Embrey, 2009; Johnson, 2003; Laidlaw & Henwood, 2003) collected data using interviews; unstructured (Laidlaw & Henwood, 2003) or semi-structured interviews (Edwards, Barlow & Turner, 2007; Embrey, 2009; Johnson, 2003) and one study utilised focus groups (Malcomson, Lowe-Strong & Dunwoody, 2008). Thematic analysis was the predominant analytic method utilised (Edwards, Barlow & Turner, 2007; Johnson, 2003; Laidlaw & Henwood, 2003; Malcomson, Lowe-Strong & Dunwoody, 2008) although a named method of analysis, Giorgi’s (1985) framework analysis was reportedly used in one study (Embrey, 2009).
3.5.1 Quality appraisals

The overall quality scores attributed to the publications are presented as the percentage of CASP criteria met (see table 8 and appendix E). The highest scoring studies only scored 59.5% of criteria met, whilst the lowest rated study scored 40.5%. Studies frequently failed to report their justifications of both sample size and the reasons for selecting a particular sample. Whilst studies were usually clear on how data were collected and recorded, poor reporting of analysis was a major contributor to low scores. For example, four studies (Edwards, Barlow & Turner, 2009; Johnson, 2003; Laidlaw & Henwood, 2003; Malcomson, Lowe-Strong & Dunwoody, 2008) reported using a form of thematic analysis but made no reference to an iterative process. Only one study (Embrey, 2009) reported a theoretical perspective (phenomenology). Findings were, overall, clearly reported, however a lack of demographic information made it difficult to assess the transferability of findings.

3.5.2 Data analysis

Once the data had been extracted, it became clear that the relative paucity of papers identified for inclusion, and the breadth of areas researched in these papers, ensured that resulting data were too heterogeneous to utilise an in-depth qualitative synthesis method such as a meta-ethnography (as proposed by Sandelowski et al., 1997). Therefore, as outlined in previous studies investigating qualitative research, for example, Lie, Robson and May (2008), it was necessary to utilise a narrative summary approach to present the main findings of all studies in a narrative form. Both SCS and I summarised the findings of the studies and compared them to check for accuracy and consistency. Once this was completed we compared the aims and topics explored in these studies. The reported aims of these studies could be broadly categorised into two areas, the process and experience of diagnosis (n = 4) (Edwards, Barlow & Turner, 2007; Johnson, 2003; Laidlaw & Henwood, 2003; Malcomson, Lowe-Strong & Dunwoody, 2008) and palliative care (n = 1) (Embrey, 2009). These findings will now be presented in the form of a narrative summary.

3.5.2.1 Diagnosis

Studies focussed on the experience of various aspects of diagnosis. Subthemes of information and experiences of access to services and health care support were found to mediate emotional reactions and improve the emotional experience of diagnosis.
Information was key for the diagnostic process whilst access to services and health care professional support were highlighted as subthemes for continued care.

Three studies reported a prolonged investigative process and negative experiences of receiving a diagnosis (Edwards, Barlow & Turner, 2007; Johnson, 2003; Laidlaw & Henwood, 2003) and two studies reported dissatisfaction with the way in which diagnosis was managed (Johnson, 2003; Malcomson, Lowe-Strong & Dunwoody, 2008). Time taken to reach a definite diagnosis was sometimes lengthy (Edwards, Barlow & Turner, 2007; Johnson, 2003; Laidlaw & Henwood, 2003; Malcomson, Lowe-Strong & Dunwoody, 2008), in two studies people with MS reported waiting over 17 years for a diagnosis (Johnson, 2003; Malcomson, Lowe-Strong & Dunwoody, 2008). However one study reported confirmation of a diagnosis of MS in less than two years (Malcomson, Lowe-Strong & Dunwoody, 2008) and another study reported cases diagnosed within 12 months (Edwards, Barlow & Turner, 2007). In summary, the process of diagnosis was overall a negative and lengthy experience.

Emotional reactions to the diagnostic process were widely reported and transcended all stages of diagnosis (Edwards, Barlow & Turner, 2007; Johnson, 2003; Laidlaw & Henwood, 2003; Malcomson, Lowe-Strong & Dunwoody, 2008). Before diagnosis, reported emotions were an awareness that something was wrong, distress, uncertainty, fear and anxiety (Johnson, 2003; Malcomson, Lowe-Strong & Dunwoody, 2008). During the diagnostic testing period these emotions continued to be present. After diagnosis, emotional responses were described as devastating or shocking unless people with MS had prior suspicions of MS (Johnson, 2003; Malcomson, Lowe-Strong & Dunwoody, 2008) although feelings of relief at the identification of the condition were also reported (Johnson, 2003; Malcomson, Lowe-Strong & Dunwoody, 2008).

Information received

Information was described as necessary for participants to understand their MS and a lack of timely information was found to cause increased anxiety and distress (Laidlaw & Henwood, 2003). A lack of advice and information about MS at the time of diagnosis and difficulties accessing information regarding MS were reported (Edwards, Barlow & Turner, 2007). MS knowledge at the time of diagnosis was reportedly important for all participants in one study and this involved a process whereby the participants became more informed and were able to identify relevant support services (Johnson, 2003). Another study highlighted that provision of information on the MS society at the time
of diagnosis would have been beneficial (Laidlaw & Henwood, 2003). The only study investigating the experiences of MRI scanning, revealed a lack of information at all stages of the MRI scan; before scanning, at the time of the scan and when the results were ready (Laidlaw & Henwood, 2003). One study reported conflicting findings: a small number of participants were happy with the information provided; however many more reported that they had not had adequate information or advice on MS (Edwards, Barlow & Turner, 2007). Dissatisfaction with health care services was commonly linked to lack of information provision and understanding (Laidlow et al., 2003; Malcomson, Lowe-Strong & Dunwoody, 2008).

This reported lack of information caused anxiety, fear and lessening patient perceptions of control of both the scanning experience and MS in general (Laidlaw & Henwood, 2003). Frustrating encounters were reported with health care professionals, including GPs, who could not provide information on MS or relevant support services, in comparison to occupational therapists, physiotherapists, and community nurses who were felt to be more knowledgeable (Johnson, 2003). In one study participants reported that their GPs were *ill-informed* and *not knowledgeable* on MS (Edwards, Barlow & Turner, 2007).

Timeliness and access to information is therefore of great importance, and variation was found in the level of knowledge of MS demonstrated by health care professionals.

**The post-diagnostic phase: Access to services and experiences of health care professional support**

Difficulties were also reported in accessing treatments for MS later on in the disease course (Edwards, Barlow & Turner, 2007) and one study reported a focus on physical health needs at the exclusion of psychosocial support (Malcomson, Lowe-Strong & Dunwoody, 2008). One study reported mixed findings, as whilst a small number of participants were happy with the care they received, overall most of the participants in this study received little or no treatment for MS and were often refused funding for treatment by the National Health Service (NHS) (Edwards, Barlow & Turner, 2007). Continuity of care was an issue at the time of diagnosis, and later on bridging diagnosis and subsequent care. Neurologists were reported as *trying to solve the puzzle* of MS and then *withdrawing* when that was achieved (Johnson, 2003). In one study participants reported feeling *abandoned* and *isolated* by the health care system, unless
they received support from another health care professional, such as a GP or MS Nurse (Johnson, 2003).

Three studies discussed unsatisfactory health care professional support (Edwards, Barlow & Turner, 2007; Laidlaw & Henwood, 2003; Malcomson, Lowe-Strong & Dunwoody, 2008). Communication with health care professionals was also perceived negatively by participants in one study who reported that their professionals had been off-hand, casual and unsympathetic (Malcolmson, Lowe-Strong & Dunwoody, 2008). Participants in another study recalled their diagnosis being given in a manner that lacked sensitivity, empathy and understanding (Malcolmson, Lowe-Strong & Dunwoody, 2008).

Participants in one study reported difficulties in initiating symptom investigation as they felt they were not believed by health care professionals (Edwards, Barlow & Turner, 2007). This study also reported that although a suspicion of MS was noted in their medical records they were not informed of this (Edwards, Barlow & Turner, 2007). Access to health care and the professional manner and communication demonstrated by health care professionals has a large impact on participants’ experiences of continuing health care services for MS (Edwards, Barlow & Turner, 2007; Johnson, 2003; Laidlaw & Henwood, 2003; Malcomson, Lowe-Strong & Dunwoody, 2008). Continuity of care, and specifically poor experiences of continuity, between different health care professionals and services is therefore a key factor in the experiences of people with MS.

3.5.2.2 Palliative care

Embrey (2009a, 2009b) was the only study (reported across two publications) to report the experience of palliative care for people with MS. Therapeutic interventions were found to improve symptom relief, provide a sense of achievement and fun, improve optimism, and provide an opportunity for health promotion, although a downside was the infrequency of therapeutic interventions and worries over continuity of this palliative care service. Group support provided friendships based on shared health condition, allowed an awareness of each other’s problems, provided positive experiences with hospice staff, and reduced carer burden by providing time off for carers. Participants reported being initially fearful and worried about using a hospice but appreciated the relaxed environment which improved their self-confidence.
3.5.3 Further analysis

Once this initial analysis was completed it was felt it would be of value to see if there were any tentative commonalities between these two areas of care. Whilst a full meta-ethnography was not possible, the initial elements of a basic thematic synthesis were conducted. As outlined in Thomas & Harden (2008) I completed line-by-line coding for all sentences in the findings sections of the six included studies. Next SCS and I jointly compared these codes to create overarching themes.

Despite the very different aims of diagnostic care services and palliative care, some themes of experiences emerged which transcended the care pathway (see Figure 3), namely: the emotional experience of care, perceived support from health care professionals and the importance of continued care and access to services. Two themes were developed that were unique to the particular care setting: Experiences of diagnostic procedures and the benefits of palliative care services. These five themes were then discussed within the wider supervisory team to check consistency of interpretation and ensure that the themes were grounded in the studies and not extrapolated beyond the data. Due to the limited and varied nature of the data we did not complete the defining stage of a narrative synthesis, which was to “go beyond” the content of the original studies to create an explanation of experiences of health care or generate theory on this topic (Britten et al., 2002).

Figure 3. Presentation of themes from diagnosis and palliative care studies.
3.6 Discussion
Included studies fell broadly into two distinct areas of research: experience of diagnosis and experience of palliative care. However, similarities were identified between the two areas of care in terms of issues with health care professional support, access to continued care and the emotional experience of using health care services. Primarily, descriptions of diagnosis presented mainly negative experiences and poor service provision, suggesting this is still an area in which MS care can be improved, as reported in the included papers by people with MS from across the UK.

3.6.1 Summary of review findings
This review provides an overview of the literature relating to people with MS’ experiences of health care in the UK and two discrete areas of research into diagnosis and palliative care. Diagnosis was presented as a primarily negative experience whilst the limited evidence on palliative care suggested a positive experience. Themes of importance for both areas were found to be the emotional experience of health care, continuity of care and access to services, and support from health care professionals. These themes present areas of great importance for the designing, commissioning and delivery of clinical care which require attention and change. However, the empirical evidence is currently limited to a homogenous group of people with MS’ experiences of the start and end of the illness trajectory. This therefore leaves a considerable gap in knowledge relating to the majority of the illness management experience and the views of minority groups including young people and those from ethnic minorities. Future research should work to improve patient care in these areas and provide knowledge on the experiences of care across the care pathway, which I addressed in this PhD (chapters 5 & 6).

3.6.2 Implications for practice and future research
Communication with health care staff has been a key finding in research investigating MS care (Edmonds et al., 2007a; Thorne et al., 2004). However, the studies in this review were relatively recent (as of 2008), suggesting that this is still a current and significant issue, despite being noted as a key principle of the 2003 NICE guideline for MS recommendations for clinical practice (NICE, 2003, CG8). A clinical priority should therefore be to improve health care professionals’ awareness of the emotional impact of ineffective communication, with the provision of medical education and training on
appropriate styles of communication if necessary, similarly to those utilised in oncology services (Schofield, Green & Creed, 2008).

This review highlighted the emotional reactions people with MS experience in relation to their symptoms, and the treatment they receive, particularly during diagnosis when uncertainty, fear and anxiety appear at their highest. The NHS has previously acknowledged the need to improve the patient emotional experience in order to improve patient experiences overall (DH, 2005c) and this is evidently necessary for people with MS.

A lack of timely information on diagnosis, living with MS, and treatment was found to directly link to negative emotional states such as anxiety and fear. Providing timely and credible information on these topics should therefore be a priority in improving the patient emotional experience (DH, 2005c).

The included studies suggested that the experience of diagnosis could be improved by better responsiveness and increasing the continuity of care between and within primary, community and specialist care and ensuring relevant emotional and informational support structures are in place for people receiving a diagnosis of MS.

Although all studies in this review were published within the last decade, many participants in these studies had been diagnosed for a long period of time before these studies took place. It is possible that a perceived improvement of MS patient experiences occurred due to earlier or more timely diagnosis as a result of the increasing use of technology such as MRI to identify lesions suggestive of MS (Granberg et al., 2013). It may also possibly be due to the increased support and information provided by SNs since the increasing implementation of their role throughout the 2000s (De Broe, Christopher & Waugh, 2001) however these assertions cannot be confirmed from the evidence provided by the included studies.

3.6.3 Implications for commissioning

Patient concerns over the continuity and quality of care services in the UK are a pertinent and current issue due to budget restrictions and the cessation of certain National Health Service (NHS) facilities (Appleby, Thompson & Jabbal, 2012). Access difficulties due to funding restrictions, or procedures, may change with restructuring accompanying the Health and Social Care Act 2012 (House of Commons, 2012). The inclusion of neurological conditions (including MS) in one of the four strategic clinical networks is hoped to improve the continuity of care across primary and secondary care.
services, and provide expert clinical information to the commissioners of services for this patient group (NHS Commissioning Board, 2012). This strategic clinical network also encompasses mental health care, reflecting that the UK now has an increasing focus on prioritising mental health needs in people with physical health conditions (DH, 2011), including MS. However, a service audit of MS care in 2011 revealed difficulties accessing relevant services dependent on local funding priorities, referrals and availability of services (Royal College of Physicians, 2011) and further variety may be displayed due to the priorities of clinical commissioning groups (DH, 2010a). It will therefore be necessary for further research to investigate these issues within the new NHS structure.

3.6.4 Strengths and limitations of the study

These conclusions are drawn from a limited body of research, some with poor quality methodology or reporting. There is therefore a need to utilise high quality qualitative research to gain a more thorough understanding of the full health care experience for people with MS, in order to maintain or improve the health care experiences provided. There are few qualitative studies published on the health care experiences of people with MS and those that exist have been limited to issues around diagnosis and palliative care. Although palliative care was found to provide a positive experience with increased peer support and psychological and physical benefits, little qualitative evidence exists on this aspect of care. Overall the available body of literature omits many aspects of MS care, as the studies identified only cover the very beginning and the very end of the health care pathway, with no investigations of rehabilitation and continuing care experiences.

From the limited demographic data provided it is difficult to assess how well the above findings represent the experiences of a wide variety of people with MS. From the available information it appears that more participants under the age of 35 should be studied, as MS can be diagnosed from childhood (Compston et al., 2006), however the views of young adults with MS are currently unrepresented in the literature. In addition, only one study reported ethnicity data, leaving a large gap in our knowledge of any differences of experiences between ethnic groups. As MS may affect people from all ethnic groups (Compston et al., 2006), and there are well-established difficulties in help seeking and barriers to accessing health care reported by people
from ethnic minority backgrounds (Szczepura, 2005), it would appear pertinent to explore the views of these individuals.

The results of the above systematic narrative review and accompanying qualitative study provided the foundation for this PhD research. The next chapter will outline the research methodologies used and theoretical framework for the primary data collection.
Chapter 4: Methodology and methods

4.1 Background to this study/Introduction

In this chapter I present a discussion of the methodology and methods used in this thesis.

The literature on people with MS’ experiences of health care (presented in chapter 2) and findings of my systematic review (presented in chapter 3) suggest that experiences of health care are highly variable and may comprise difficult to access, poorly coordinated and unresponsive care, characterised by negative interpersonal communication with health care professionals and a lack of person-centredness. As there is only a small body of mixed quality research exploring this topic within the UK, there is a need to research people with MS’ experiences of health care services in the UK. My first research question was therefore:

1. What are the health care experiences of people with MS in the UK for both physical and psychological symptoms?

There is limited literature on health care professionals’ experiences of managing people with MS (as outlined in chapter 2). GPs and PNs are involved in caring for people with MS due to their role in front line health services managing people with LTCs more generally. However due to the low numbers of patients with MS seen by individual primary care professionals the literature is currently unclear in relation to the roles and experiences of GPs and PNs in UK primary care services for people with MS. Therefore, my second research question was:

2. What are the experiences of primary care professionals (GPs and PNs) providing services for people with MS?

The role of SNs is well established for managing physical symptoms in MS. The literature (as outlined in chapter 2) suggests that they may be responsible for providing emotional or psychological support; however this has not been investigated. My final research question was therefore:

3. What are the experiences of SNs providing services for people with MS?

I will now present the methodology, method and theoretical framework underpinning these three research questions.

4.2 Justification for qualitative methodology

Person-centred care (as defined by the Health Foundation, 2014) views patients as autonomous partners in their health care who are entitled to respectful care focused
on their unique needs. Qualitative research can allow a person-centred understanding of the subjective emotions, perceptions and actions of someone living with a particular condition, (including reasoning behind health care decisions) by enabling people with chronic conditions to voice their experiences and contribute to improved care (Holloway, 2005).
Murphy & Mattson (1992) suggests that qualitative research matches the ethos and aims of general practice in its focus on personal meanings and views of the individual as a social being within a larger context. There is a wealth of qualitative research investigating issues of relevance to general practice including studies identifying barriers and facilitators to care (Coventry et al., 2011), experiences of health care professionals (Maxwell et al., 2013) and service users experiences’ and perceptions of services (Nelson et al., 2013).
Health care services more broadly require an understanding of issues important to the specific individual in order to support them and maximise their wellbeing (Flensner, Ek & Söderhamn, 2003), indeed this is the basic premise of medical practice based on individual case-related knowledge (Feinstein, 1967). Increasing the understanding of why patients chose specific health care professionals and services may enable professionals to more effectively engage patients (Cheong, Armour & Bosnic-Anticevich, 2014).
MS has primarily been subject to the study of disease, as opposed to the study of illness (Riessman, 2003). Previous research has focussed mainly on the pathology and treatment of the condition (Rice et al., 2009; Rosti-Otajarv & Hämäläinen, 2011), not the subjective experiences of those living with MS, including their experiences of health care services.
MS is currently a condition with no known cure, meaning that a large part of care revolves around symptom management, similar to most LTCs. There is a need for doctors to learn about their patients’ lives and how they view their illness experience and progression, in order to adapt their treatment and advice to aim for the best possible quality of life (Gerhardt, 1990; Olsson, Lexell & Söderberg, 2005). This may increase the benefit and relevance of the support provided by health care services as clinicians are more understanding of, and “sensitized” to, service users’ perspectives and experiences (Gerhardt, 1990; Green & Thorogood., 2011, p. 32).
As illness experience and progression are highly varied in MS, using quantitative research with predefined questions may miss vital aspects of the psychological and social factors relevant to the experience of a specific individual (Mohr et al., 1999). Qualitative data may be used more widely in the areas of health care policy by highlighting areas for change, as identified by those with direct views and experiences of the issues involved (Green & Thorogood, 2011). In this study I therefore used qualitative methods to investigate participants’ experiences of health care.

4.3 Epistemological considerations

Bryant and Charmaz state that “any research method makes epistemological claims; a method must indicate why its application will lead to a development of knowledge, otherwise researchers would have no basis for choosing it in the first place” (2007, p. 32).

Whilst the following epistemological approaches do not have to be investigated through qualitative means, they are complimentary to them (Green & Thorogood, 2011), by appreciating the subjectivity of meaning and unique participant experience; for example, using a phenomenological study to investigate the lived experience of feeling well in women with MS (Olsson, Skär & Söderberg, 2010).

Where the experiences of individuals living with chronic illness are a focus, sociological theories may be used to highlight and interpret findings. These may cover issues such as the impact of symptoms on daily living and health service use, whilst still taking into account the context of issues that may not have a primary medical focus, such as identity (Gerhardt, 1990). I will now briefly explain some sociological epistemologies and how they may apply to my research (Table 9).
<table>
<thead>
<tr>
<th>Theory</th>
<th>Key aims</th>
<th>Advantages or disadvantages</th>
</tr>
</thead>
<tbody>
<tr>
<td>Positivism</td>
<td>The positivist approach endorsed by Auguste Comte (1798-1857) believed that methodology applicable to the natural sciences could also be applied to the sociology and psychology of humans. This implied that human behaviour can be objectively observed and measured, identified as a product of cause and effect and then used to create theories of behaviour. Within this theoretical approach are the assumptions that unobservable factors such as feelings, meanings and purposes are unreliable and not of importance (Crotty, 1998).</td>
<td>The positivist approach is crucial for research on Multiple Sclerosis investigating issues such as objective measurements of recovery, however it cannot investigate the subjective subtleties of illness experience and the reasons why individuals chose the health services they do. This issue is of particular relevance to the theoretical framework I used, which views participants’ perceptions as central to understanding their access, use and navigation of health care services. Therefore an approach which does not facilitate this understanding is not appropriate.</td>
</tr>
<tr>
<td>Phenomenology</td>
<td>Phenomenological analysis, as described by Edmond Husserl (1859- 1938) aims to investigate the lived experience of a phenomenon; that is, how an individual experiences certain events and their subjective interpretation of them (Mapp, 2008). This theoretical stance posits that there is no such thing as an observable human behaviour, as humans create an understanding of phenomena by subjectively categorising and interpreting them (Crotty, 1998).</td>
<td>My research contained elements of a phenomenological approach by appreciating the subjective creation of understanding. For example, whilst a consultation for an MS symptom may be measured objectively as high quality, the way in which the patient interprets the consultation (including the professional’s behaviour, goals etc.) may have an impact on their future help seeking behaviour. It is therefore necessary to understand how they interpret services and which aspects of this interpretation are viewed positively or negatively. However, I did not agree with the premise that understanding is created by one individual alone, due to the interactive nature of health care consultations, and therefore I took a more interactionism based approach as outlined below.</td>
</tr>
<tr>
<td>Interactionism</td>
<td>Interactionism aims to understand the meaning that actions hold for people and views meaning as dynamic, developing and changing based on context and experiences (Haralambos &amp; Holborn, 1991). Actions can depend on how an individual believes they are perceived by others and how they perceive themselves. This perception of self has been coined “self-concept”, explaining how individuals view themselves as physical, social and moral beings, through a reflexive process developed in social interaction (Grecas, 1982).</td>
<td>Interactionism was key for my research investigating perceptions of health care use as it can account for the role of both the self-concept and interaction in health care access and use. Interactionism believes that meaning is jointly constructed between two people i.e. a patient and a health care professional. An individual’s self-concept is important as it may influence their help seeking behaviours, whilst the negotiation developed between two individuals in a health care interaction may determine health related outcomes. Interactionism believes that although roles may be provided for an individual e.g. health care professional or patient, any role is</td>
</tr>
<tr>
<td>Social constructionism</td>
<td>Using similar principles to interactionism, social constructionism is the view that knowledge and meaning of phenomena, and therefore perceptions of reality, are built or constructed, out of interaction between an individual and a phenomenon (Crotty, 1998), including social interactions with other people (Berger &amp; Luckmann, 1966). Social constructionism argues that there is no such thing as “meaning realism” whereby a concrete truth exists and can be discovered, instead truth is constructed by an individual and communicated by language (Denzin &amp; Lincoln, 2003, p. 307). This suggests that there is no such thing as an objective phenomenon as every individual ascribes different meaning, and meaning can be co-constructed in social interactions through communication and negotiation (Berger &amp; Luckmann, 1966).</td>
<td>Experiences of health care will therefore be different for every participant as they will ascribe meaning differently, due to their own beliefs, values, and schema (Denzin &amp; Lincoln, 2003). In addition no one develops knowledge in isolation. Therefore, all knowledge is created alongside cultural understanding that differs by individuals and communities. Understanding an individual's experiences of health care services therefore depends on an understanding of how their meaning was constructed and communicated, including within the health care consultation. Social constructionism has been acknowledged as an appropriate epistemology for understanding illness experience and interactions between people with chronic conditions and professionals (Brown, 1995) and this is why I selected this approach for my research.</td>
</tr>
</tbody>
</table>
For the purposes of this research I therefore investigated participants’ experiences of health care services and the meaning they attribute to these using an interactionism approach, including elements of phenomenology, and social constructionism. This allowed my research to investigate subjective perceptions of meaning constructed by both people with MS and professionals, and how these related to help-seeking, service navigation and service use and provision.

4.4 Research design

4.4.1 Semi-structured interviews as a method

Interviews are commonly utilised to understand more about the experiences and perceptions of participants (Taylor & Bogdan, 1998) and can therefore address the subjective experiences central to the chosen epistemological approach. Berg (2009) presents three types of interview on a “structure continuum of formality” (p. 105): standardised interviews, semi-structured interviews and unstructured interviews. These will now be discussed alongside their relevance to this research (Table 10).
Table 10. Interview types and their relevance to this research (Berg, 2009).

<table>
<thead>
<tr>
<th>Interview type</th>
<th>Relevance to this research</th>
</tr>
</thead>
<tbody>
<tr>
<td>Standardised interviews</td>
<td>• Standardised interviews utilise a formal structure, rigid question wording with no adjustments permissible, no clarification of questions and no additional questions allowed. As my research was exploratory and not firmly grounded in established literature it would have been impossible to create a standardised interview schedule from the onset.</td>
</tr>
<tr>
<td></td>
<td>• Highly structured interviews may not have allowed participants the flexibility and freedom to determine what information to provide (Green &amp; Thorogood, 2011). In addition, as experiences of both living with MS and related health care use were so varied, a fixed schedule would not have allowed the option to investigate certain topics in more depth or omit questions that were not relevant; therefore limiting the iterative nature of this process.</td>
</tr>
<tr>
<td></td>
<td>• This approach assumes that the every question holds equal meaning for all participants (Kumar, 2005), which as discussed earlier, is not conducive to an interactionism guided approach.</td>
</tr>
<tr>
<td>Semi-structured interviews</td>
<td>• Semi-structured interviews have a structure but are flexible in their question order, wording and use of probes (Green &amp; Thorogood, 2011). Semi-structured interviews are best suited for this research as there are specific topics to be discussed and comparison is needed across interviews, however it is also necessary for patients to volunteer the information which they feel is relevant and judge the importance of the topics discussed (Green &amp; Thorogood, 2011).</td>
</tr>
<tr>
<td></td>
<td>• Semi-structured interviews are designed with the awareness that individuals may interpret language and meaning in different ways (Gubrium &amp; Holstein, 2003). This approach allows the level of language to be adjusted. Semi-structured interviews are frequently used in research on the experiences of people with MS including Boeije et al. (2002) and Edmonds et al. (2007a).</td>
</tr>
<tr>
<td></td>
<td>• In order to investigate and analyse the experience of living with MS, and individuals’ experiences and needs of health care services, semi-structured qualitative interviews were conducted.</td>
</tr>
<tr>
<td>Unstandardised interviews</td>
<td>• Unstandardised and therefore unstructured interviews support the concept of an interview as “simply a conversation with a purpose” (Berg, 2009, p. 101).</td>
</tr>
<tr>
<td></td>
<td>• The underlying assumptions that not all questions are previously known to the researcher is pertinent to my research, however, the purpose of this study was to gain information on a predefined topic from a group of participants who often experienced fatigue, thus limiting the time span of potential interviewing.</td>
</tr>
<tr>
<td></td>
<td>• Therefore, it was necessary to have a more directive approach than simply an unguided conversation, in order to address the specific research questions outlined (Green &amp; Thorogood, 2011).</td>
</tr>
</tbody>
</table>
4.4.2 Ethical considerations and research governance

Ethical approval was granted by the Greater Manchester Central Research Ethics Committee (REC: 12/NW/0385; appendix F) and University of Manchester ethics committee (appendix G). Research governance approval was granted for Central Manchester PCT, Stockport PCT, Trafford PCT and Salford Foundation Trust (appendix H). Ethical approval was later granted for an amendment to extend community recruitment of participants into North Staffordshire and East Cheshire (granted 21st January 2013). Further research governance approval amendments allowed the addition of Bury PCT as a recruitment site for health care professionals, and the expansion of SN recruitment to cover the whole of the North West of England (granted 14th August 2013). Due to difficulties with initial recruitment, ethical approval to reimburse GPs £50 and PNs £30 for their time was requested, and granted by substantial amendment on the 14th August 2013 and 9th September 2013 respectively. Participating in interviews can potentially lead to distress (in patients, particularly). Upon seeing someone becoming distressed I turned the Dictaphone off immediately. I asked all three participants with MS who experienced distress if they would like to stop the interview. All participants reported that they were happy to continue and after a brief period of normal conversation the interviews were resumed. At the end of the interview I recommended participants contact their GP or relevant health care professional and provided signposting where appropriate. I finished every interview with a brief informal discussion to ensure that participants were comfortable and were not left feeling upset due to topics covered in the interview.

4.5 Data collection technique/process

4.5.1 Sampling of participants

The theoretical premises of the representative sampling method do not apply to qualitative research (Marshall, 1996). For example, the characteristic of interest i.e. experiences of health care, will not be normally distributed within a population and some participants will provide richer and more insightful data than others (Marshall, 1996). Another key difference between quantitative and qualitative sampling techniques is that qualitative research does not rely on power calculations, but simply that the sample size utilised may potentially answer the research question (Marshall, 1996). In order to achieve this I used constant comparison analysis (Lincoln & Guba, 1985) incorporating a flexible and iterative research design, where data collection was
stopped upon achievement of data saturation. This saturation referred to data saturation as defined by Guest, Bunce & Johnson (2006): where no information is generated to change or add to existing themes, not theoretical saturation as originally described by Glaser and Strauss (1967) as theory was not the intended product of this analysis.

For this study, I used maximum variation sampling. This was defined by Sandelowski as a decision made a priori in order to “have representative coverage of variables likely to be important in understanding how diverse factors configure as a whole” (1995, p.182). As discussed in Patton (1990), this is a type of purposeful sampling by deliberately targeting characteristics known to be of relevance. For this research a broad range of participants were sought, varying in characteristics that have been noted to affect experiences of health care in previous literature. These included age (Alemayehu & Warner, 2004), gender (Wang et al., 2013), ethnicity (Szczepura, 2005), type of MS (Holland et al., 2011), and level of MS disability (Strupp et al., 2014). Once data collection and analyses were under way participants were sought who represented deviant or disconfirming cases defined as “elements in the data that contradict the emerging explanation of the phenomena under study” (Pope, Ziebland & Mays, 2000, p. 51). These cases can be used to test and refine devised categories and themes by illuminating limitations and boundaries. In my research these included people who had disengaged from health care services or were not members of an MS society, to give a richer insight to the limitations of my themes and analysis and allow exploration of alternative interpretations (Booth et al., 2013). Snowball sampling (Sadler et al., 2010) was used to recruit men who did not commonly respond to community recruitment strategies.

4.5.2 Modes of interviewing

Face-to-face interviews are the traditional mode of semi-structured interviewing, due to the benefits of increased rapport and the additional contextual information provided by body language, emphasis and gesture (Novick, 2008). However, certain aspects of MS may mean that telephone interviewing is less demanding for participants than face-to-face encounters, such as limiting fatigue and limited mobility. Limited evidence comparing face to face and telephone interviewing has concluded that the method of telephone interviewing does not necessarily link to lower quality data (Sturges & Hanrahan, 2004) and may be more convenient for busy participants such as health care
professionals, and those from advanced geographical distances (Holloway & Wheeler, 2010).

It has been suggested that emotionally sensitive topics benefit from face-to-face interviews, where the interviewer can respond to visual cues, anticipate distress and provide comfort (Sturges & Hanrahan, 2004). Also, given the communication and speech difficulties experienced by some people with MS, face-to-face interviewing was the preferred method for this study; however, the option of a telephone interview was provided to all participants.

4.5.3 Confidentiality and anonymity

I assured participants of total confidentiality; with the exception of where information was disclosed suggesting the participant was a threat to themselves or others. All participants signed consent to this breach of confidentiality, but it was never required during this study.

Many participants wished to discuss negative experiences of health care, and I reiterated that even where a participant had been recruited through their GP, their GP (or any member of their wider health care team) would not be privy to any information discussed in the interview.

Possible anonymity risks were posed where gatekeepers, such as team leaders or MS Society group leaders, wished to be aware of those who had taken part in the study. Therefore, I informed gatekeepers in advance that neither participants nor information discussed in the interview could be shared with the gatekeeper at any point during or after the research had taken place. This was essential for all participants, including health care professionals, where the gatekeeper was commonly a team leader or a senior member of staff, or people with MS who were commonly recruited by MS Society group coordinators.

For both analysis and publication purposes I assigned all participants an identification number. Whilst this number could be combined with gender or MS type for clarification in the text, this number was never associated with factors that could make the participant identifiable (e.g. combining participant number with age, location etc.). I took measures to protect both soft and hard copies of participant information: signed consent forms and contact details were locked in a filing cabinet within a locked office. Electronic versions of identifiable information (including audio files of recorded interviews) were stored on an encrypted laptop. Transcripts were anonymised as soon
as possible, and transcripts transcribed by the University’s supplier were uploaded and downloaded through a secure delivery system. Where transcripts were analysed jointly within the supervisory team all data had been anonymised previously, and no participants were discussed that were potentially related professionally to members of the supervisory team.

The majority of participants signed their consent for direct anonymised quotations to be used. All participants signed consent for anonymised information to be stored by the University of Manchester for up to 10 years and for records to be accessed by the University of Manchester, from regulatory authorities or from the NHS Trust where required (in line with NHS research ethics requirements).

4.6 Eligibility and recruitment strategies

4.6.1 Recruitment strategies for people with MS

All study documents are in appendix I. Inclusion criteria for people with MS were a fluent level of English (due to the nature of qualitative interviews and the need for informed consent), a self-reported diagnosis of MS and currently residing within Greater Manchester, East Cheshire or North Staffordshire. In order to investigate differences in participants who utilised different types of healthcare or had disengaged with healthcare, I used a variety of recruitment strategies.

1. Recruitment from primary care

I contacted GPs via postal recruitment packs or direct e-mail and invited them to participate in the study (see section 4.6.2; appendices li & lii). GPs were also given a list of search criteria and a pre-prepared information pack and were asked to forward this information to people with MS registered at their practice (appendices liii & liv).

2. Community recruitment

I utilised a range of recruitment strategies to try and recruit the varied groups that lacked representation in the literature (presented in Box 2).
Box 2. Recruitment strategies

- Flyers and posters (see appendix Iv) in public places including in newsagents, GP waiting areas, supermarkets, libraries and physiotherapy centres.
- Adverts to charities and support groups for people with disabilities in the Greater Manchester area including: Breakthrough UK, Manchester Disabled Peoples’ Access Group, and Manchester Community Central (a voluntary agency).
- Advert on Manchester Beacon (a network for public engagement).
- Advert on the University intranet for students and staff (appendix Ivi), an advert sent to the University of Manchester Disability Support Office and posters around the University campus.
- Adverts on MS Society and MS Trust websites, as well as websites that focussed on MS research and forums for people with MS. I contacted carers groups in case a group member cared for someone with MS, and placed an advert on the carers.org Facebook page.
- Contacted specific support groups to request help with recruitment of groups not included in previous literature; shift.ms (a group for young people with MS) and Asian MS. The shift.ms group did not respond to repeated e-mail contact and no telephone number was obtainable. The Asian MS group posted an advert in their online newsletter but no responses were received.

3. I e-mailed every MS Society group in Greater Manchester with active contact details (appendix Ivii). Due to response from only one Manchester branch (Trafford) an ethical amendment was sought to contact MS Society groups in a wider geographical location (amendment approved 21st January 2013). Overall three MS Society branches supported the research; Trafford MS Society, East Cheshire MS Society and North Staffordshire MS Society. This was by far the most successful recruitment method and resulted in 11 participants. They were initially contacted directly by the information displayed on their branch website page. The branch leaders then informed group members about the study and provided my contact details for further information. This resulted in biases, whereby people who not considered to be coping well physically or psychologically were often not invited to participate.

All participants were asked to recommend potential participants and pass on information regarding the study, thus utilising snowball sampling. This was useful in recruiting male participants who were harder to reach.

4.6.2 Recruitment strategies for General Practitioners and Practice Nurses

Inclusion criteria for GPs and PNs were that they were working within Manchester, Stockport, Bury or Trafford PCTs.
I obtained a list of GP surgeries within Stockport, Trafford, and Manchester PCTs from PCT websites. A sample was selected purposively to represent a variety of practice sizes, training vs. non-training practices and rural vs. urban practices and I then contacted these practices directly. I sent an invitation letter and participant information sheet (appendix li & lii) addressed directly to both the practice manager and every named GP and PN on the practice website. The original large scale postal recruitment drive for GPs (packs sent to 265 GPs and 55 Practice Managers) provided three respondents despite rigorous follow up after two and four weeks where I attempted to contact both practice managers and individual GPs by telephone or by email to provide further details about the study. The primary reported reason for non-participation was a lack of time (as reported in previous MS research: Golla et al., 2012; While et al., 2009).

I contacted the Local Medical Committee and they placed an advert in their newsletter which was circulated to GPs in the Manchester area. However, no participants were recruited through this method.

An ethical amendment was then submitted to reimburse GPs at an amount of £50 per 30 minute interview (amendment approved 9th August 2013). To compensate for difficulties in recruitment, specific GPs known to the Centre for Primary Care at the University of Manchester were then targeted based on characteristics of interest. Using direct e-mail contact resulted in eight participants and snowballing from this led to another two participants who were not affiliated to the University.

GPs interviewed were asked if a PN at their practice would be interested in participating. An amendment was approved to reimburse PNs £30 per 30 minute interview (amendment approved 1st September 2013). The majority of PNs were recruited by direct postal or e-mail contact (154 recruitment packs sent; Appendices Ivii & lix) and two were recruited by snowballing, where participants informed their colleagues about the study and asked them to contact me. Many of the PNs had not previously participated in research. Although various key individuals in PN networks were contacted e.g. the Programme Leader for the non-medical prescribing diploma at Manchester Metropolitan University, and the chair of the Manchester Central Branch of the Royal College of Nursing, no responses were received.
4.6.3 Recruitment strategies for MS Specialist Nurses

SNs were eligible to participate if they worked with patients in the North West of England. Research and Development approval was sought for all Foundation Trusts in the North West and Sheffield (who covered areas within the North West). Contact details for Multiple Sclerosis SNs were available in the public domain online on the MS Society website and all nurses were recruited through direct e-mail or postal contact (Appendices iX & IXi). The chair of the SN North West group e-mailed study information to all SN in this area but no participants were recruited through this method. R and D governance managers also contacted nurses in their Foundation Trust to invite them to the study.

To obtain an overview of the coordination of MS care in the North West and involvement of voluntary agencies I interviewed a Service Development Officer of the MS Society (no further ethical or governance approval was required).

4.7 The interview process

Upon starting every interview I explained the purpose of the study using the information sheet (appendices lli, liv, lix, lixi) for reference. I clarified what participation involved and clarified what participants were providing consent for. I then provided the opportunity to ask any questions before obtaining written consent. All participants were given an information sheet in advance. For telephone interviews consent forms were posted in advance with a self-addressed envelope and received before the interview was completed. Where consent forms had been received prior to the interview, the consent form was reiterated to ensure that participants were still able and willing to give consent (appendix IXiii, IXiv, IXv, IXvii).

4.7.1 The interview process for people with MS

I interviewed people with MS in either their own home (n = 14), a private interview room in a University building (n = 4), a private area in a public place where our conversation could not be overheard (cafe, n =1) or in a quiet, private space at an MS Society branch meeting (n = 4), depending on their preference. One participant was interviewed via the telephone. All interviews were digitally recorded with consent. It was emphasised strongly that no information would be fed back directly to participants’ health care teams and any quotes used would not identify participants, even to health care professionals who knew them well.
I attempted to ensure rapport before the start of the interview. I started interviews with a general question asking about how the participant spent their time daily and weekly. This gave an idea of their priorities and the impact of any MS disability which allowed more relevant tailoring of questions regarding their service needs and preferences. As several participants were nervous of the formality of the interview consent process and had never been involved in research before, I used this period of questioning to help them settle into the interview process. Once this was established I began the interview using a semi-structured interview guide. Initially this guide (see appendix IXvii) covered:

- The experience of living with MS and the impact on daily life
- Experiences with health care services
- Psychological symptoms and coping methods

The topic guide was iterative and evolved to cover specific examples of health care consultations with GPs, PNs, SNs and Neurologists (see appendices IXvi & IXvii). It also included differences within relapse and remission care, examples of a good and bad clinical consultation, and the role, function and ease of access for the four staff groups. Finally, where time permitted, the guide contained questions on use of complementary and alternative medicines and the role of voluntary agencies. I concluded the interview by asking participants what they thought were the major strengths and weaknesses of their health care and (if not already covered) if they would like anything additional provided. Where information required for the demographic questionnaire had not arisen throughout the interview I completed this form with participants (see appendix IXviii).

4.7.2 The interview process with professionals

I interviewed GPs in their surgery (n = 2), office outside of surgery (n = 2), home (n = 2), university building (n = 1) or by telephone (n = 6). All interviews except one were digitally recorded; this was because the participant did not consent to audio recording. I emphasised that all responses were confidential. This was particularly important where more than one staff member from a PCT participated or where they had been introduced by a colleague. I began each interview with the broad question of “could you tell me about your practice/place of work and the type of patients you see?”
Further questions then covered: (see appendix IXiX):

- Experiences and perceptions of working with people with MS
- Any problems or challenges in caring for people with MS
- How people with MS present with psychological issues such as depression
- How services may be improved

The topic guide was iterative and evolved to cover training needs as this was raised frequently by participants.

All PNs except one were interviewed over the telephone, primarily on their lunch break. One PN interview was completed in person at the participant’s place of work. All interviews bar two were digitally recorded with consent. PNs were asked the same questions as GPs; however the final question allowed them to expand on any areas in which they would like to be more involved in the care of people with MS (see appendix IXX).

All SNs were interviewed in person at work, bar two who were interviewed via the telephone. All interviews were digitally recorded with consent.

They were asked the same questions as GPs and PNs; however given the saturation in the literature about the role of SNs the focus was moved as soon as possible on to the role of supporting patients with emotional distress and psychological needs as this was the gap that needed addressing (appendix IXXi).

All professionals completed a demographic questionnaire during the interview (see appendices IXXii-IXXiv).

4.8 Topic guide for people with MS

In order to guide the flow of conversation in interviews a topic guide was developed and used. The initial guide was developed by the research team to cover very broad areas of health care. A rigid framework based on prior literature was not used.

However, the literature review identified issues that could potentially be of relevance, and the combined experiences of the research team in working in health services research had sensitised us to relevant topics (Holloway, 2005). This topic guide was then checked by two people with MS. The first was recruited from the University of Manchester Centre for Primary Care Public and Patient Involvement group (PRIMER) and the second from a local branch of the MS Society. Both provided feedback on the wording used and order of the questions (as recommended in Berg, 2009); in particular the placing of more sensitive questions regarding periods of distress. They also
supported the use of rapport building questions at the beginning of the interview to assist those who were unfamiliar with research or the interview environment.

A continuous iterative process was used whereby alterations were made to the interview schedule after every five interviews. These modifications were made based on increasing knowledge (gained from initial interviews) as to which health care professionals were most influential in MS care in the North West, including those that were not known to the research team or highlighted in the original literature review.

Changes were also made to ensure more specific details on what constituted a good or effective health care experience. Hunter et al. (2013) investigated patient experiences of emergency care using the candidacy and recursivity theoretical framework utilised in this PhD research. As in their study I asked participants to reflect on a specific experience they had e.g. using a GP, what the circumstances were and why they made the decision that they made. This allowed exploration of people with MS’ knowledge, choices and perceptions, which is vital in addressing candidacy and recursivity. In version 5 of the interview schedule changes were made to further investigate the relevance of the theoretical model of candidacy to MS (section 4.10.1).

Anonymised memos were made immediately after every interview by either dictating a short sound file or writing immediately into a research diary; whichever was most practicable (as outlined in Box 3). Different types of memos were created (as outlined in Wilson, 1989). Observational notes recorded things seen or heard (e.g. amount of support equipment required) with no interpretation. Methodological notes recorded ways the interview could have been improved or done differently to assist both the development of the study and the development of my research skills. Theoretical notes described ways in which an interview may have related to the theoretical framework and highlighted this for later analysis. Personal notes recorded my personal reflections and experiences for later analysis.
Box 3. Examples of memos.

Observational note:
The participant lives in a very isolated and rural area. The area was very difficult for me to access in the bad weather due to the condition of the country lanes. The participant lives at the top of a very steep hill which would be impassable in severe weather and very isolating. The participant has a disabled parking space outside the house but otherwise there were no evident signs of disability supports or alterations.

Personal note:
The participant presents themselves as a strong character who is used to being busy and valuable. They present their identity as still being that of a busy professional and seem to be struggling to integrate the limitations caused by their disability. It appears that due to cognitive difficulties they find it difficult to maintain prolonged conversation and frequently lose the thread of questions and conversations. After the interview I recommended the participant contact their GP to discuss potential neuropsychological testing and available support. The participant reported being very lonely with limited social contact and asked many personal questions of me. I responded honestly but providing limited personal information. I think this need for connection related to the participants’ discussion of feeling lonely with limited social connections and family living far away. For this participant health care professionals were the sole source of social contact, potentially suggesting an increased role for emotional support?

Theoretical notes:
This older participant (similarly to others with an advanced stage of MS) described a different narrative to those of younger people with relapsing remitting MS. His narrative was less urgent and crisis filled and presented MS as a constant presence which rarely necessitated urgent care. Perhaps this may suggest that candidacy differs between different subtypes of MS and I should explore this in future interviews.

Methodological notes:
The participant was a health care professional. I asked the question from the topic guide regarding depression and the participant vehemently denied that they had ever experienced depression. Later on in the interview the participant reported the low mood they experienced when relapsing after the birth of their first child. When asked about this period they discussed wanting to crawl under a table and disappear. When I probed further they discussed “feeling low” and how they felt “really down”. I think this suggests that using the phrase “depression” even to professionals may not match their experiences of low mood. I will change this on v2 of the topic guide and use terminology that matches peoples’ experiences (and is possibly less stigmatising?) going forwards.
4.9 Analysis

Thematic analysis is defined as “a method for interpreting, analysing and reporting patterns (themes) within data” (Braun & Clarke, 2006, p. 79). It is a “foundational method” of all qualitative analysis (Braun & Clarke, 2006, p. 78) as “thematizing meaning” is the underpinning skill for all qualitative methods (Holloway & Todres, 2003, p. 347). It has previously been debated whether thematic analysis is a method or a tool (Boyatzis, 1998; Braun & Clarke, 2006) and for the purposes of this research it was used as a process (Ryan & Bernard, 2000) within the constant comparative method.

As identified by my systematic review, there was not enough information available to generate a hypothesis on people with MS’ perspectives on MS health care services. It was therefore important to use a method based on the principles of grounded theory (Glaser & Strauss, 1967), to investigate the themes that arose from the data without imposing a framework onto the data and forcing it to fit pre-defined categories. A strength of grounded theory is that it is inductive (McGhee, Marland, & Atkinson 2007). This was valuable for this exploratory research question as data were not restricted and all findings and interpretations were based on the empirical data set, not on previous research or the previous clinical or research experiences of the research team (Holloway, 2005). This study only used grounded theory as an approach, not a method, as the objective of this study was not to create new robust theories but simply to investigate participants’ experiences.

4.9.1 Constant comparison approach

The constant comparison approach was first outlined by Glaser and Strauss in 1967 and later expanded by Lincoln and Guba in 1985. This approach creates codes which are then compared both within and across participants (Lincoln & Guba, 1985). The aim of constantly comparing data is to conceptualise codes into a higher, more encompassing and therefore potentially more theoretical category (Bryant & Charmaz, 2007), but unlike grounded theory this stops short of creating a novel theory. This constant comparison allows the identification of categories and themes across an entire dataset. In addition, constant comparison analysis has been used across datasets incorporating different groups e.g. health care professionals and people with chronic conditions (Burroughs et al., 2006) suggesting it is therefore appropriate for the multi-group dataset used in this PhD research.
Green and Thorogood (2011) state that constant comparative analysis is the most commonly utilised method in qualitative health research. In addition, the constant comparative method has been demonstrated to have a well-structured and systematic procedure for ease of use and replicability (Boeije, 2002). This method has been previously utilised in similar research collecting data through semi-structured interviews with participants with MS (Boeije et al., 2002) and found to be effective at investigating participants’ experiences. The overall process of constant comparison analysis followed the systematic process outlined in Boeije 2002 (outlined in Table 11).
<table>
<thead>
<tr>
<th>Step</th>
<th>Description</th>
<th>Aim</th>
<th>Questions asked of data</th>
<th>Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>Step 1: Comparison within a single interview</td>
<td>Open coding to investigate how segments of the same interview relate to each other or differ, within the context of the narrative as a whole. This allows awareness of discrepancies and contradictory information within the same interview and provides an opportunity to explore the varying dimensions and properties of each code.</td>
<td>Develop an understanding of categories</td>
<td>What is the core message of the interview? How are different fragments related? Is the interview consistent? Are there contradictions? What do fragments of the same code have in common?</td>
<td>Interview summaries Provisional codes Memos</td>
</tr>
<tr>
<td>Step 2: Comparison between interviews within the same group who share experiences</td>
<td>This process began from the second interview of each group. Comparing sections of different interviews (as demonstrated in Table 12) allowed examination of the interpretation of codes, in turn allowing the creation of a coding framework (example for MS is</td>
<td>Conceptualise the subject and produce a coding framework</td>
<td>What do both interviews reveal about the category? What combinations of concepts occur and how is this interpreted? What are the similarities and differences between interviews?</td>
<td>Expansion of codes Description of concepts</td>
</tr>
</tbody>
</table>

Table 11. The overall process of constant comparison analysis followed the systematic process outlined in Boeije (2002).
presented in appendix J at end of document) and identification of patterns. Comparison of participants contributed to theoretical sampling and the more purposeful selection of further participants.

**Step 3:**
Comparison of interviews from different groups with different experiences

| Interviews from two different groups are compared with regards to a single concept (an example is provided in Table 12). This provided broader context and a broad variety of examples pertaining to that concept. | Complete the picture and enrich the information | What does group one say about themes and how does this differ from what group one has to say? What themes appear in group one but not group one? Why do they see things differently? | Triangulation of data Additional information |
4.9.2 Coding process

4.9.2.1 Coding

For this research a code was defined as a word or phrase characterising the crux of a segment of data relevant to the research question (Saldana, 2009); similarly to ‘concepts’ described by Strauss and Corbin (1990, p.61) as “conceptual labels placed on discrete happenings, events and phenomena”. Codes were derived from the data (a posteri) not imposed upon it a priori. The coding process was designed to analyse and begin to order the data (Strauss & Corbin, 1990), enabling discussion with the supervisory team pertaining to the meanings and assumptions attributed to data and their labels. Coding and memo writing started with the first interviews and field notes (Wiener, 2007). Essential information about participants e.g. demographics, was summarised at the top of their transcript, allowing easy reference and retaining context throughout the data analysis process by preventing unnecessary ‘fragmenting’ (Boeijie, 2002,p. 394). Transcripts were read multiple times whilst listening to an audio recording of the interview to ensure familiarity with the data. During this process initial codes were made through open coding which was primarily descriptive (including in vivo quotes). Open coding has been defined by Strauss and Corbin (1990, p.61) as “the process of breaking down, examining, comparing, conceptualizing and categorizing data”. When conceptualising data I attempted to answer the question posed by Strauss and Corbin (1990) “what is this and to what phenomena does it relate? (p.68)” This provided a descriptive overview of broadly similar sections of the data.

Data were coded on their original transcripts for as long as possible to prevent reducing the data down too soon. When it became essential to isolate data to allow comparison, data were transferred to excel spreadsheets to allow comparison between participants. My supervisors analysed these charts to ensure there were clear links between the codes and selected data.

4.9.2.2 Categorising

Selective (axial) coding then aimed to specify a phenomenon or category by defining the environment in which it occurred, surrounding context (‘intervening conditions’), how the phenomenon was managed and resultant consequences (Strauss & Corbin, 1990). In doing so coding became more focussed on the key research question (experiences of health care) (Urquhart, 2013), suggesting potential further sampling needs. Contemporaneous data collection and analysis were used, ensuring I was
constantly interacting with the data (Bryant & Charmaz, 2007), so theoretical sampling and the identification of deviant cases were possible and topics of interest could be incorporated into future interview schedules. The constant comparison of codes allowed the identification of recurrent categories and themes which addressed the research question. As described by Strauss and Corbin (1990, p.61) a category was defined as “classification of concepts. This classification of concepts is discovered when concepts are compared one against another and appear to pertain to a similar phenomenon. Thus the concepts are grouped together under a higher, more abstract concept called a category” (displayed in Tables 12 and 13). The names given to categories were those that appeared most relevant to the data and concise and coherent enough to communicate the essence of the data to the reader; some existed in the literature as the concepts associated with established terms communicated the content (and positioning) of the data best. However, care was taken within the supervisory team to ensure that the use of established terms did not prevent further inquiry and scrutiny of the data, or that alternative or contradictory meanings could be attributed to it (Strauss and Corbin, 1990). Although theory was not the desired end product of this analysis, all final categories had ‘proven theoretical relevance‘ as they were ‘repeatedly present or notably absent when comparing incident after incident’ (p. 177, Strauss & Corbin, 1990).

As described by Grove (2010), initially in coding the codes are placed by ‘intuition’ (albeit with constant input from the supervisory team to ensure clarity of interpretation). By the categorising stage of analysis codes are grouped by, and in turn contribute to, ‘provisional rules’ and ultimately the properties of categories become more explicit.
<table>
<thead>
<tr>
<th>Category</th>
<th>P1</th>
<th>P2</th>
<th>P3</th>
</tr>
</thead>
<tbody>
<tr>
<td>Navigation</td>
<td>The nurse has more time, the nurse can administer changes in pain relief and types of pain relief and the dosage that you take and just different things like that and she’s more accessible. I can phone her up directly and she’ll leave a message and she’ll get back to me.</td>
<td>If I wanted to I could get in the back door, if I wanted to, that sounds bad, I’ve got contacts that if I wanted, if a situation arose that I wasn’t getting seen I think I know the route to take.</td>
<td>It took me a long while to come to terms with what was happening. And it just seemed as though I was dropped into a black hole. I didn’t know, I really didn’t know where to turn to.</td>
</tr>
<tr>
<td>Timeliness and availability</td>
<td>I’m supposed to see my consultant every 6 months and that was pushed back so it become 12 month appointments and I said well touch wood I’m ok at the moment I can wait 12 months and then it was pushed back to 18 months and then my 2 year appointment would have been this month and it’s just been pushed back.</td>
<td>I suppose if I was, if I was having a relapse I’d just phone their rapid access and get in straight away.</td>
<td>By the time you get to the counsellor the heat has gone off it because its 12 months later, 18 months. Nothing is instantaneous. You don’t get the support and the help when you need it.</td>
</tr>
<tr>
<td>Staying in the loop/system</td>
<td>You kind of know your own body and I did a lot of research myself. I felt disappointed in the system and it kind of put me off wanting to go back for anything else.</td>
<td>I kept saying “what is the point of you seeing me every year, what a waste of an appointment”, “what’s the point of me coming?” So I got out of the loop and its quite difficult to get back in. So they said to me</td>
<td>I thought I’m turning my back on conventional services because it’s just not working. So I’ve got to look at more alternative, I can’t just sit back and just not do anything, I have to do something to try and improve things. And so I sort of</td>
</tr>
</tbody>
</table>
“just come every year, just so if you need us”, because they have like a rapid access clinic,” if you need us you can just access us”. But I just go once a year and that’s it. bucked the system for a while. And of course it came back and bit me on the bottom didn’t it because then I had the relapse.

Overall these categories appeared to be discussing different facets of accessing services e.g. having the knowledge and contacts to know how to access support, the timeliness and availability of accessing various services, and the conscious decision to stay in the system (therefore accessing services) or to disengage with services. The overall theme was therefore labelled ‘access’ (as displayed in the thematic map in Figure 5).
<table>
<thead>
<tr>
<th>Category</th>
<th>GP1</th>
<th>PN1</th>
<th>SN1</th>
</tr>
</thead>
<tbody>
<tr>
<td>Time</td>
<td>I think it’s really helpful, for example, sometimes if you spend half an hour talking to neurologist, looking up a few things, having a think about the patient, you could come up with a management plan, but if you haven’t got that time you’ll think, well I’d better refer them because I haven’t got the time really to sort that out.</td>
<td>But it’s difficult because of the time frames we have to appointments. That can only take a number of minutes, and then you can crack on with what they’re there for but sometimes unless you do that bit at the front, you’re not going to get a satisfactory outcome at the back of the consultation.</td>
<td>We do a lot of symptom management, but very briefly, because they’ve only got a half an hour slot.</td>
</tr>
<tr>
<td>Holism</td>
<td>Investment in primary care is always seen in secondary care terms; in terms of disease models, and I don’t think that works. We need a patient centred way of looking at it, saying these kinds of patients need more resources for multiple issues overall and that that would then permit us to have longer consultation times and that kind of thing.</td>
<td>For a practice nurse, with MS patients, that wouldn’t be us that would be the doctor. Because we’re only going to see them for vaccinations and smears really. If they have any other disease conditions like asthma or heart disease then we’re going to see them for that so we’re going to get to know them from that perspective.</td>
<td>So I think that’s where we may be a bit different, I think, from a doctor to a nurse. It’s nurses, we tend to know about the kids, the family, their life, their work, because we’ll ask that way.</td>
</tr>
<tr>
<td>Professional-patient relationship</td>
<td>We get on okay and we have a sort of reasonable understanding and I’m fairly flexible. I think</td>
<td>We, I mean I’ve been with this part of this practice since [] so some of the patients have nurses who have known</td>
<td>So we see people from diagnosis to – when they stop seeing us – I suppose their death – so we look after...once they</td>
</tr>
</tbody>
</table>

Table 13. An example constant comparison table of inter-professional categories of ‘patient-centred care’
with chronic illnesses where there’s no clear cut management plan... you can’t sort of say, well at this stage you ought to be having that, because people might stay at that stage forever, you know. So I think all those things, I much prefer to kind of meet people half way and try and negotiate with them about what they think works.

them for many years so we can see if there are changes going on. And if we feel like something is not quite right we’ll say hang on a minute, let’s stop the interview and pull back from this and see what’s going on with you, you know.

are diagnosed we’re, sort of, their point of call.

The categories discussed across professional groups appeared to correspond to the concept of ‘patient-centred care’ and therefore this was used as the overall theme (as demonstrated in Figure 5).
To understand the links and connections between different categories thematic maps were used. These showed where codes could be clustered into similar categories, enabling reflection and discussion of potential overlying themes. By the end of data processing and data analysis all important ‘incidents’ identified within datasets had been categorised, categories were saturated and a ‘sense of integration’ had been achieved (Grove, 2010, p.276).

4.10 Theoretical framework- the concepts of candidacy and recursivity

After initial analysis of the data from the first ten interviews conducted with people with MS, and discussion within the supervisory team, I suggested that two theoretical concepts from the literature on access to healthcare, entitled candidacy and recursivity (previously applied to access to services for people from under-served groups: Dixon-Woods et al. 2006; Rogers, Hassell & Nicolaas, 1999) could provide an interpretive framework for my findings.

4.10.1 Candidacy

Health services research commonly views entry into formal health care services as the primary point of health care access (Kovandžić et al., 2011). However, what an individual believes about their LTC and its potential management may have an impact on whether they use formal health care services, and if so, at which time points they utilise services and which ones they chose (Horne & Weinman, 2002; Lowe et al., 2011). For example, illness beliefs or representations of people with MS suggest that they may view MS as a condition with no cause or cure over which they have little or no control (Vaughan, Morrison & Miller, 2003). Potentially this could impact on service use where people with MS feel that accessing services is futile due to a lack of care, or alternatively result in high service use where it is felt self-management is not possible due to low perceived control of MS. Research investigating illness beliefs and representations in MS has primarily focussed on their association with psychosocial needs and adjustment (Jopson & Moss-Morris, 2003; Vaughan, Morrison & Miller, 2003) without necessarily explaining how this translated into presentation at services or additional barriers to care. What was therefore needed for this study was a framework that could incorporate both the personal beliefs about a condition and services and the facilitators or barriers to care (Kovandžić et al., 2011). Candidacy has been identified as a framework which may help explain why patients engage with
health care services by holistically incorporating both these research foci (Kovandžić et al., 2011).

Dixon-Woods et al. (2006) conducted a critical interpretative synthesis of available literature on access to health care. From this synthesis they developed the concept of candidacy: the method by which people’s eligibility for health care services is a collaborative process dependent on both patient and health care professional factors and beliefs. Candidacy incorporates seven sections as outlined in Figure 4. Between them these seven sections follow an individual’s experience through help seeking, symptom management and formal care pathways.
Figure 4. The concept of candidacy (Dixon-Woods et al., 2006).

<table>
<thead>
<tr>
<th>1/Identification of candidacy:</th>
<th>2/Navigation:</th>
<th>3/Permeability of services:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Service users must identify themselves as a suitable candidate for care</td>
<td>Service users must be aware of the services available to them and have the necessary resources to access them</td>
<td>Services that are easier to utilise e.g. through direct access are preferable to those which require referrals</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>4/Appearances at health care:</th>
<th>5/Adjudications:</th>
<th>6/ Offers and resistance:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Service users have to assert their need for health care (sometimes repeatedly) in order to receive appropriate services</td>
<td>How health care professionals perceive symptoms influences how they respond</td>
<td>Service users chose to accept or reject medical offers based on their experiences and perceptions of treatments</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>7/ Operating conditions:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Experiences of health care commonly depend on local influences such as resources and local finance arrangements</td>
</tr>
</tbody>
</table>
Koehn has argued that the candidacy model "accounts most fully and systematically for the phenomenon of access and the way in which vulnerabilities arise in relation to it" (2009, p.3). This makes it a suitable model to investigate access to health care services for people with MS. In my systematic review and my qualitative study of perspectives of people with MS, access emerged early on as a key theme. In addition, candidacy has been used as a theoretical framework in studies of groups whose low prevalence has been viewed as "too few to constitute a problem" (Koehn, 2009, p.586), such as ethnic minority seniors in Canada (Koehn, 2009). It has also been applied to groups of individuals who are considered hard to reach, i.e. experience inequities accessing care and unresponsive services when they do access care (Dowrick et al., 2009). This suggests that this framework may be relevant to a rare condition such as MS where individuals may experience barriers to care (as discussed in chapter 2). In a study of 36 adults with type 2 diabetes Ockleford et al. (2008) found that how participants perceived their ‘diabetic’ identity was related to whether they viewed themselves as candidates for a group education intervention. Their findings suggest that people who did not experience symptoms attributable to diabetes did not see themselves as ill, and therefore did not perceive a need to learn about lifestyle changes or medical management of their condition. This highlights the value of investigating patients’ perceptions where they may prevent help seeking or service use inappropriately.

Candidacy has been utilised as the theoretical framework for research investigating both physical (Ockleford et al., 2008) and psychological symptoms (Garrett et al., 2012; Kovandžić et al., 2012) suggesting that it is appropriate for research taking a holistic approach to wellbeing.

The full concept of candidacy is not always presented in the literature; often a more simplistic version is used where the phrase “candidacy” is used to describe the patient’s identification of themselves as a candidate for a particular care service, with no reference to the involvement of the health care professional (e.g. Ockleford et al., 2008). Not including the health care professional’s perspective may potentially limit knowledge on the latter aspects of the candidacy concept which focus on the health care professionals’ role in facilitating or preventing access, thus limiting the applicability of findings.

Koehn (2009) investigated candidacy through focus groups with 56 seniors from ethnic minority communities and four focus groups with 26 multi-disciplinary community
health care workers. Her findings show that this framework has the potential to explain both patient and professional findings in an integrated manner.

As described previously the epistemological stance taken by this PhD research included phenomenological, interactionist and social constructionist approaches, accounting for a subjective interpretation of a co-constructed phenomenon. The framework of candidacy matched this epistemology by "recognising both the validity of all knowledge and its co-construction and the operation of symbolic power in relationships" (Koehn, 2009, p.3) thus incorporating the roles of both professionals and people with MS.

4.10.2 Recursivity

There is a need for everyday activities of self-management and professional management of long term conditions to be "potentially mutually reinforcing" or "recursive" (Rogers et al., 2005), and not viewed as separate issues. The concept of recursive health care informed the Whole Systems Approach developed by Kennedy and Rogers (2001), which focused on the roles of the patient, professional and health care systems structure in supporting self-management. This mirrors the focus of candidacy on the patient (identification), professional (adjudication) and service level provision (local operating conditions).

I chose the models of candidacy and recursivity due to their relevance to the data collected and similarities with the issues discussed within the first ten interviews with people with MS. Access emerged early as a theme within my interviews with people with MS. An example of this data is provided in Box 4.

**Box 4. Example data relating to access in early interviews**

"When I had the next relapse after that I was out of the system, because I kept saying "what is the point of you seeing me every year, what a waste of an appointment". So I got out of the loop and it's quite difficult to get back in. So they said to me “just come [for a follow up] every year, just so if you need us you can just access us”, because they have a rapid access clinic, so that’s what I do now." P2, female, R-R MS

"The GP said “well I’m going to refer you to [Neurology hospital]. But unfortunately by the time I went there, I’d recovered and I was doing quite well and I was back on track again. But the thing is that it’s like everything you need to see somebody when you need to see somebody. And that’s the tricky part, because in the beginning you don’t know where to go or who is who.” P3, female, R-R MS
It became clear from interviews early on that people with MS experiencing similar symptoms made very different decisions regarding the need for health care intervention and the choice of available services. Due to this I wanted to investigate why these decisions were made and how they influenced experiences of care. To do so it was necessary to move past models of access to health care (such as that outlined by Levesque, Harris & Russell, 2013) to a theoretical framework capable of exploring perspectives and beliefs that may incorporate cultural and social factors. Past experiences (as demonstrated by P2 in Box 4) showed the importance of recursivity in health care seeking and utilisation decisions, which was not incorporated within the candidacy framework. Therefore, I combined these two theoretical frameworks to produce the most appropriate theoretical framework for my research. I conducted the remaining patient interviews using a version of the semi-structured interview schedule that investigated these issues in further detail. All seven aspects of the candidacy model were investigated in interviews with people with MS. I conducted all health care professional interviews and analysis with an awareness that candidacy and recursivity would be used to interrogate the data.

**4.11 Quality and rigour in qualitative methods**

In the same way that qualitative methods do not fit well with a positivist approach, the standards on validity, replicability and reliability that apply to quantitative research have long been deemed inappropriate for qualitative studies (Cicourel, 1964). In particular given the epistemological approach of this PhD research, concepts such as objectivity and reliability cannot account for a unique and subjective experience of reality, and a focus on replication and generalisability would omit crucial contextual factors. Alternative components of high quality qualitative research were suggested by Lincoln and Guba (1985), namely credibility, transferability, dependability and confirmability, and these have been widely accepted by the qualitative research field (presented in Table 14). Additional criteria have been identified including the ethical nature of the research and the importance of the research (Cohen & Crabtree, 2008) and these are addressed in the method (chapter 4) and discussion (chapter 7) sections of this thesis.
### Table 14. Quality criteria for qualitative research.

<table>
<thead>
<tr>
<th>Criteria</th>
<th>Evidence from this research</th>
</tr>
</thead>
</table>
| Credibility is a reader’s confidence in findings and the degree to which they make sense (Lincoln & Guba, 1985). It is comparable to the concept of internal validity (Silverman, 2013). Credibility may be judged based on clarity regarding how the researcher has interpreted observations and how this work relates to previous research (Peräkylä, 2011). | • To avoid the “problem of anecdotalism” (Silverman, 2013, p. 286) or “cherry-picking data” (and the implicated ethical and procedural problems caused; Morse, 2010) I aimed to show the representativeness of the dataset as much as possible by providing the maximum amount of evidence possible (in the form of anonymous quotations in chapters 5 & 6) and providing explanations and context around quotations. The maximum amount of context as was provided within the limited journal and thesis word restrictions.  
• Providing evidence in the form of quotations and interpretations as prose provides the reader with the opportunity to see whether they would interpret data in the same way, and whether judgments appeared justified.  
• By using multiple datasets (people with MS and three professional groups) it was possible to compare different perspectives of experiences and triangulate findings (Silverman, 2013).  
• The constant comparative analytical method used ensured that data were compared from as many angles as possible, both within and across datasets.  
• As is described in approaches using elements of grounded theory, disconfirming evidence and deviant cases were presented to try and show the variance in experiences as much as possible and suitably highlight the boundaries of analytical categories and themes.  
• To ensure good practice my supervisors and I coded transcripts independently prior to monthly critical discussions to achieve consensus of interpretation and to prevent bias and ensure interpretations were grounded in the data. By analysing data as a team the credibility of data was increased as the process broadened the perspectives the data was viewed from and ensured all possible explanations were |
investigated.

- The supervisory team comprised varied backgrounds, including general practice and health services research, ensuring varied theoretical perspectives and interpretations. Discussion ensured debate to maximise comparisons of the data and ensure that viewpoints were sustainable and confirmed by evidence in the text (Olesen et al., 1994). Any ambiguous or controversial data were re-analysed as a group until a consensus was reached.

- My service user consultant commented on findings and provided an additional angle for interpretation and triangulation by providing suggestions from the perspective of someone living with the condition who was also familiar with the requirements of research.

- These data were compared to other studies presented in the literature/systematic review and discussion sections to view how these findings compared to the wider literature on health care experiences for chronic conditions.

Transferability corresponds to the quantitative concept of external validity or generalisability. In qualitative research it is judged by whether a thick description is provided (Holloway, 1997) thus presenting enough information to assess the applicability of findings to other settings or populations. Transferability has been identified as a major issue in previous qualitative studies of MS (Methley et al., 2014) where lack of demographic and contextual information prevents assessment of the transferability of findings.

- The limits of this sample were clearly explained to prevent unsubstantiated transferability. Participation was limited to individuals residing or working in the North West and local operating practices (that may prevent transferability) are discussed in the results and discussion section.

- Detailed demographic information and context was provided for all participants thus the reader may decide for themselves whether these findings apply to a chosen group.

- Similarly, detailed information was provided on methods used such as the data collection methods and the time period of data collection, so that readers may judge the relevance of these methods to a chosen group (as recommended in Shenton, 2004).
Dependability corresponds to the quantitative term of reliability. Due to the subjective experiences of reality utilised in the epistemological approach of this research, there is no sense in testing reliability as no two individuals have the same experiences, and one individual may not have the same experience twice. Therefore it is more important to see if the researcher can account for the quality of the research conduct and documentation.

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>• There was no selection or cherry picking of data (Morse, 2010) and the whole dataset was utilised and represented (within the restrictions of word limits).</td>
<td></td>
</tr>
<tr>
<td>• To ensure transparency the method and analysis were clearly documented.</td>
<td></td>
</tr>
<tr>
<td>• All contact with participants was carefully documented and stored.</td>
<td></td>
</tr>
<tr>
<td>• Decisions were justified based on the literature or prior research, documented and presented in this thesis.</td>
<td></td>
</tr>
</tbody>
</table>

Confirmability corresponds to the quantitative term of objectivity. In qualitative research this is concerned with identifying and addressing the researcher’s perspective, and any influence this may have on the data, and ensuring that findings have not been biased towards a particular viewpoint.

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>• To limit bias through leading questions transcripts were regularly reviewed with the supervisory team to check questioning style for bias or lack of clarity and identify ways to improve it.</td>
<td></td>
</tr>
<tr>
<td>• Purposive sampling of a varied participant sample attempted to ensure that negative cases were investigated where possible.</td>
<td></td>
</tr>
<tr>
<td>• Reflexivity was a major issue for this study and as such is reported in detail in the discussion section</td>
<td></td>
</tr>
</tbody>
</table>
4.12 Service user involvement/PPI

Including service users from the beginning ensures that the outcomes of research will be meaningful and relevant to those living with the condition and using those services (Chalmers, 1995).

Patient and Public Involvement (PPI) in both clinical practice and research is currently advocated by the NHS (DH, 2005c) as shown in the report “creating a user-led NHS”. It is suggested that including people in research regarding the services they use improves the relevance of research and increases the likelihood of successful implementation of research findings into clinical practice (Hanley et al., 2004). In addition, including service users from the beginning ensures that the outcomes of research will be meaningful and relevant to those living with the condition and using those services (Chalmers, 1995).

PPI involvement was sought from both the MS Society and the University of Manchester Centre for Primary Care patient and public involvement group (PRIMER). Feedback from the MS Society and a member of PRIMER with MS was incorporated into the study protocol. Alterations to the protocol included the addition of telephone interviews as a mode of data collection to prevent fatigue and the incorporation of routine yet sensitive questions investigating participants’ current symptoms (e.g. fatigue or incontinence) to ensure the interviews were not detrimental to their wellbeing, as it was acknowledged that many participants would not disclose this unprompted. This PRIMER member agreed to take on the role of an informal service-user consultant to the study, acting as a key stakeholder and ensuring constant PPI input throughout the entire study. This is in line with the consultation style of involvement described by INVOLVE, the national advisory group funded by the Department of Health (Hanley et al., 2004). This is a collaborative approach whereby the service user plays a more active role and a more equal partnership was suggested to prevent a “tokenistic” approach (Beresford, 2003). However for the service user in question this was not preferable in relation to her availability, variable good health and time commitment to become more involved in the research management. As such she has participated as a consultant (Fox et al., 2007). Her primary contributions have been in providing feedback on the concept of the study, practical advice on information and consent sheets, suggestions for recruitment techniques and locations, providing feedback on findings and contributing suggestions for dissemination.
Service-user controlled or led research was not appropriate for this research study, given the nature of the PhD as an independent training course.

**4.13 Chapter summary**

In summary, an in-depth qualitative research method was used to explore participants’ experiences with iterative flexibility. An interactionism epistemological approach was used, including elements of phenomenology and social constructionism, to understand participants’ subjective co-constructed experiences of health care services and the meaning of a good health care consultation.

Using semi-structured interviews combined with iterative constant-comparative analysis allowed the development of themes explaining both people with MS and health care professionals’ experiences of help-seeking, service navigation and service use and provision, in adherence with standards of high quality qualitative data collection.

Using the theoretical frameworks of candidacy and recursivity allowed me to explore both people with MS and professionals’ experiences and perceptions of health care services. In the next chapter I present the findings of my qualitative investigation of the health care experiences of people with MS, framed through the theoretical framework of candidacy and recursivity.
Chapter 5: Results- The health care experiences of people with Multiple Sclerosis

5.1 Introduction

In this chapter I explore the perceptions and reported experiences of 24 people with MS. The themes presented are the participants’ experiences of MS, through the emergent themes of access to care, continuity of care, interactions with health care professionals, and self-management. These themes were developed through thematic analysis of the data. Following the initial analysis, these themes were mapped onto the theoretical framework of candidacy to investigate how the experiences of people with MS fitted with this framework. Chapter 6 presents the findings on health care professionals’ experiences. The chapter begins by describing the characteristics of the patient sample and demographic and recruitment factors.

5.1.1 Sample characteristics

5.1.1.1 People with MS

In total I conducted 24 interviews with people with MS. In one interview the participant with MS was a full time carer for their spouse who also had MS but who was unable to participate in an interview due to an advanced level of MS disability. As their health care experiences were joint and symbiotic, I have provided the spouse’s anonymised demographic and clinical information as context to their experiences. The average duration of the interviews was 63.34 minutes (range of 22.45 minutes to 2 hours 30 minutes) and data were collected between October 2012 and September 2013.

Demographic characteristics of the sample are presented in Table 15. Participants were purposively recruited using a combination of community (n = 23) and primary care (n =1) recruitment methods (see chapter 4).
Table 15. Demographic characteristics of people with MS.

<table>
<thead>
<tr>
<th>Gender</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>5</td>
</tr>
<tr>
<td>Female</td>
<td>20</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Age</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>18-30</td>
<td>0</td>
</tr>
<tr>
<td>31-40</td>
<td>4</td>
</tr>
<tr>
<td>41-50</td>
<td>3</td>
</tr>
<tr>
<td>51-60</td>
<td>8</td>
</tr>
<tr>
<td>61-70</td>
<td>8</td>
</tr>
<tr>
<td>71-80</td>
<td>2</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Employment</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Full time</td>
<td>9</td>
</tr>
<tr>
<td>Part time</td>
<td>2</td>
</tr>
<tr>
<td>Long-term sick</td>
<td>3</td>
</tr>
<tr>
<td>due to MS</td>
<td></td>
</tr>
<tr>
<td>Retired (not</td>
<td>11</td>
</tr>
<tr>
<td>due to MS)</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Marital status</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Single</td>
<td>3</td>
</tr>
<tr>
<td>Married/cohabiting</td>
<td>16</td>
</tr>
<tr>
<td>Separated/divorced/widowed</td>
<td>6</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Ethnicity</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>White British</td>
<td>24</td>
</tr>
<tr>
<td>Iranian</td>
<td>1</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Highest qualification</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>No qualifications</td>
<td>3</td>
</tr>
<tr>
<td>1 to 4 ‘O’ levels</td>
<td>5</td>
</tr>
<tr>
<td>A levels</td>
<td>3</td>
</tr>
<tr>
<td>NVQ</td>
<td>4</td>
</tr>
<tr>
<td>Professional qualifications</td>
<td>3</td>
</tr>
<tr>
<td>First degree</td>
<td>5</td>
</tr>
<tr>
<td>Higher degree</td>
<td>2</td>
</tr>
</tbody>
</table>

5.1.1.2 Demographic commentary

Demographic and clinical characteristics were collected for all participants (and as anonymised contextual information for the spouse of one participant) and are presented when they set the context for the data and interpretation.

Five men and nineteen women with MS participated in this study. This reflects the higher prevalence of MS in women (approximately 2.5 to 1; as discussed in chapter 2)
and may be associated with the higher proportion of women attending support groups for MS (Finlayson & Cho, 2011; Peters et al., 2003). Clinical characteristics of the sample are provided in Table 16. There was a large variety in the length of time since diagnosis, ranging from 1 year to 35 years. It should be noted that many participants reported a delay in receiving a diagnosis, so the length of time since diagnosis is not an accurate proxy of the length of time experiencing MS symptoms or utilising services. All participants lived independently although one participant reported requiring 24 hour support for themselves and their spouse with MS by a team of paid carers. Some participants reported using family members for support such as purchasing food or driving them to appointments (although it was not made clear where participants viewed this support as that of informal carers, compared to an expected reciprocal family relationship. Others paid domiciliary care workers (n = 4), although for two participants this was only at periods of relapse. This sample was varied with regards to the subtype of MS. The majority of the sample had Relapsing-Remitting (R-R) MS (n = 12), seven had Secondary Progressive (SP) MS, two had primary progressive MS (PP), two had benign MS and one person reported a diagnosis of Rapidly Evolving MS (REMS). All participants were asked upon booking an interview if they had a diagnosis of Multiple Sclerosis from a neurologist and all confirmed this. All confirmed this again at interview bar one participant who said she had not received a formal diagnosis but was certain that she had MS due to a family history of the condition and was seen regularly by the Specialist MS team. Her interview is included as it provided a useful perspective of the access and service provision issues experienced without a formal diagnosis of MS.
**Table 16. Clinical characteristics of people with MS.**

<table>
<thead>
<tr>
<th>Time since diagnosis</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>0-5 years</td>
<td>3</td>
</tr>
<tr>
<td>6-10 years</td>
<td>6</td>
</tr>
<tr>
<td>11-20 years</td>
<td>4</td>
</tr>
<tr>
<td>21-30 years</td>
<td>5</td>
</tr>
<tr>
<td>31 years +</td>
<td>3</td>
</tr>
<tr>
<td>Not provided</td>
<td>4</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Disability</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Fully ambulant</td>
<td>11</td>
</tr>
<tr>
<td>Mobile with crutches/walker</td>
<td>9</td>
</tr>
<tr>
<td>Wheelchair user</td>
<td>4</td>
</tr>
<tr>
<td>Very limited movement</td>
<td>1</td>
</tr>
</tbody>
</table>

5.1.1.3 Recruitment commentary

Only one GP Practice reported assisting with the mail out request and only one participant reported being recruited through their GP practice. This means that primarily this sample volunteered to participate after becoming aware of the study through community advertising or their MS society branch, and therefore may have had different experiences to those who chose not to participate. For example, Peters et al. (2003) found that people with MS were more likely to have attended a support group meeting if they had been in contact with a health professional within the last 12 months, potentially suggesting differences in service use. Of those recruited through community sampling in my research, 20 were recruited through MS charitable organisations including the MS Society, the MS Trust and the Multiple Sclerosis Research Centre.

Many participants were related to health care services through their previous or past employment including areas such as nursing, health care support work, cosmetic surgery, anaesthetics, medical receptionist and basic scientist, and therefore may have been more knowledgeable of services than lay people who had no relation to health care services. This is expanded in the section on limitations of my study, in my discussion chapter (chapter 7).
Figure 5. A thematic map showing the themes and categories of people with MS’ experiences of health care
The five themes displayed in Figure 5 will now be discussed and where they relate to the candidacy model this will be highlighted. Two examples of how the candidacy framework can be applied to case narratives are provided in Figures 6 and 7.
Identification of candidacy
“I’d just ring the doctor up and tell him, that’s all they do isn’t it, there’s no other way. I mean my hands at the moment are really stiffening up. The reason I finished work as I said was I couldn’t hold a pen to write, these are really stiffening up now and I’m just wondering whether to do it…I need my hands to do [wife]’s pegs, I’ll give it another week and ring him up.”

Navigation
“I don’t even think we’ve had an MS nurse. I know the names of them I think, only because of the internet you see.”
“I needed a speech therapist, so, I got on the internet and there are millions of them, I narrowed it down to Cheshire and there’s about 20. I went through all the bio’s and I thought, this one looks good, so I rang this lady up, a speech therapist, just to get information about options.”

Appearances at health care
“[Neurologist] comes in and presents himself and sits down in the same chair opposite you and he says, “I don’t know who you are or why you’ve come”. So, I said, fine, so I took my brakes off my wheelchair, started back out, I said, we’ll go then. I said, thanks very much and we went, never went back since. That was a few years ago.”
“If you’re in the loop, providing you keep seeing these neurologists, then if anything comes up you’re in the loop, if you’re not in the loop then that’s… We aren’t in the loop, we’re okay, they’ve got nothing for progressing MS, there’s nothing at all. So, we’re just quite happy, somebody will knock on our door one of these days and say, if you take that you’ll be cured, and I’ll go, alright we’ll take it. But, until then we just carry on on our own you see, because we’re coping I think, we can do nothing else.”

Adjudications
“I went to this six month report and I said to him, can I have some physiotherapy. So, he said, no physiotherapy is for the muscles, yours is a disease of the nerves so it will do you no good whatsoever. I said, fine. He said, and thank your lucky stars you’re not like these blokes outside there in wheelchairs. So, I said, fine thank you and went to the [Central hospital], went to see Dr [] he said, “right if you have a relapse if we give you some steroids intravenously and physiotherapy, we’ve found we get the best results we can with what we’ve got available.” I says, I’ll do that, and I thought they’re six miles apart, totally different treatment of MS. What are you supposed to learn?”

Permeability of services
“The physio said “[wife] will need exercises from now on.” I said, “fine, can you give me a list of exercises?” “No, because you’ve not got a [local] address.” We are the [NHS hospital] Rehabilitation Team and we only treat people in [local area], I can’t give you a list of exercises.”

Offers and resistance
“When I was going through that patch at the beginning, if it got really bad I just went to the doctors and they just put me onto hospital steroids straight away, which were great. Although, decades later you’re paying the price because I have osteoporosis in my hip and my back now which they say relates to these steroids that I took, but it kept me working, it got me a pension, you know, it’s just a small price to pay in the end, you know.”

Operating conditions
“The problem with all care companies, they’re time bound. Care companies say right next on the list, you’re a commodity rather than somebody we like and love and care for, that’s the difference I think. And, I don’t think you can buy that can you.”
Figure 7. The pathway of participant 1: Relapsing-remitting MS

Identification of candidacy
“Initially I went to A & E for the pain and was sent home. And then two days later I passed out from the pain at home and my partner took me to A & E and I was in hospital for 3 weeks for scans.”

“With one relapse I knew I’d hurt myself quite a lot because I kept falling over but it was the same leg that kept going and I thought I’d fractured it because I couldn’t walk on it and I went to hospital and the pumped me full of steroids.”

“I live in my body, I know the little changes, I know what is significant and what isn’t. And I need medical professionals to respect that.”

Navigation
“I was passed from pillar to post, from different hospitals to different consultants to different levels of consultant.”

“I make sure I always do my research and have an idea of what’s going on and what and where my options are, before I talk to anyone.”

Permeability of services
“I’m supposed to see my consultant every 6 months and that was pushed back so it became 12 month appointments and then it was pushed back to 18 months and then my 2 year appointment would have been this month and it’s been pushed back again.”

“I went to the GP and asked for a neurolinguistic practitioner but it’s not a service they offer or one they recommend so I ended up having to go and do it privately. Most of the things I’ve done privately would benefit many people if they were offered on the NHS.”

Offers and resistance
“The second set of medication changed all my hormones in my body so overnight I gained 3 stone, acne, facial hair, just things I’ve never experienced before. And it took me a year to try and convince my GP that these were side effects and they were adamant that they weren’t so I came off them myself and asked to be put on something else.”

“I’d rather take symptomatic pain relief, I’ve got a high tolerance of pain and I can manage that. Because the first relapse we didn’t know I’d had it. And I’d rather know”

Appearances at health care
“I would only go to the GP if I felt that there was something majorly wrong or a big difference”

“I keep support from health care professionals to a minimum. I try and self-manage as much as I can because I don’t want to go to say “oh my little toe’s hurting today” and then two weeks later “oh my big toe is hurting today”. It’s pointless and it’s not hindering me too much on a day to day basis then I’ll just get on with it and update the nurse next time”

Adjudications
“With each investigation the technology develops and they still weren’t finding anything and I had endoscopy, cameras everywhere, tubes everywhere and it was one of the student nurses who said “what about an MRI?” and the consultant was all “oh no it’s gall stones” kind of “you’re a number and I know what it is and I’ve got the most experience” kind of attitude. So it was obvious that other people had picked up on what it could be or ways of finding it, I was just under the wrong consultant at the time I think”.

“I never got Physiotherapy because they didn’t offer it when it started in my upper body and when it got to my lower body they said “just manage it”.”

Operating conditions
“I think with everything budget cuts are involved. Credit crunch, crisis, whatever you call it.”

120
5.2 Experience of MS

5.2.1 Impact of symptoms

Participants reported a variety of typical symptoms including vision loss, mobility impairment, fatigue, pain, and numbness due to their MS. No participants were interviewed whilst they were experiencing a relapse due to ethical concerns. Due to the purposive sampling method used, participants varied in their severity, from those who experienced severely limiting disability to participants who were not aware of symptoms at all.

“As the years have gone on and I've not gone that bad, it doesn’t bother me anymore, so I do forget I have MS sometimes.” P16, female, benign

For the minority of participants, as demonstrated above, MS could be perceived as having a minor impact on their life. The other end of the severity spectrum (as demonstrated below) were people with MS who required full time care, including the support of paid carers, for activities of everyday living and personal care.

“By that time [wife] had got pretty bad, she'd become incontinent and things like that, so they put in care in from [local] Social Services, so we had carers in morning, dinner time, teatime and evening.” P13, male, PP

Identification of candidacy for care was most clearly defined by people with severe, visible symptoms such as mobility impairments, as these symptoms and the support needed for them could not be easily contested. Although most participants reported that their disability was limiting to their autonomy, some participants reported objectively severe disability which they perceived as having a minimal impact on their lives, where they were fully able to utilise support from others to maximise and retain independence.

“I do very well. I have to have carers to put me in bed and then to bring me out of bed. Once I'm in this chair I'm totally self-sufficient. I don't have as much pain as a lot of them.” P22, female, SP

This highlighted the importance of subjective viewpoints, as two objectively similar situations e.g. self-sufficiency and the use of paid carers, could be perceived very differently. Social comparisons were also used to explain why a participant was better or worse off than others they knew with MS or a different chronic condition, and this could lead to either a positive or negative view of self.
“*I compare myself a lot to other people and other people’s lives and you know mine’s ok, I can still work and be a mum and do what I need to do. And to have it at this stage in my life [older age], I feel there’s lots of other people in similar health situations. So, actually I don’t think I’m so bad.*” P2, female, R-R

Participants could experience symptoms that were highly indicative of MS e.g. vision loss or mobility impairment or more ambiguous (and milder) symptoms such as numbness or tingling. Pain or discomfort seemed to be related to help-seeking.

“I *first started with optic neuritis as my first symptom, and it fell that it was a bank holiday weekend, so I went to the A&E department, because I’d just...I’d always suffered with migraines all my life, and I know migraines are supposed to be bad, but this was horrendous. I felt like chopping my head off. It was that painful.*” P15, female, R-R

Obvious symptoms were easier to identify candidacy for care whilst more ambiguous symptoms were harder to differentiate as MS or not, and in some cases whether health care intervention was necessary at all. Family members or close friends could be used to identify candidacy and often facilitated help-seeking where they deemed health care intervention necessary. Similarly, participants who knew other people with MS would ask their opinion of symptoms and experiences to assist with the identification of candidacy for care and the likelihood that a symptom was caused by or related to MS. Recursivity was relevant to identification of candidacy, whereby recurring symptoms stopped being ambiguous when they were named and treated by a medical professional. Similarly, where symptoms were perceived to be discredited by professionals, participants may be less likely to identify themselves as candidates for care. Discomfort and impact on routine activities were key factors in identifying oneself as a candidate for care. Participants often utilised MS specialists where candidacy for MS care was unclear.

5.2.2 Uncertain progression

Rapid onset of severe MS symptoms and lack of knowledge regarding possible recovery, or speed of recovery, were relevant to participants identification of themselves as candidates for care, where they were most likely to seek help out of fear or worry. Recursivity played a role in these examples as participants were more likely
to return to a knowledgeable service that provided fast access to treatment, whether
this was a primary or secondary care setting.
Awareness that the disease was likely to progress, but uncertainty surrounding the rate
of progression was distressing for many participants. Identification of candidacy was
harder for progressive symptoms, as there was no clear cut off point at which services
were needed to intervene, in comparison to a fast onset relapse. The diagnosis of
secondary progression was described as particularly emotionally significant to
participants, as it was felt to signal the beginning of a negative period with no hope of
recovery. Reflecting on how far disability had progressed could be very upsetting for
participants.

“[MS]’s not something that just cropped up, so with me actually it’s got
worse gradually. So you learn to adapt but when I think about what I was
like when I was able to do things then it’s an extraordinary amount of
difference to what I was then to what I am now. It is quite upsetting when
you think about it.” P19, female, R-R

This has relevance for health care services, as participants noted that their annual
review with specialist services was often the only time they appraised their disability
progression and the things they were no longer able to do. This suggests that annual
reviews may provide a good opportunity to discuss perceptions of candidacy for
various health care services and provide the setting for discussion of potentially
relevant interventions. The majority of participants reflected that in daily life they tried
not to focus on limitations but aimed to stay positive and upbeat about what was still
possible rather than focussing on health care needs or service input.

5.2.3 Identity and labels

The majority of participants discussed their identity. As described by Charmaz (1995) I
took a symbolic interactionist approach to defining identity, viewing it as a
phenomenon of meaning to participants, which is created dynamically within social
interactions. As detailed by Charmaz I interpreted identity as the way in which people
“define, locate and differentiate self from others” (1995, p. 659). In addition my
interpretation incorporated the concept Charmaz defined as “identity goals”, namely
the ways in which participants prefer or wish to define themselves, which may be
explicit or unstated (Charmaz, 1995). Although there are a myriad of conflicting
definitions of identity, I selected this definition due to its fit with both the
phenomenological elements of my epistemology, and the subjective nature of the qualitative research method I used.

Participants discussed social roles that contributed to their identity (Stryker, 1980). Social role has been defined as “a behavioural repertoire characteristic of a person or a position; a set of standards, descriptions, norms or concepts held for the behaviours of a person or a social position” (Biddle, 1979, p.9). In my findings participants described their social roles including father, grandmother, employee, group member etc., and discussed the impact MS had on the roles that were salient or meaningful to them (Stryker, 1980). The data suggested that participants were most likely to identify themselves as candidates for care when their MS interfered with a valuable role e.g. being able to care for their children or maintain employment.

Participants were divided as to how much MS subsumed their identity. Some people incorporated their MS into their identity and wanted other people to acknowledge them as someone with a disability. These people felt others were not appreciative of their invisible and unseen disability and therefore did not appreciate the impact MS had on their life.

For others, maintaining a positive identity meant being viewed by themselves and others as more than just someone with MS, with an appreciation of other aspects of their identity, such as social roles, employment or hobbies.

“There’s a lot of people who wallow, and there’s a lot of people who their whole life is about having MS, and it’s just not me. I’ve got lots of other things going in my life, and MS is just a little bit at the back of it.”

P16, female, benign

Minimising the impact of MS on life appeared most common in people whose MS was well maintained and who subjectively perceived that their symptoms did not have a major impact in their day to day life. This lessened their candidacy for care when they minimised the impact of symptoms and felt that life did not have to revolve around MS. In comparison, sometimes invisible symptoms could be a positive when they meant that the person did not noticeably have MS and it was therefore easier to prevent the judgements of others as just seeing them as a person with MS. A difference was identified between participants who used and were recruited through MS society services such as social groups and those who did not, with group members being more likely to have friends with MS and to view MS as a large and integral part of their
identity. They were less likely than those recruited through non-MS Society settings to be employed and so employment was less of a crucial part of their identity. They were also more likely to view themselves as ongoing candidates for care, due to often experiencing more advanced MS symptoms.

In addition to MS or physical disability labels, other participants reported the frustration of having labels attached to them for using professional services such as psychiatry or psychology. These labels were viewed by participants themselves, and reported to be viewed by health care professionals, as inherently stigmatising and judgemental, making claims about the participant’s innate characteristics and identity. This lessened participants’ perceptions of candidacy when they did not agree with the stigmatising judgements attributed to service use, and affected service use recursively where participants were unwilling to return to a service which they felt was stigmatising. I did not directly ask all participants about all available sources of psychological support but one participant reported seeing a psychiatrist, three reported seeing a psychologist and eight reported using anti-depressants of which all but one were prescribed for them from a GP.

“You’re fighting for your identity all the time. You’re getting labelled all along the way because you’re seeing different people [professinals] due to different circumstances, and they label you as neurotic.” P3, female, R-R

These negative perceptions and experiences of being labelled could in some cases cause participants to form negative perceptions of health care professionals and services, and delay or prevent utilising services.

In summary, participants reported experiencing highly varied MS symptoms and disability, the impact of which varied by person both objectively and subjectively, subsequently affecting perceptions of candidacy and recursivity. Participants worried about the future due to the uncertainty of the speed and progression of MS and awareness of progression and limitations was highly emotive for many participants. Maintaining their preferred identity and being viewed in this way by others (including health care professionals) was very important to participants, and this could be challenged by the labels attributed by professional services, lessening perceptions of candidacy for participants.
5.3 Self-management of symptoms

5.3.1 Expert patients

Participants felt that in many ways they were expert patients, with more knowledge than their health care professionals, gained through lived experience and dedicated research and information searching. This was particularly prevalent amongst older people with MS who had lived with the condition for many years, and particularly noticeable amongst the men in the sample. For those living with progressive MS for a long period of time, few reported seeing any significant changes in management or treatment of progressive MS.

“Well, I don’t think there’s much information we need, I mean we’ve been at it 34 years now so we’ve got a lot of experience of it.” P13, male, PP

As people lived with MS over many decades (8 participants 20 years+) they described how they had learned how to manage their symptoms effectively, and felt that they were less reliant on health care services for information, instead choosing to proactively seek out information as and when it was relevant to them. This may also be due to the pace of relapses slowing down as participants move from relapsing-remitting to secondary progressive MS. This changed their perceptions of candidacy and recursivity, where they perceived services as of less use to them than less expert patients, due to their advanced knowledge and experience and therefore did not return regularly to such services.

In parallel to seeing themselves as expert patients, participants viewed some health care professionals as less knowledgeable than they were on particular topics which changed their perceptions of candidacy for these services. GPs were particularly mentioned as knowing less MS specific information than some people with MS.

“It’s no use going to the GPs to talk about MS because they might have 500 people and might have 1 or 2 people with MS. You can’t expect a GP to know, I know more about MS than my GP when I go to the GP.” P21, male, SP

Whilst this was not judged negatively (as mentioned previously participants respected the generalist nature of the GP role), it did mean that GPs were not always viewed as a responsive service for managing MS, or potentially MS related symptoms, and so may not be seen as an appropriate service for these issues. However, not all participants
saw themselves as expert patients, a minority preferred a more passive role and saw the health care professional as the authority on any topic.

“I'm not the expert, they're the ones who should tell me if there's something that can help me.” P14, female, SP

This was associated with a less proactive management of MS and a reliance on professionals to suggest ideas for symptom management and disease modifying treatments, suggesting that these participants still perceived themselves as appropriate candidates for care and support.

5.3.2 Management strategies

Many participants discussed self-care, where they tried to stay as healthy as possible with the aim of preventing any unnecessary strain on their immune system and therefore prevent further physical decline. This was achieved through various strategies e.g. staying fit and active, decreasing alcohol and caffeine intake and eating healthily. Participants also perceived that stress and relapses were linked and so aimed to decrease their exposure to stress to prevent further relapses.

“I've just drunk less and less [alcohol], I don’t drink any caffeine, I don’t drink any fizzy stuff, just because it all irritates my bladder and just makes things worse. I can see looking back I've only had about 4 relapses, it's definitely linked to stress so I try and avoid stressful situations like working full time.” P2, female, R-R

Where these health promotion strategies were not enough to control symptoms and prevent relapses, participants then used other self-management strategies to minimise the impact of symptoms on daily activities. Participants described a range of physical and psychological management strategies. Some participants utilised support from health care professionals in obtaining necessary equipment, medication, services and knowledge to ensure that when their MS became symptomatic, they had the tools to manage these symptoms as autonomously as possible.

“I have a seat that I can sit on if I'm having a shower, things like that, and supports that I can lean against when I'm working in the kitchen.” P24, female, R-R

These management strategies could then be used as and when required to minimise the impact of MS and prevent further disability accruing where possible. Some participants used management strategies temporarily e.g. physiotherapy techniques
for pain, whilst others used them to manage daily symptoms such as fatigue or mobility impairments. These strategies were perceived as allowing participants to maintain their independence, irrespective of their symptoms. These strategies changed participants’ perceptions of candidacy, as they only viewed themselves as eligible for service use once these strategies were so longer sufficient for managing symptoms.

“I have cleaners come in so they can hoover through the house and do the bathroom and kitchen and the other things that I want them to do. Which is nice because it means that if I can do it I do it, if I can’t at least it’s done at some stage.” P5, female, SP

Whilst the majority of self-management was conducted to maintain independence in daily life, in some situations self-management was necessary when no formal interventions had been effective and participants had no further available avenues of interventions to try. Commonly described examples were pain and fatigue. In participants’ descriptions of managing pain they often discussed a situation where the GP or neurologist prescribed many different types of painkillers before eventually taking the fatalistic approach that the pain was unmanageable with medication. This left participants in a situation where the only option was to self-manage their symptoms.

“And he [GP] tried every painkiller under the sun for my pain and couldn’t find anything to suit me and just said “well you’re just going to have to take off the counter ones, paracetamol, because nothing I’ve given you’s worked.” P10, female, R-R

This perceived attitude from health care professionals could lead participants to feel hopeless about ever fully managing their symptoms, and preventing them from impacting on their daily life. Fatigue was commonly mentioned as a difficult symptom to manage, due to its variation and unpredictability. No participant felt that their fatigue was fully controlled, and many had had negative experiences with medication intended to prevent fatigue. Due to the side effects of fatigue medication (e.g. causing increased alertness that prevented sleep and increased fatigue) many participants had to self-manage as no alternatives were perceived as available. This matched the offers and resistance component of the Dixon-Woods et al. (2006) candidacy framework, by explaining how service users could reject medical offers based on previous experiences.
of treatments. Participants therefore managed their symptoms by using legal stimulants or modifying their behaviour in the most extreme cases.

“Tiredness is not something you ever get used to, dealing with, it varies through the seasons, the month, the day. I generally rely on coffee, red bull and if I’m really, really tired then [I use the] walking stick or stay at home.”

P1, female, R-R

The majority of participants did not feel that self-management was the appropriate solution, however they reported feeling they had to self-manage when they perceived that no further support could be gained from formal health care services. In these situations participants’ presented themselves as being trapped in a circular situation where they perceived themselves as candidates for care but the only care available was not responsive to their needs, resulting in the need for self-management. In summary, many participants viewed themselves as expert patients, with more knowledge than professionals, due to lived experience and dedicated information searching, lessening perceptions of the need for services.

Participants utilised a variety of physical and psychological self-management strategies. These were often developed through support from health care professionals and then utilised for symptom management as and when needed. Sometimes self-management strategies were used due to participant preference for independence, but in other cases they could be the result of unresponsive intervention. Perceptions of candidacy therefore depended on participants’ motivation for management and experiences of responsiveness.

5.4 Access
5.4.1 Navigation

Navigation of services (as explained in Dixon-Woods et al. (2006) framework of candidacy) relies on awareness of relevant services. Participants reported varying levels of awareness of services available to them for support with their MS. As GPs were frequently also used for non-MS related issues, all participants were highly aware of their services. In addition, their geographical closeness often resulted in them being the first point of call and some participants reported that their GPs had initiated fast access systems for people with MS, making them highly permeable services from the participant perspective.
“Um it’s easier sometimes to just go to my GP, because it’s just down the road. And since I’ve come down with MS they’ve put me down as ‘urgent’.”
P6, female, R-R

Finding out which additional services were available, and how to access them, could be a difficult and lengthy process for participants (preventing navigation), where signposting was not perceived as available from health care professionals.

“I couldn’t just resume my normal life because there were all these difficulties put in my way. And nobody seemed to have the answer. You have to find out bit by bit how these things work.” P24, female, R-R

Over time, participants reported becoming more knowledgeable on MS and available services. This increasing knowledge could be from health care professionals, information accessed on the internet or through relevant charities such as the MS Society or the MS Trust. In addition, people learned from others with lived experience of MS either in person at support groups or via online support and internet forums. Once this knowledge had been developed participants reported becoming more confident in navigating the many services utilised for MS care.

“I know exactly where to go now. I’m under the care of [neurologist] at [local district hospital]. I’ve got the MS nurses number which [neurologist] gave me and I’ve got the girls at the [MS society] yoga, I’ve got my GP who’s wonderful, so I know exactly where I’m going, it was just very confusing in the beginning.” P10, female, R-R

MS Society services were reported to be helpful in assisting participants to learn how to navigate local and national services. Improving knowledge of available services improved participants’ identification of candidacy, as they reported becoming better at knowing which service to utilise for which symptom, and developed a clearer understanding of which symptoms were linked to MS, making them clear candidates for MS care.

5.4.2 Timeliness and availability

Many participants discussed delays in access to services including SN services, physiotherapy, and psychological care, which limited their perceived permeability. The lack of a personal response (in comparison to an answering machine) was viewed as frustrating, and the majority of participants were dissatisfied with the time taken to
reply to messages which they usually perceived as urgent when relapsing or experiencing discomfort from existing symptoms.

“When I was having problems, I’d pick up the phone, ring the MS nurse, end up with an answerphone, so you leave a message, you’re lucky if they get back to you within a week. Well, when something's happening there and then people need answers.” P15, male, R-R

In addition to the delay experienced with SNs, access to psychological services was experienced as poor due to lengthy delays. This was felt to not be responsive to the seriousness and acute nature of psychological problems and left participants without support when they needed it.

“By the time you get to the counsellor the heat has gone off it because its 12 months later, 18 months. Nothing is instantaneous. You don’t get the support and the help when you need it. I had to wait 18 months.” P3, female, R-R

When services did become available after such a prolonged time they were perceived as ineffective, as the cause of the distress had usually ceased or subsided. Neurology outpatient appointments were also reported to be subject to lengthy delays and frequent cancellations, although this differed between Foundation Trusts.

“We need quicker appointments, not waiting so long for appointments. You can wait ages, then a few days before your appointment you’ll have another letter and then they’ll give you another time, and then that will be cancelled.” P6, female, R-R

These lengthy waits and rearrangements caused frustration where participants felt they were not receiving suitable follow up in the meantime. The delay in awaiting tests and results was also reported to be highly frustrating, especially when in the meantime participants felt uninformed as to what was happening and unaware of the cause of their symptoms for a long period of time.

“The time lapses between getting something done and then getting to see somebody to get results and feedback is weeks and weeks. I had an MRI scan last year and it was nearly two months before I got to see the consultant to get the feedback on the results. It’s quite frustrating really being kept in the dark.” P20, female, R-R
These delays in access to services were primarily reported for secondary and community care services. Primary care was viewed as suitably fast access for both psychological and physical urgent care needs, although the majority of participants reported increasing delays in pre-booking appointments.

“So I went to the doctor’s at five o clock in the evening. I broke down at reception. And I went straight in and that was when Dr [] realised that I was having a bit of a do and put me on the anti-depressants.” P10, female, R-R

Fast and easy access (defined as good permeability by the candidacy framework) were viewed very positively and felt by participants to maximise their wellbeing and minimise the impact of their physical and psychological symptoms.

Whilst limited access to some services was reported to cause delays in care, other services were not available at all through the NHS, or prohibitive due to the time and processes needed to approve certain treatments or services, such as specific medications:

“I was sort of cautious of going for this drug and I wanted another one. But it wasn’t available on the NHS. They would have had to have made a separate application to the PCT to get funding. But that would have taken up to three weeks. And I didn’t have time to wait for that, and as I was I just had to go for that Tysabri”. P9, male, REMS

This delayed process meant that for those participants who wanted to apply for specialist treatments or medications through PCTs, the time delay would have potentially resulted in further (often severe) disability and so applications or contestations were not possible. This was perceived as severely limiting participants’ choices and ability to fully and autonomously participate in shared decision making, when the end result was predetermined by access requirements and availability.

Discussion of the availability of drugs also included participants’ experiences of accessing clinical trials for disease modifying treatments. Three of the seven male participants and one female participant raised the topic of eligibility for drugs trials. Participants discussed their frustrations at the eligibility criteria for trials, such as a

---

1 Tysabri is the brand name for Natilizumab. It is administered monthly by a health care professional and used to treat aggressive MS, aiming to prevent disabling relapses. The drug has recently received publicity due to reports of deaths where Tysabri caused Progressive Multifocal Leukoencephalopathy (PML), a viral infection in the brain. The clinical benefits are perceived to outweigh any risks of PML and so this treatment is still routinely prescribed.

---

132
maximum age limit of 65 years. Frustration was also expressed at the length of time to get new drugs approved for use, licensed and available on the NHS when participants clearly perceived themselves as candidates for trials. Participants believed that the cure for MS would be pharmacological in nature and the belief in a cure allowed hope. However, participants had seen many claims of potential cures dismissed over their life with MS and were cautious of raising their hopes too high.

“I’ll switch the telly on one day and they’ll say massive cure for MS, fantastic news and then. But I’m not holding my breath and I’m not living my life hoping for that.” P12, male, PP

This meant that in the meantime participants focussed on self-management of their symptoms and living as full a life as possible with their MS, which for some included the maintenance of employment. Differences were found between participants who worked and those who did not work, with regards to the accessibility of health care and management of MS symptoms, which could cause difficulties in maintaining full time employment. The majority of participants in employment had had to adapt their work to fit around their symptom management or health care use. Two participants had changed their employment hours or working pattern to fit around medication side-effects or hospital appointments, whilst others changed their work role to include less physically demanding tasks.

“Because I’m not working the treatment doesn’t really interfere with anything. The fact that towards the end of each 4 weeks I sort of dip, and afterwards it knocks me out for a day or two. I don’t think I’d go back full time, just because I have that many hospital appointments and to keep the peace I’d rather work part time and use the other days to accommodate for my appointments.” P9, male, REMS

The impact of health care on employment was dependent on the apparent acceptance and flexibility of employers. Good employers were perceived as those who accommodated flexibility in working routine and employment hours to enable the person with MS to manage full time employment alongside the side effects of medication, hospital appointments and MS symptoms.
“[Managing treatment and work] it’s not a problem at all. My employers are quite good. When I started on the Avonex\(^2\) treatment and I realised it was actually making me poorly once I’d had the injection, I’ve worked my hours, so I do 36 hours Monday to Thursday, which is why I work until six o’clock every night, and then have Fridays off.” P16, female, benign

Flexible employment also enabled participants to enjoy a social life and hobbies alongside employment and health care needs. The uncertainty of MS disability and recovery time could cause difficulties where employers were not flexible and participants were unsure of return to work dates.

“I can take as much time off as I want. You know there’s no issue, if I say I’ve got to be off to go to the hospital, it’s not a problem. Like if I’m ill, like the other day they said don’t come back until you’re right, there’s no point making yourself worse.” P11, male, R-R

Good employers were perceived as those who cared about the wellbeing and health of the participant and did not create difficulties when participants required leave at short notice due to symptoms or hospital appointments.

Participants reported faster and easier access to both diagnosis and treatment through private health care (often through their employer) than on the NHS.

“It was around the July time that I wasn’t very well and I went into hospital in October until November and I got diagnosed end of January. So it was about a 6 month period but I genuinely believe that if I hadn’t gone private to get that consultant to send me for an MRI I don’t know how long I would have been waiting.” P1, female, R-R

This potentially creates discrepancies and inequities in access between those in employment and that not in employment, especially when those with the poorest health due to MS may be the ones most in need of timely health care access and those least likely to be in employment. Where participants rely on private health care through employment this may prevent a disruption in continuity of care or lack of access if this employment ceases.

In summary, participants reported varying awareness of services. This awareness increased over time, sometimes due to signposting from professionals. Staying

\(^2\) Avonex is the brand name for Interferon-Beta 1a. It is taken once weekly to decrease the number of relapses experienced and therefore slow down the progression of disability in relapsing-remitting MS.
informed and ensuring fast access to care upon relapse were key motivators for long-term engagement with health care services. Where participants could not perceive any personal value from service use then they chose to disengage (however, this was uncommon). Delays in accessing secondary and community services were common, whilst primary care provided quick access. Some services and medications were not available on the NHS. Difficulties could be experienced in managing the use of health services and maintaining employment, however this depended on the flexibility of the employer. Use of private health care services was reported to increase access to timely care and inequities in care could be possible between those able or unable to utilise private services.

5.4.3 Staying “in the loop/system”

Many participants discussed the need to be and stay “in the loop”. This referred to being in a situation where they were in contact with the right people to keep their knowledge of MS up-to-date and to be aware of appropriate services and treatments, and could incorporate many aspects discussed in the section on navigation. For some people reaching the stage of being in the loop was reported to take a long time to achieve, however for others it happened early on in their MS experience. Being in the loop assisted participants in identifying candidacy by providing information on eligibility for services and access to professionals where candidacy was uncertain.

“It was a friend that was taking in all the information and [neurologist] gave her contacts for my MS nurse and for a social worker and everything else, and they came to visit me here and then I was in the loop, so to speak.” P4, female, R-R

Being in the loop also referred to ensuring access, by being in regular contact with specialist MS services and staying “in the system”. In this way individuals were known to members of staff and ensured that they knew where to go to receive both ongoing support and emergency access for treatment such as steroids upon relapse, improving navigation. Many participants made efforts to remain in contact with services to increase permeability and ensure fast access for future relapses, even if services were currently not of value to them. This was because fast access was viewed as so valuable, and difficult to regain, that it was considered worth investing in unnecessary appointments during periods of MS stability to ensure that access remained there when needed. In part this perception existed where participants felt they could only
gain the necessary emergency support through their candidacy for specialist MS services.

“I had the next relapse after I was out of the system, because I kept saying “what is the point of you seeing me every year, what a waste of an appointment, what’s the point of me coming?” So I got out of the loop and it’s quite difficult to get back in. So they said to me “just come every year, just so if you need us”, because they have a rapid access clinic, “if you need us you can just access us”. So I just go once a year and that’s it.”

P2, female, R-R

However, one participant with progressive MS reported deliberately choosing to disengage with services and become “out of the loop”, as these services were perceived as offering so little value that they no longer viewed themselves as an appropriate candidate for care, similar to expert patients.

“If you’re in the loop, providing you keep seeing these neurologists, then if anything comes up you’re in the loop, if you’re not in the loop then that’s... Well we aren’t in the loop, we’re okay, they’ve got nothing for primary progressing MS, there’s nothing at all.” P13, male, primary progressive

This was linked to a broader issue regarding the futility of service involvement for people with primary progressive MS, when there were currently no innovations in care or medication viewed as on the horizon, in either research or clinical practice. This lessened their perceptions of themselves as appropriate candidates for care and recursively predicted that they would not engage with these services again in the future. As primary progressive MS did not commonly present with large or fast variations in disability (as seen in relapses) it was not seen as essential to have the fast access to information or care provided by staying in the loop.

5.5 Interactions with health care professionals
5.5.1 Loss of personhood: Attitude of professionals

Many participants described negative interactions with health care staff, particularly neurologists. Participants’ emotional reactions were highly emotive when discussed, even years or decades after the event, and could have an impact on their future engagement with health care services. This corresponds with the “appearances at health care” component of the Dixon-Woods et al. (2006) framework, as participants
could chose not to appear at services, even when they identified themselves as candidates for this care.

“I saw a junior doctor [neurologist registrar] and he was so rude, he slammed the notes on the desk and walked out and I burst out crying and I went home really upset. I think I was reluctant to go back again because of this young doctor’s treatment of me.” P10, female, R-R

Perceived impoliteness and unsympathetic behaviour from health care professionals was felt by participants to be inappropriate, unnecessary and upsetting. As displayed in the above quote, negative experiences frequently centred on perceived poor interpersonal skills and a perceived lack of empathy, politeness and/or respect for the patient. Some participants described experiences were they felt perceived by health care professionals to be malingerers and felt they were not treated with the respect or sympathy that their credible ill health required. Reported behaviour could be experienced as rude, intimidating and not appreciative of participants’ physical state and emotional anxiety or distress.

“So I went in and the doctor [neurologist] said [harsh voice] “come in and sit down there” so I sat down and he said “Well. You’ve given me a right job to do now. I’ve got to put you in a very expensive hospital bed”. And then I tried to stand up and he said “look at you, you can’t go anywhere, you’re like a death-watch beetle.” P7, female, R-R

This behaviour significantly increased participants’ distress and was considered by participants to be an unjustifiable manner of behaving, particularly to people who were severely vulnerable and not in a position to argue back. Overall, negative experiences (of varying severity) reported by participants made participants feel like they were not being valued as human beings with a sense of worth, and reported feeling as if they had lost their sense of personhood. Participants reported that this impression was conveyed by professionals who were more focussed on financial costs or procedural issues such as bed availability and prioritised these over the physical and emotional needs of the individual person with MS. This led to participants being made to feel like a number or an inconvenience, not an empowered patient with a right to a care, as they perceived they should be treated. Participants reported that not being listened to made them feel like their opinions, experiences and feelings were not valued by their
health care provider which contributed to the wider feeling of not being treated like a person of value.

“I just found the consultants half the time don’t listen, you’re a number not a person, you’re occupying a bed that they wanted free and you’ve got an allocated time and it’s time to go.” P1, female, R-R

In addition to feeling that some professionals did not listen to them, some participants felt poor experiences were expounded by an apparent lack of knowledge and interest in the individual patient and their circumstances.

“We went in and he [neurologist] says, “I don’t know who you are or why you’ve come”. So I took my brakes off my wheelchair, took [wife]’s brakes off and started back out, I said, “we’ll go then, thanks very much” and we never went back since. That was a few years ago, I thought, you ignorant pig. They’re so flaming arrogant aren’t they.” P13, male, PP

It was therefore perceived to be insensitive and disrespectful to not appear concerned about the priorities or experiences of people with MS and this prevented a positive professional-patient relationship developing. Where participants had experienced negative encounters with health care professionals they chose to accept or reject further medical offers based on their experiences (as outlined in the Dixon-Woods et al. (2006) candidacy framework).

In comparison to these negative experiences, positive interactions with services were reported which had a positive impact on participants’ health and emotional wellbeing.

“I mean, in the main my one GP, she’s brilliant, so when I went with the initial symptoms 11 years ago now, she’s the one I went to originally, because I knew she’d take me seriously.” P17, female, benign

Positive experiences with health care professionals were perceived as those where the participant felt taken seriously, and where the professional offered reassurance instead of negative judgments. They were also felt to be those who took an interest in the participant and took responsibility for the responsiveness of care, and ensuring that necessary tasks were accomplished.

“I went to see the neurologist and I just remember he was a lovely man. And we talked for a little bit and he said “oh ok I’ll just examine you” and we went round to the side where the bed was with all these tests. And he
just opened his arms, and I just went to him and he gave me a big hug and he said “don’t you worry, I’ll look after you now.” P5, female, SP

In this narrative the participant explained how from a confusing and frightening situation, this neurologist had made her feel safe and confident that her MS could be managed, showing the impact of responsive care demonstrating good interpersonal skills.

In summary, experiences of health care professionals with negative attitudes could make participants feel vulnerable, distressed and like they were not treated or valued as a person. It prevented responsive care and a responsive professional-patient relationship and in some cases could prevent further help seeking. In comparison, encounters with professionals who showed a sensitive, empathic and non-judgemental approach could reassure participants and improve their confidence in their health care professional and the overall management of their MS.

5.5.2 Professional judgements

In line with the adjudications component of the Dixon-Woods et al. (2006) candidacy framework, participants described how the way health care professionals perceived both participants and their symptoms influenced the health care decisions they made. Participants discussed two types of judgements that health care professionals made. Firstly, they discussed how professionals made judgements about the participant in general (i.e. their credibility or legitimacy as a patient) and secondly they made judgements about the cause of a symptom (i.e. MS or not). Participants reported that they preferred GPs who seemed open minded as to the cause of symptoms, rather than those who classified everything as MS, or alternatively normalised symptoms and did not consider MS.

“He [GP]’s always said to me “don’t put what’s the matter with you in the MS bag, we have to separate it and make sure that it’s not MS before we pile it into that group”. So I like that, he’s always been one not to put things off.” P19, female, SP

GPs who acted in this way were perceived as thorough in their exploration of candidacy and participants reported trusting them more as it was felt that they investigated all symptoms, instead of attributing them to MS and not investigating further. These GPs were also perceived as tackling issues head on, and not prevaricating and avoiding issues they were unsure on, which was viewed positively by participants.
The opposite of this positive experience was where participants perceived that GPs attributed symptoms to MS and then did not act further, thus not significantly exploring candidacy for alternative appropriate care services and making unjustified adjudications. Some participants felt that once a symptom was judged as being MS related by GPs, no further investigation or management was instigated.

“I was in a terrible, terrible way, I was in so much pain and it triggered off all kinds of symptoms, a whole raft of symptoms. You know, I couldn’t move my leg, I was in a bad way. And to cut a very long story short the GP she said it’s MS. So I was left bedridden, 6 months I just couldn’t move, I was in a mess.” P3, female, R-R

This lack of action could leave participants experiencing severe symptoms without any further support or service involvement, where referrals were reliant on GP initiation. In this case the adjudication and judgements of GPs were related to participants’ access to services.

5.5.3 Responsiveness

Although participants acknowledged that access to GPs was often the easiest and most permeable route, GPs were not always reported to be knowledgeable about MS, and this lack of knowledge was seen to lower their responsiveness to people with MS’ needs.

“Worst of it though, a lot of the GPs down the surgery where I go don’t know that much about MS. They’re there “er, we think you’re having a relapse but we’re not sure, if you’ve got a really bad chest infection that can cause you to have a relapse, but we’re not 100% sure?” P6, female, R-R

This uncertainty resulted in the need for the use of specialist services for MS symptoms, which could be harder to access. Although some participants stated “I think they [GPs] should be better informed, frankly” (P24, female), the majority, as demonstrated in the quote below, did not perceive lack of specialist knowledge as a negative issue. Many participants simply acknowledged that their GP could not be a specialist in all areas but did not feel this prevented a good patient-GP relationship.

“To me doctors can’t know everything can they. So that’s why you’ve got specialists. But you know my GP is one of the best. He’s always there and makes you feel part of the family. And I’ve had him now for must be 30 odd years.” P22, female, SP
Services were judged as responsive when professionals “got things done” and acted on patient needs to a successful outcome. They were therefore judged as nonresponsive when professionals promised to follow up on an issue and the participant never received confirmation or evidence of this. This perceived unresponsive service caused participants frustration and lowered satisfaction with services, which were not felt to be trusted to achieve a given outcome. The narratives participants told varied widely from stories of where services had not been as responsive as hoped, to examples that could be perceived to constitute medical neglect (in accordance with the Department of Health definition of neglect as neglecting medical and physical care needs, 2010b).

“They sent [wife] to a place called [respite centre], for two and a half weeks and it was the most despicable place ever. She came back with three pressure sores, she’s never had a pressure sore before or since. As soon as she came into the kitchen I took one look at her and I burst into tears, it was atrocious. We got the doctor straight out, the district nurse straight out and everything.” P13, PP

This highlights the emotional distress experienced by vulnerable individuals and their family members when services were not responsive enough to meet their health care needs, and could potentially cause additional medical needs where care was not appropriate or responsive. For this participant, who required full domiciliary support, buying private services was the only way to ensure effective and high quality care for his wife with advanced MS.

“That is the difference I’ve found with the NHS and the private physiotherapy, is if you put money on the table you get an answer to it, if you don’t put money on the table it’s crap. The NHS comes in and they don’t do the job it doesn’t matter, it’s public money and nobody is accountable. If it wasn’t for our money now we’d just be rotting somewhere.” P13, male, PP

Therefore, for this participant, responsiveness of services was linked to the motivation of the health care professionals (primarily financial) and the accountability of individual professionals, which was felt to be lacking in the NHS.

Responsive care for MS was viewed as that which allowed participants to act as empowered contributors to their own health care planning, in collaboration with
professionals. Participants described positive experiences of shared decision making with their health care professionals, whereby their knowledge and preferences were appreciated and decisions on treatment or management were made together. As with the concept of expert patients, shared decision making was portrayed as a conversation amongst two equals, who both had valid points and a good understanding of the topic.

“So, I said to my consultant, “I know you’re advising that, but what about this? I’ve had a look at this, and I don’t mind doing injections myself. Can we...what do you think?” He did advise me against it. He said, “but it’s totally up to you, because you’ve got to do it, so if you feel better with that”, and that was really good.” P15, male, R-R

Where people with MS’ preferences were appreciated and listened to, the end result was that participants felt more confident about their treatment decisions and their overall relationship with their health care professionals. This shared decision making was applicable to both physical and psychological management of symptoms and participants reported positive experiences of antidepressant use where this decision had been reached collaboratively, without undue pressure or influence, and in line with their personal beliefs about medication use,

“It was a full and frank discussion. He didn’t say I’m going to put you on [anti-depressants], he said how do you feel about, and I jumped at it, I have no qualms about taking pills at all.” P12, male, PP

Making decisions in collaboration with a health care professional was also valued for non-pharmacological management e.g. self-catheterisation, where it could be tailored to a participant’s preference about the intensity and time span of a treatment to maximise autonomous self-management.

“I’ve come to an agreement now with my GP that I stay off the catheter until such time I need to have it, then just use it for a short while and then come off it again. And he’s happy with that. And I’m happy with that!” P4, female, R-R

Shared decision making was not valued by the minority of participants, as some felt uncomfortable making complex decisions about DMTs, however the majority of participants preferred this collaborative method of working.
In summary, participants reported negative interactions with staff that were strongly emotive and could have an impact on future health care services use. Negative encounters were due to poor interpersonal skills demonstrating a lack of empathy and respect. In comparison, positive interactions demonstrated warmth, personal responsibility and taking the patient seriously, which had a positive impact on wellbeing and future engagement with services. Health care professionals’ judgements about symptoms were important and participants preferred an open-minded approach which was neither a blinkered focus on MS, nor normalising of MS symptoms. Services varied in perceived responsiveness, based on participant need for specialist knowledge, the patient-professional relationship and professionals’ ability to follow up on actions to a successful result. Lack of responsiveness resulted in frustration, lack of trust and at the most extreme disengagement with services and lowered physical wellbeing.

5.6 Continuity of care

5.6.1 Relational continuity with health care professionals

Different styles of continuity have been reported by Haggerty et al. (2003): informational, management and relational. Informational continuity is the knowledge and use of information on both the individual circumstances and medical history of a person. Management continuity is where services are delivered in a responsive, consistent and coordinated manner, potentially involving more than one health care professional. Relational continuity of care is where participants receive continued services from one professional for a prolonged length of time (Freeman & Hughes, 2010). Although the need for both information and management continuity were reported by participants, relational continuity with health care professionals was mentioned most frequently by people with MS, and was reported to be very important to participants. A minority of participants relied on health care assistants or support workers to assist with personal care in the home. As this was often when they had severely restricted mobility participants described how vulnerable they could feel utilising this support. As relational continuity of care was rarely possible with health care agency staff it prevented the build of trust, and meant that they reported constantly letting strangers into their home to assist with their most personal health care needs, which was felt to be scary and undignified.
“If it was the same person that would be a great help. Because then you get to know them, and there’s a lot of trust got to be there as well, because I mean it’s a complete stranger coming into your house.” P4, R-R

However, one participant reported a local health care agency which provided good relational continuity of care. This allowed autonomy as the participant was assured not simply the same carers, but also those of a similar age who were happy to engage in the participant’s preferred activities, such as swimming.

In primary and secondary care, long term relational continuity also allowed the professional to get to know their medical histories (informational continuity), which made participants feel supported. Where medical histories were complex and transversed a long period of time, many participants worried about getting their facts correct and felt care was more responsive when they did not have to provide this information at every consultation. Informational and relational continuity of care was felt to protect against this anxiety and risk of error, to a certain extent.

“I would say that I feel quite safe with him [GP]. I think it makes me feel safe that I don’t actually have to remember to say what year it was I done this, can you remember when, so I don’t have to have the explanations because he’s got it all there and he knows.” P19, female, R-R

In addition to not having knowledge of participants’ illness timelines and medical histories, health professionals who were not familiar with the patient and their medical history were perceived as not able to judge the appearance of new or progressed symptoms. This was felt to potentially lead to incorrect assumptions about symptoms, lessening the responsiveness of care and making participants feel that their concerns were not taken seriously or listened to.

“My GP changed. My GP retired part way through and the GP that replaced him wasn’t as aware of my situation and my symptoms and when they changed they said “oh no you must have always been like this.” P1, female, R-R

Lack of relational and informational continuity also meant that professionals were perceived as not being aware of a participant’s personal situation (incorporating both medical and non-medical factors) and therefore could not offer a holistic appraisal of a given situation or symptom.
Differences in relational continuity were reported for different professional groups, and could affect the perceived responsiveness of a given professional. Long-term relational continuity of GPs was often reported, sometimes lasting years or decades, often including the period during which a participant underwent diagnostic tests and received the diagnosis of MS.

“I’ve had my doctor [GP] since we moved to this area, and we’ve been here five years. I would be lost without her, to be honest, because she...well, she knows me, and she knows all about me. Going through my diagnosis, she was a great help.” P14, female, SP

This meant that GPs could be greatly valued and trusted by participants as they were aware of how they had supported them at a time of personal and medical uncertainty and distress.

In comparison to often long term relationships with GPs, participants reported limited relational, informational and management continuity with neurologists. Participants reported both a lack of relational continuity with individual neurologists, and periods of neurologist absence where they would not see a neurologist for many years, with no explanation provided.

“I only very rarely see my neurologist. Once I was diagnosed it was back to the MS nurses. Then for treatment the neurologist jumped back in again, but a different one, and then once I’d made my mind up on the medication he disappeared again. So, like I say, I’ve not seen him for 18 months.” P14, female, SP

Poor relational continuity prevented participants from building up a trusted relationship with an individual neurologist and often they were not viewed as a part of a participant’s regular health care team. Participants reported feeling confused and frustrated when contact with a neurologist was intermittent with no explanation.

Relational and informational continuity of SNs was reported to be variable, with some participants naming one SN as providing care, whilst others reported that they saw a variety of nurses from a SN team; this differed by geographical area. Some participants experienced long term relational continuity with their SN and two even travelled long distances to stay with the same SN once they had moved out of the official catchment area.
“I’ve been with [MS nurse] since it first started and she said years ago cos I moved out of [catchment area] and she said “you should really move to, to [local hospital] MS nurses” and I went actually I’d like to stay with you so I see [MS Nurse] once every 12 months just for a check-up and like I say if I need steroids.” P20, female, R-R

This long term relational continuity provided reassurance and ensured easy navigation of services and improved access, as participants felt they always knew there was a trusted and knowledgeable health care professional to go to in times of relapse or progression.

The minority of participants reported that they did not have a named SN and would see any available SN when they attended for routine follow ups. This was reported to be frustrating when this lack of relational and informational continuity resulted in a less responsive service which was perceived to ask unnecessarily repetitive questions.

“Over many years I would go up there [district hospital] on an annual visit, you could see an MS nurse one year and then not see her again for 3 or 4 years. And there were many questions as a result that were the same question, you know. I wouldn’t say you got fed up with it but...” P12, male, PP

In summary, a long term relational and informational continuity of care ensured easier identification of candidacy, a better patient-professional relationship, more responsive adjudications, greater reassurance and improved navigation and access.

5.6.2 Variation of follow up

Participants reported divided opinions over the usefulness of follow ups with SNs and neurologists (often at 3 months, 6 months, 1 year or 2 years). Some perceived them as “keeping a check” which was felt to be positive as it meant that a professional took responsibility for monitoring health and medication.

“I always go to my appointment for my MS nurse, then she can keep a check up on me, also doctor keeps a check up on all my medication every year to see if I still need them, so that’s good, so at least I am being checked on things that I am taking.” P23, female, SP

Other participants did not see these appointments as valuable but attended due to the fear of not being monitored preceding a negative event occurring, and this was a key motivator for the “appearances of health care” component of the candidacy
framework. Follow-ups were therefore seen as preventative in nature by trying to ensure that health was maintained. Follow-up and monitoring were expected and viewed as part of the specialist MS teams’ role, even in periods of MS stability.

“Sometimes they’ll ask the question and I’ll think well I really shouldn’t have come here, I don’t think I needed to come, but then on the flip side is it better being safe than sorry? You know it’s their job isn’t it? Really, even if nothing’s changed.” P24, female, R-R

Participants reported that where follow up appointments did not achieve anything, they could be perceived as not being valuable. This was mostly reported by older people with more progressive MS, whose condition was decreasing slowly with no major relapses and who had lived with the condition for a long time.

“I don’t really get anything out of [annual review] now because I’ve spoken to so many, over the years, there’s nothing they can really tell me. Unless there’s something new coming out of course in which case they’ll tell me, but no I don’t get anything out of it really. But I still go every time.” P21, male, SP

Other participants reported feelings of being “abandoned” by HCPs if they were not kept in regular contact with services through follow up communication or appointment. Where participants felt they were not in contact with services they reported concerns that potentially the specialist MS team were not aware of, or monitoring, their symptoms.

“I was diagnosed and then just left, nobody got in touch with me, because they’d just lost all my records and hadn’t even been in touch with my GP. So I felt quite abandoned and, that’s bad. With appointments at least you’re on the radar, you’re in touch.” P14, female, SP

Participants’ expectations of communication with professionals relied on professionals being proactive and initiating contact. This differed from the expert patient narrative of needing to seek out and manage care services.

5.6.3 Coordination and communication

Coordination of health care professionals, and therefore relational and management continuity of care, differed by the stage of a participant’s MS trajectory. In the diagnostic stage participants reported seeing many health professionals in a short period time as the cause of unknown symptoms was established and MS diagnosed.
"I was passed from pillar to post from different universities, to different consultants, to different levels of consultant." P1, female, R-R

As relationships with the majority of these professionals (with the exception of GPs) only lasted a short time, participants were not able to form relational continuity, at a period of intense ambiguity and distress for participants. Once MS had been diagnosed the majority of participants entered a more stable phase of their MS where they required community services for both short term assessment and ongoing rehabilitation. Participants reported how coordination of these ongoing community services differed by the geographical area in which participants lived, as different services were commissioned in different PCTs or CCGs, and access was not equitable across all parts of the North West. This also corresponded to the “operating conditions” component of the Dixon-Woods et al. (2006) framework of candidacy, which explains how experiences of care depend on local influences such as resources and finance arrangements. Ease of coordination therefore differed between participants, and within participants, when they had moved to a new area or health care authority boundaries changed. A minority of participants reported being under the care of a multidisciplinary team comprised of professionals who were seen as comprising the core disciplines required for ongoing rehabilitation in MS. As these professionals worked in a close knit team, this small group of participants felt that referrals between services were faster, continuity and communication were better and the participant’s holistic needs were managed better.

"Under one health authority they had a team made up of 5 different agencies; one was an occupational therapist, one was a physiotherapist, there was a psychologist, there was a speech therapist and there was the MS nurse. So you came under the umbrella of that team and they all discussed with each other." P3, female, R-R

Where participants moved house or boundaries of health care authorities changed, participants could end up living in the same area or close to it, yet experience totally different access to care (as demonstrated by the above and below quotes from P3). The majority of participants reported that their GP referred them to community services but each referral was individual, lengthy and did not ensure communication or continuity between all involved health care professionals.
“Moving here, there isn’t that team system so the GP will say “well yes I can refer you to a speech therapist or a continence advisor or this and that” but they’re all separate and they all take ages, ages, ages to get to see.” P3, female, R-R

MS nurses and GPs seemed to be central figures in coordinating services on participants’ behalves and in some situations acted as advocates where access to services was limited or lengthy.

“She [MS nurse] was really helpful with my injections because I was having problems with BUPA delivering my medication to me when I was first registered with them. And they kept making excuses up so my MS Nurse gave me her mobile number so I used to ring her or text her and then she’d try and sort it out for me and then get back to me.” P6, female, R-R

Participants felt that professionals acting as advocates improved their access to medications and services in a way that they could not ensure on their own as non-professionals. Professionals advocated in a wide variety of areas from procurement of equipment to assistance with benefits, in addition to more routine assistance with referrals.

GPs played a key role in coordinating responsive services. Participants with positive GP relationships discussed how their GPs took their symptoms seriously and were content to refer them on to other services for further investigation or treatment. Participants described how their GPs made decisions based on their previous experience and knowledge of managing MS both generally and with a specific patient, in addition to their knowledge of available services.

“The GP coordinates the various services. When she came to see me during my last relapse she was sort of thinking “what can I do for her?” and she’d been on some sort of lecture or something with [Neurology hospital], so she said “well I’m going to refer you to [Neurology hospital].” P3, female, R-R

Where GPs were knowledgeable on available services they were able to refer participants to the appropriate service in a responsive manner. Where symptoms appeared to be linked to MS participants reported that GPs were mainly quick to refer back to specialist MS teams.
MS nurses and GPs appeared to act as gatekeepers to neurologists, and the majority of participants were content to only see the neurologist when the severity or ambiguity of symptoms was judged by these gatekeepers to necessitate it.

“The nurse works between you and your consultant. She’s the hub, everything is going around her. So you don’t need to see your consultant. Unless you really do.” P7, female, R-R

Where the SN successfully coordinated all services and acted as the main point of contact, then a lack of neurologist involvement was viewed as acceptable by participants where the SN judged it as acceptable. It was not clear from the data at what point neurologists were perceived as necessary but narratives usually included ambiguous or unusual symptoms, aggressive symptoms that increased in severity quickly or potential complications with medication.

Participants reported a trade-off between fast access to health care professionals and ensuring relational continuity of care with a frequently seen and well known health care professional. This was applicable to GPs, SNs and PNs. Whilst relational continuity of care was preferred, sometimes fast access necessitated that participants saw a new or unknown health care professional and potentially experienced problems due to this lack of relational continuity. Where non-urgent consultations were required participants reported waiting to see, for example, a GP or PN who they felt was understanding of their limitations and had prior knowledge of their MS symptoms.

“Booking an appointment with her [PN], it’s not easy, I’ve got to have a smear test so you can only book up to a month in advance but she doesn’t work every day so I’m limited and she’s limited. I want her to do it because she understands how difficult it is to get on and off the bed. And also I never know what’s going to happen, if my legs are going to kick off with the spasms!” P18, female, SP

When relational continuity of care was perceived to have been achieved, this lessened participants’ anxiety about consultations, (in addition to the other perceived benefits already discussed) and was therefore judged as worthwhile enough to delay access to services.

In summary, relational continuity of care was highly valued by participants as it allowed health care professionals to learn about participants as individuals, and about their medical histories and needs. Long-term relational continuity was reported most
commonly for GPs, with variable relational continuity for SNs and poor relational continuity with neurologists. Patient views on the management and information continuity provided by annual follow ups varied, some participants valued out-patient neurology follow-up appointments as a way of letting professionals keep a check on them, whilst others perceived no value in these appointments. A contradiction was reported in the data where participants reported poor management continuity with neurologists but a minority also reported that they did not value follow up appointments, especially if they had progressive MS and had used specialist services long term and had a low perceived value of them. A minority of participants received no contact from services over a long period of time and reported feeling abandoned. Participants often described services as being poorly coordinated, with health care professionals not communicating with each other over patient needs, thus preventing timely care. GPs and SNs coordinated care and acted as gatekeepers to neurologists and participants reported making service use decisions by weighing up the value of continued care from a named provider versus faster access to care.

5.7 Chapter summary
The data presented in this chapter covered five main themes of patient experiences of health care services for MS: the experience of living with MS and managing symptoms, access to care, continuity of care and interactions with health care professionals. Where appropriate, aspects of candidacy and recursivity theory were used to explore these themes: experiences of living with MS and managing MS symptoms were highly varied. To cope with uncertain progression of their condition many participants became expert patients and utilised a variety of self-management methods to proactively manage their condition where possible. This required varying levels of support from health and social care professionals.

Participants reported the need for increased timeliness of services from secondary and community settings, combined with better coordination of care services across primary, secondary and community settings. An integral finding was participants’ need to be valued as a person, achievable through empathic and person-centred care from continued care professionals, who utilise personal responsibility and professional competency to successfully meet patient needs, whilst maintaining participants’ self-worth and positive identity. The next chapter will now explore GPs’, PNs’ and SNs’ experiences of providing health care services to people with MS.
Chapter 6: Results- The perspectives of health care professionals on providing care for people with MS

6.1 Introduction

In this chapter I present the data from interviews with GPs, Practice Nurses (PNs) and MS Specialist Nurses (SNs). Findings of all three health care professional groups are presented in this chapter, providing the opportunity to compare and contrast findings (as highlighted in Table 17). The themes emergent from the analysis were: Professional role, patient-centred care, access, and management of MS. This chapter begins by presenting the characteristics of the health care professional participants before presenting the inductively derived themes, explored in relation to candidacy and recursivity where appropriate.
Table 17. Differences in findings between health care professional groups.

<table>
<thead>
<tr>
<th>Themes</th>
<th>Health care professional groups</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>PN(s)</td>
</tr>
<tr>
<td>Primary care role for MS</td>
<td>• Clearly defined by QOF and the expectations of their employers.</td>
</tr>
<tr>
<td></td>
<td>• Incorporates similar elements to the GP role but with less responsibility for people with MS and less need to manage ambiguity.</td>
</tr>
<tr>
<td></td>
<td>• Clearly defined as managing comorbid health needs but not being responsible for MS.</td>
</tr>
<tr>
<td></td>
<td>• Expressed more professional limitations and less autonomy in their role than GPs and SNs.</td>
</tr>
<tr>
<td></td>
<td>• Uncertainty resolved by referral to GP.</td>
</tr>
<tr>
<td></td>
<td>• Rarely corresponded with MS Specialists directly.</td>
</tr>
<tr>
<td>Patient centred care for MS</td>
<td>• Reported low knowledge of services and health care needs of people with MS, which was felt to lessen the person-centredness of the care they provided.</td>
</tr>
<tr>
<td></td>
<td>• Where they developed relational continuity were able to learn the patient’s holistic needs and preferences as with any other chronic condition.</td>
</tr>
<tr>
<td></td>
<td>• Viewed time as a barrier to incorporating more contact with people with MS.</td>
</tr>
<tr>
<td>Access for MS care</td>
<td>Management of MS</td>
</tr>
<tr>
<td>-------------------</td>
<td>------------------</td>
</tr>
<tr>
<td>• Ensured access to care through signposting to community services and influencing GP referrals.</td>
<td>• Perceived a very limited role in working with people with MS and did not see the need to develop a more involved role due to their lack of knowledge and the rarity of MS.</td>
</tr>
<tr>
<td>• Ensured access to PN services by working in settings which were physically accessible, conducting home visits where permitted by their employers and ensuring flexible appointments around patients’ needs.</td>
<td>• Viewed GPs as a central person to manage MS in primary care.</td>
</tr>
<tr>
<td>• Provided access to both primary care, and secondary care through expedited referrals to neurologists or SNs.</td>
<td>• Not all PNs were aware of SNs.</td>
</tr>
<tr>
<td>• Unlike PNs directly communicated with neurologists and SNs.</td>
<td>• Unlike PNs, often had to deal with ambiguous symptoms of unclear aetiology, causing more problems due to a lack of specialist knowledge.</td>
</tr>
<tr>
<td>• Relational continuity of one GP increased access, in a way that was not possible for PNs with their limited role.</td>
<td>• Demonstrated a greater knowledge of the uncertainty related to MS progression and potential difficulties in care planning.</td>
</tr>
<tr>
<td>• Influenced access to neurologists, and access to community services through referrals to the GP.</td>
<td>• Unlike PNs, the GP role was in part determined by the involvement and ease of access to specialist services, where health needs were viewed as outside the remit of primary care.</td>
</tr>
<tr>
<td>• Achieved this access through their specialist knowledge and awareness of local services.</td>
<td>• Had a strong and current knowledge of MS and available services, as required for their role.</td>
</tr>
<tr>
<td>• Emphasised limited access to both their services and community psychological and physical health services, more than GPs discussed this issue.</td>
<td>• Emphasised how the uncertainty of MS was problematic to management of both physically and psychological symptoms.</td>
</tr>
<tr>
<td>• Were the only group to refer to potential inequities in access to care between people prescribed disease modifying treatments and those without.</td>
<td>• Referred to the impact of MS on carers and children and their role in supporting the family with MS.</td>
</tr>
<tr>
<td>• Influenced access to neurologists, and access to community services through referrals to the GP.</td>
<td>• Placed a bigger focus on self-managing MS than PNs or GPs, potentially due to their greater knowledge of symptoms and the effectiveness of available treatments.</td>
</tr>
</tbody>
</table>
6.1.1 Sample characteristics

6.1.1.1 Sample characteristics of Practice Nurses

In total I conducted thirteen interviews with PNs, with a mean duration of 30.68 minutes (range of 19.01 to 39.47 minutes) between October 2013 and February 2014. Demographic characteristics are presented in Table 18 below.

<table>
<thead>
<tr>
<th>Table 18. Demographic characteristics of Practice Nurses.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
</tr>
<tr>
<td>Female</td>
</tr>
<tr>
<td>Age</td>
</tr>
<tr>
<td>31-40</td>
</tr>
<tr>
<td>41-50</td>
</tr>
<tr>
<td>51-60</td>
</tr>
<tr>
<td>60+</td>
</tr>
<tr>
<td>Ethnicity</td>
</tr>
<tr>
<td>White British</td>
</tr>
<tr>
<td>Years qualified as a Nurse</td>
</tr>
<tr>
<td>6-10</td>
</tr>
<tr>
<td>11-20</td>
</tr>
<tr>
<td>21-30</td>
</tr>
<tr>
<td>30+</td>
</tr>
<tr>
<td>Years working as a PN</td>
</tr>
<tr>
<td>&lt;5</td>
</tr>
<tr>
<td>6-10</td>
</tr>
<tr>
<td>11-20</td>
</tr>
<tr>
<td>21-30</td>
</tr>
</tbody>
</table>

*PN role*

PNs worked in general practices with list sizes varying from 4,900 to 36,000. Many nurses worked at more than one practice. Before practice nursing they were employed
in a variety of nursing roles including: community/district nursing, inpatient wards, midwifery, A&E (n = 3), paediatrics and renal nursing. They had varied and multiple specialisms/clinical interests including: respiratory conditions (n = 6), diabetes (n = 5), COPD, sexual health, womens’ health, immunisations, renal conditions, learning disabilities and paediatrics. Nurses interviewed included PNs (n = 10), a Senior PN with an extended role and two Advanced Nurse Practitioners.

6.1.1.2 Sample characteristics of General Practitioners

I conducted thirteen interviews with GPs (from different practices to the PNs), with a mean duration of 37.29 minutes (range of 27 to 53 minutes) between October 2013 and March 2014. Demographic characteristics are presented in Table 19 below.

| Table 19. Demographic characteristics of General Practitioners. |
|------------------|---|
| Gender           |    |
| Male             | 6  |
| Female           | 7  |
| Age              |    |
| 21-30            | 3  |
| 31-40            | 5  |
| 41-50            | 1  |
| 51-60            | 4  |
| Ethnicity        |    |
| White British    | 7  |
| British Asian    | 2  |
| British Chinese  | 1  |
| Arab             | 1  |
| Mixed            | 1  |
| Other            | 1  |
| Years qualified as a GP |    |
| <5               | 5  |
| 6-10             | 3  |
| 11-20            | 1  |
| 21-30            | 4  |
Training practice

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>9</td>
</tr>
<tr>
<td>No</td>
<td>4</td>
</tr>
</tbody>
</table>

Teaching practice

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>11</td>
</tr>
<tr>
<td>No</td>
<td>2</td>
</tr>
</tbody>
</table>

Employment hours

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Part time</td>
<td>12</td>
</tr>
<tr>
<td>Full time (9 sessions+; BMA, 2014)</td>
<td>1</td>
</tr>
</tbody>
</table>

Partner or salaried status

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Partner</td>
<td>6</td>
</tr>
<tr>
<td>Salaried</td>
<td>5</td>
</tr>
<tr>
<td>Trainee registrar</td>
<td>1</td>
</tr>
<tr>
<td>Other</td>
<td>1</td>
</tr>
</tbody>
</table>

GP role

GPs worked in very varied settings, from surgeries in deprived areas, through to surgeries in more affluent areas. List sizes of practices varied from 3,000-18,000. GPs’ reported specialist interests included teaching and research (n = 4), womens’ and childrens’ health (n = 5), diabetes (n = 1), urgent care (n = 1), minor surgery (n = 1) and cardiology (n = 1).
6.1.1.3 Sample characteristics of SNs

I conducted nine interviews with SNs, with a mean duration of 30.71 minutes (range of 24.10 to 44.53 minutes) between October 2013 and April 2014. Demographic characteristics are presented in Table 20 below.

<table>
<thead>
<tr>
<th>Gender</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Female</td>
<td>8</td>
</tr>
<tr>
<td>Male</td>
<td>1</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Age</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>31-40</td>
<td>1</td>
</tr>
<tr>
<td>41-50</td>
<td>4</td>
</tr>
<tr>
<td>51-60</td>
<td>4</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Ethnicity</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>White British</td>
<td>9</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Years qualified as a Nurse</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>11-20</td>
<td>2</td>
</tr>
<tr>
<td>21-30</td>
<td>4</td>
</tr>
<tr>
<td>30+</td>
<td>3</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Years working as a SN</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt;5</td>
<td>1</td>
</tr>
<tr>
<td>6-10</td>
<td>2</td>
</tr>
<tr>
<td>11-20</td>
<td>6</td>
</tr>
</tbody>
</table>

**SN role**

SNs in specialist MS services described their role as being multi-faceted, comprising education and information giving, coordinating, referring, assessment, and medication management. They worked solely with people with MS, across the illness trajectory from diagnosis until palliative care, and dealt with a wide variety of sub-types of MS, stages of progression and symptom severity. SNs reported a personal caseload of 70 (n = 1) to 300/400 patients (n = 8), as part of a wider team caseload.
The four themes displayed in Figure 8 will now be discussed. Interconnections existed between themes and categories; however these have not been graphically displayed as it was felt this would decrease clarity.
Figure 8. A thematic map showing the themes and categories of professionals’ experiences of MS care.

- **Rarity and specialist knowledge**
- **Unpredictability**
- **Management of MS**
- **The role of specialist MS services**
- **Access to primary care**
- **Access for MS care**
- **Access to community and specialist care**
- **Facilitating access to care**
- **QOF**
- **Primary care role & role in MS care**
- **Support**
- **Coordination of care**
- **Patient-centred care for MS**
- **Professional-patient relationship**
- **Holism**
- **Time**

**Perspectives of health care professionals**

- **Holism**
- **Professional-patient relationship**
- **Coordination of care**
- **Support**
- **Primary care role & role in MS care**
- **QOF**
- **Management of MS**
- **The role of specialist MS services**
- **Rarity and specialist knowledge**
- **Unpredictability**
- **Access to primary care**
- **Access for MS care**
- **Facilitating access to care**
- **Access to community and specialist care**
6.2 Primary care role and role in MS care

Practice Nurses (PNs) reported being responsible for the routine management of people with LTCs, and described a list of routine tasks within their remit (related to QOF). The content and format of routine review consultations was described as defined with a clear agenda and targets.

“In that consultation we ask them questions around their lifestyle, appetite and diet. We offer alcohol advice and smoking cessation services. We then talk to them about any issues around their mobility problems and exercise. And then we would do the usual look at the height, weight, BMI, blood pressure, pulse, any bloods that are required. And then usually we just have a little look at their medication list and arrange referrals or follow ups.” PN3

Duties varied by participants’ roles, and clear distinctions were presented in the role and responsibilities of members of the practice nursing team. Health care assistants were viewed as freeing up qualified PNs’ time to allow them to manage chronic diseases.

“The health care assistants tend to do ear syringing, BPs, new patient health checks, which doesn’t need us to do it, and the blood tests now are done by them now mainly. So the qualified sisters tend to see the chronic diseases.” PN7

Within the practice nursing team, PNs did not prescribe unless they had completed an advanced nurse practitioner qualification. This created clear boundaries and limitations of the PN role, where PNs were not involved in any prescribing or triage. The senior PN and two advanced nurse practitioners reported extended roles which allowed them to focus more on diagnostic and treatment duties, instead of routine assessment.

Both PNs and GPs described their role as comprising routine assessment and management tasks, completed within more general principles of good quality care. PNs emphasised the repetitive and routine nature of their duties and the clearly defined conditions for which they were responsible.

“Patients that I see most often are chronic disease patients. It’s the same sort of conditions: diabetes, asthma, CHD, and COPD. And then we also see patients for vaccinations, travel, childrens’ vaccines, smears.” PN1

Although both PNs and GPs highlighted the importance of QOF in defining their roles and compulsory tasks, this was more pronounced with PN participants who reported being more responsible for the management of QOF conditions.
“Well everything’s now to do with QOF isn’t it? Quality outcomes, you know, the framework.” PN12

For PNs, QOF was the underlying guidance for the majority of their interactions with people with LTCs. They suggested this led to protocolised care, and perceptions of their role as focusing on the assessment, monitoring and recording of health measures and targets in accordance with QOF outcomes and requirements. Whilst some PNs were ambivalent about the predominance of QOF, others felt it restricted their autonomy and ability to work flexibly with patients.

“They [patient] might have opened up to me but I’d be tense and thinking but I’ve got to get these boxes ticked, I’ve got to get all these measurements taken. So there might have been times where I would have just shut the door on that. And just got on with what I had to do.” PN 1

Both PNs and GPs reported that the PN focus on LTCs resulted in less need for GPs to be involved in the routine management of these conditions, so that it became rarer for GPs to see people with these conditions unless complications presented.

“The nurses manage most, all the chronic conditions that are on QOFs. So diabetes and COPD and asthma, I don’t tend to see a lot routinely.” GP10

In contrast to the defined nature of the PN role, GPs emphasised the breadth of their work and the wide variety of their responsibilities.

“The beauty of general practice is you can have anything and everything walk through the door. It can be a minor illness, a cough or a cold. It can be a complex long term condition chronic disease that you need to manage with multiple medications. It can be something administrative, something that somebody wants to chat about, or it can be a life threatening emergency or it can be some completely rare disease that you only see once in a blue moon.” GP7

GPs described their roles as involving a variety of management strategies ranging from signposting, prescribing medication and providing patients with the opportunity to discuss issues of importance to them and be listened to.

“Well it’s a GP role, isn’t it? It’s to listen to them, to see whether I think they need medication or support, or whether they just want to get something off their chest that particular day and tell me about it.” GP10
These activities were seen as central to the GP role. No distinction was made by the majority of GPs between support for emotional wellbeing or physical symptoms, as all were incorporated in their perceived role.

“I’m providing their psychological support, social support, treatment of other medical flare ups, coughs, colds, chest infections, things like that, so it’s about providing holistic support for all their needs, psychological, social or physical really.” GP12

The above quote demonstrates how GPs did not segregate psychological or physical needs but aimed to provide person-centred and holistic care to people with MS. The majority of PNs stated that they did not see people with MS routinely or regularly and therefore did not view people with MS as candidates for routine PN care, unless they had a comorbid chronic condition viewed within the PN remit.

“For a practice nurse, MS patients wouldn’t see us, that would be the doctor. Because we’re only going to see them for vaccinations and smears really. If they have any other disease conditions like asthma or heart disease then we’re going to see them for that so we’re going to get to know them from that perspective.” PN1

An exception to this were patients who required B12 injections (every two or three months), which were administered by PNs. PNs described how they viewed this as supplementary service to the MS care provided through secondary care, and did not view themselves as key health care professionals for people with MS. PNs reported that administration of B12 for MS was completed exactly the same as with any other patient, and did not require any specialist knowledge. They therefore included this task within their routine remit and so people with MS could be viewed as appropriate candidates for this PN service. Despite the frequency of patient visits for B12, most PNs suggested that these consultations did not lead to a close professional-patient relationship, including knowledge of the patients’ individual life circumstances, as developed in frequent consultations for common conditions such as COPD and diabetes. PNs suggested that visits were too task-focused, infrequent and short to build rapport and gain knowledge of individual life circumstances, in comparison to the 20 minute appointments for chronic disease management.

“She turns up every three months for vitamin B12 injections. So yeah, she’s doing fine but I don’t know what other treatments she’s on. I don’t know much
about them, about their life or anything. That’s all I know, that she comes to us for her B12 injections.” PN10

A minority of SNs however perceived that PNs did play a wider and supportive role for people with MS.

“I think a lot of them get quite a lot of support from their practice nurse, even if it might only be a 10 minute injection, I think they discuss their problems, it’s someone to chat to once a month.” SN1

This reveals a possible discrepancy in how PNs and some SNs view the PN role for patients with MS, whereby some SNs may assume a greater PN role in care than PNs are able or willing to provide. However, the majority of SNs interviewed concurred with the limited role of PNs in MS care.

One disconfirming case of the limited role of PNs in MS care, was that of a PN who had good relational continuity with a patient with MS, due to taking blood for monitoring whilst the patient was prescribed immunosuppressant drugs such as Azathioprine.

“The one gentleman with MS that I remember seeing quite a lot was put on Azathioprine and we just did bloods. I probably had a good relationship with him for about three years.” PN13

A potential explanation of this disconfirming case was that the patient with MS experienced significant cognitive impairments, requiring the PN to coordinate with his spouse as well as with specialist MS services. In addition to coordinating formal and informal support, this PN offered relational continuity of care.

“I just felt like I was more maintaining him, just checking bloods. I felt really probably quite useless for him, because I couldn’t really offer him much more support than he already had. He was getting everything via the MS nurses that he should have been getting, but he just wasn’t retaining the information. I felt like I was just more or less maintaining their job in the interim period until they saw him for regular reviews.” PN13

This PN echoed the feelings of other PNs who were less involved with patients with MS, by explaining how she viewed her role as subsidiary to the SNs. This case showed that where PNs had a long term relationship with a patient with MS they could potentially play a role in their ongoing health care needs, but this role may not be acknowledged by PNs.
Some GPs and PNs reported administering injectable MS disease modifying drugs such as Avonex\(^3\), where patients preferred not to inject themselves. However, this seemed to vary with local operating conditions such as practice level protocols and appeared to be in the minority of practices. For certain injectable MS medications, visits could be as frequent as weekly.

“She’s somebody that I see every week, she’s on Avonex and she won’t inject herself.” PN1

Where PNs see patients on a weekly basis, it could be suggested that they have a more involved role in MS care than is currently acknowledged, and that people with MS are candidates for PN care. Although this practice appears to be in the minority, in the rare cases where people with MS require weekly consultations, PNs may experience relational continuity of care, and increased knowledge of their patient and symptom management; however data on this topic is limited in my sample.

This data suggests a contradiction between how PNs view people with MS as candidates for PN care (not appropriate candidates) and how they demonstrate access facilitation and adjudication, through providing frequent contact for injections or other conditions. GPs described their role for people with MS as a longitudinal and continuous supportive approach, whereby they provided both emotional support and support for physical symptoms (e.g. assessment and referral) to patients throughout different stages of their condition, including relapses. As displayed in the quote below, reassurance (defined as removing unfounded doubts or fears) was an integral part of the day-to-day support provided by GPs to people with MS. GPs viewed themselves as in a key position to manage health related anxieties, as they often had positive and long term relationships with patients and additionally could provide medical knowledge and the promise of acting on health concerns.

“I’m there for her when she becomes worried or anxious about a new symptom. I’m there to support her through that anxiety, and maybe reassure her that her symptom isn’t to do with MS. Try and give her hope that the MS won’t necessarily deteriorate, or become disabling, and if anything did happen in the future to either see her through that episode, or to direct her to the appropriate medical intervention, or social support that she needs.” GP13

\(^3\) Avonex is the brand name for Interferon-Beta 1a. It is taken once weekly to decrease the number of relapses experienced and therefore slow down the progression of disability in relapsing-remitting MS.
Providing ongoing support for people with MS was viewed as the role of primary care, whilst secondary care was viewed as a more task-focused area with a specific remit. Patients with MS were therefore viewed as candidates for GP care when they required ongoing support, but were not appropriate candidates for GP care when their needs involved specialist medication or specialist follow up.

“If the care provision is purely on the basis of support, then that becomes clearly primary care’s role. If it’s more medication and treatment and follow ups, that stays under the remit of secondary care.” GP12

This task-focused definition of secondary care as the providers of MS treatment without ongoing support seemed more in keeping with all professionals’ perceptions of the role of neurologist than the role of a SN (discussed in more detail below on page 187).

This supportive role often meant that GPs were the key health care professionals for ongoing management, as perceived by themselves, PNs and SNs, as they were aware of the medical, psychological and social needs of their patients, via relational continuity through frequent contacts.

As part of this supportive role, facilitating self-management was seen as a crucial role for all three health care professional groups, but for people with MS specifically it was mentioned most frequently by SNs.

“They’ve got to learn how to manage, because- what was that statistic the other day? Over a year you see a health care professional for three hours- it’s something really tiny. If you put that into proportion, then if they can’t manage it themselves, how are they going to manage? So quite often it’s about how will they do it when there is no-one around with a little voice reminding them.”

SN1

This was part of a wider difference in attitudes between the three professional groups, highlighting differences in perceptions of candidacy. PNs, as discussed above, did not commonly work with patients with MS, GPs discussed the potential dependency of people with MS on services, suggesting that they were always candidates for care, whilst SNs highlighted the need for people with MS to take ownership of their MS. They discussed how the SN role had changed from clinician-led care to empowering patients through information and support to make their own changes and manage their MS. This suggested that even in situations where people with MS were appropriate candidates for MS care (e.g. fatigue or pain) they should be helped to self-manage. This challenged the idea that
eligibility for care was a justification for using care in situations when it may be more beneficial long term for patients to learn to self-manage and be as autonomous as possible.

“We have to change our perceptions as nurses, you know, because we’re very, kind of, touchy feeling, want to be there all the time and actually it’s about promoting self-management and independence and things.” SN3

Self-management in this context appeared to be where patients with MS managed their MS independently and limited the amount it prevented them living their lives.

“We aim for self-management where they can bring in the help that they need, like us, if and when problems arise, but they carry on living.” SN8

This move to self-management was seen as part of a wider movement in health care and government policy and was viewed positively by the majority of participants. SNs did not see self-management as lessening patients’ candidacy for care, rather that it was the preferable alternative to dependency on health care services. All SNs highlighted that self-management should be used in coordination with the use of formal health services when they were needed e.g. at times of relapse.

6.2.2 Co-ordination of care

GPs perceived coordination of health and social care services as a key part of their role. Coordination and referral were seen as a way of providing responsive and continuous care for symptoms perceived as warranting services outside of the GP remit, e.g. specialist or community services.

“I see myself primarily, as treat what you can that’s acute, treat what you can medication-wise, and then move on to coordinate the rest of the services.” GP3

Coordination and referral were implemented once GPs felt they had completed all assessment or management tasks that were perceived as within their remit. Therefore, MS patients’ candidacy for GP care depended on GP perceptions of their own role and the role of other health care professionals. The boundaries of this perceived remit, and therefore assessments of patients’ candidacy, differed between GPs based on their personal level of confidence in managing symptoms, and recursively through their previous experiences of other services. This level of confidence could differ based on their level of knowledge, available time, and perceived ease of access to specialist services. For example, some GPs were confident and able to manage psychological problems within time- constrained primary care settings, whilst others perceived a need to refer the patient to mental health
services. However, where GPs had negative experiences of referring a patient i.e. to another professional who was perceived as less competent or to a service with slow access, then GPs may be more likely to manage a patient’s needs personally. Perceptions of candidacy and recursivity were therefore highly subjective.

PNs viewed their role as assisting patients to manage their medical and social needs by providing information on available services to patients (and thus facilitating self-management), and coordinating patient care through referring patients to both the GP and community services, often in collaboration with their GP.

“There are places that I can give information about, like social services if it’s a financial thing, giving them help where they can get in touch with social workers to hopefully help them with a specific social problem.” PN10

PNs perceptions of candidacy were based on where patients required services that they did not provide within their remit, but fell under the remit of either the GP or external services. PN's roles for people with MS therefore depended on their knowledge of relevant services to help them navigate to relevant services.

GPs perceived role in coordination (and therefore perceptions of candidacy) differed along the care pathway. GPs reported that they were very involved with patients during the pre-diagnostic and diagnostic stages and were responsible for initial referrals to Neurology for diagnostic testing. GPs reported that during diagnosis, specialist MS services often took on the central coordinating role to confirm diagnosis and implement MS specific management regimes. After this period GPs perceived that primary care once again became the central coordinators, implementing daily management of symptoms, either independently or in collaboration with specialist services. GPs reported being especially involved in the care of patients who required palliative care with frequent primary care input. This further supports the concept that people with MS are candidates for GP care when their health care needs are not led by specialist services, either before or after diagnosis.

“This young man had multiple sclerosis and died at home, I used to see him quite a lot. At that point there was nothing more that anyone in secondary care could do, so it was really making sure he had all the help at home, trying to liaise with social workers, making sure the family get the respite care, all that happens really from us in a sense, you know. So I think when the hospital loses interest [laughs] is when we pick up the pieces really. And I’m much more involved at that point.” GP8
GPs emphasised the generalisability of their skills in coordinating care and highlighted they were not specific to MS. Most GPs were confident in their ability to coordinate services and refer to generic services (e.g. social services, occupational therapy). However, this could sometimes be a time-consuming and frustrating task, especially when specialist MS services were required.

“I particularly remember one patient who was very, very unwell with her MS and she was having lots of carers. My lasting memory is it was very difficult and frustrating treating her because it was trying to marry up all the different services and getting the right people involved. And it’s sometimes is quite frustrating as a GP because you feel like you can’t actually make massive in-roads yourself because it’s a bit more specialist.” GP5

Difficulties in coordination were experienced when other services declined to accept referrals for a particular patient, yet their needs could not be met in primary care. GPs described this as a difficult situation where they were aware that patients were not receiving necessary care, and yet did not have alternative sources of care to utilise. This aligns well with the permeability aspect of the Dixon-Woods et al. (2006) framework of candidacy by showing the impact of services that are impermeable to professionals and patients by not accepting, or being reluctant to accept, referrals.

“Secondary care had basically said there was nothing more we could do for this patient. They’d almost kind of washed their hands of her and she kept coming back to see us and there’s only so much we could do so that was particularly difficult. You could see the last letter from the neurologist is actually quite a terse letter. You could infer from that that he didn’t want anything to do with her anymore.” GP7

This was described as challenging for the patient-professional relationship when patients expected the GP to successfully coordinate their services and achieve shared goals, and GPs felt hindered by the actions of other services. This impermeability could lead GPs to feel that they were not providing responsive care or meeting patient needs, even though they felt they personally were providing the most responsive care possible.

SNs experienced difficulties in coordinating services with primary care, after the change from PCTs to CCGs, due to the volume of CCGs that fell within their geographical remit. Services were made less permeable when it was not clear who was responsible for providing or financing particular services within a geographical area.
“Our relationship with primary care is patchy, it’s difficult because of the area we cover. I think it’s 15 CCGs that we interact with? It’s difficult at the minute to find out who’s doing what and who’s pulling the purse strings from that view point.” SN2

All SNs perceived that they were consistent in keeping GPs informed of their actions through written communication. Frustration was experienced by SNs who felt that their communication with GPs was not reciprocated, preventing them from being aware of the primary care services their patients were receiving.

“Communication with GPs seems to be one way. We write to them, but they never tell us what they are doing, unless they want us to do something for them! We always copy our letters to the GPs, we give them directions, “dear GP, please do this” and that’s because we know they don’t read our letters.”

SN1

This lack of communication was perceived as creating a barrier between primary and secondary care services, and causing unnecessarily fragmented care that relied on people with MS to relay information between professionals. SNs were also concerned that where people’s main health care needs were not linked to their MS, there was a risk that patients could end up not being coordinated by either primary or secondary care. The greatest risk occurred where GPs did not see management of a person with MS as primarily their concern, and people with MS did not attend specialist MS appointments more frequently than annually, or indeed at all. At the most extreme this could result in people with MS not having any health care intervention at all for prolonged periods of time, and in several cases professionals reported unnecessary disability accruing in this period. How GPs viewed patients’ primary candidacy needs (i.e. whether their care should be led by primary care or specialist services) could have a significant impact on people with MS’ overall health.

“My concern is the GPs don’t see the patients, they may not just have MS and again from a general health view point is that they’re not being reviewed and that is a real big concern, because then they just fall out of that primary care situation, and then often if they don’t come to see us for whatever they’ve actually got no input. Every now and again you find someone who’s not seen anyone for years, and if someone had got in their earlier you might have made a bit of a difference.” SN2
SNs reported that some people with MS could be left at a disadvantage in comparison to those without MS, where interventions for non-MS symptoms were untimely or not provided at all. However, a minority of SNs mentioned that sometimes people with MS actively chose to ‘disconnect’ with services and not receive any further specialist MS input.

“Sometimes they don’t want any input from us because they don’t want to be reminded that they’ve got MS, or they feel that they can deal with it on their own without any input from us, and that’s fine.” SN7

Therefore, for those people with MS who were voluntarily or involuntarily not involved with specialist MS services, coordination of primary care services was essential to ensuring all their needs were addressed, both inclusive and exclusive of MS.

6.3 Patient-centred care

All professionals stressed the importance of patient-centred care. Whilst this was seen as an essential part of care for any patient in primary care, it was emphasised as especially important for patients with MS, to address an unpredictable and variable disease course that required a timely response to symptom exacerbations.

For all professionals, patient-centred care was perceived to incorporate a holistic approach, and required sufficient time to address all problems of importance to a patient. This was perceived to be achieved through a positive and long term professional-patient relationship.

6.3.1 Holism

All participants referred to the need to provide holistic care for the whole person and all their interrelated social, psychological and physical needs, instead of simply treating one medical aspect of a person’s experience. From this perspective, all patients with MS should be viewed as candidates for care due to their additional physical and social needs.

“Part of the role of general practice is to manage the whole person including their psychological and social consequences of their condition.” GP 13

Both PNs and GPs also highlighted the particular needs of people with chronic conditions, including the increased psychological needs of people with chronic conditions.

“People that have chronic conditions also tend to have a lot of mental health issues as well – depression, and...so you have to look at them holistically, not just at the disease. There’s a multitude of factors that you have to consider when you see a chronic disease patient.” PN5
This corresponded to a historical model of primary medical care as the home of the “family doctor (GP10)” who had a “bird’s eye view (GP9)” of a patient’s life and health care needs. These needs included MS, physical and psychological comorbidities, family and social relationships, housing factors and employment. Many participants said they provided services to multiple generations of families (and could be the named doctor for grandparents, parents and grandchildren), and as such were aware of family dynamics, such as spousal relationships and caring duties.

“I think there’s a real place for a family doctor that knew your mother, your grandmother, your husband, your children, and can put somebody in context. And I certainly think the patients like it.” GP 10

All SNs mentioned their role in working with, and supporting, family members of the person with MS, and many highlighted their perceived lack of support for this group. SNs worked with family members both to maximise their own wellbeing and to assist family members in helping patients to manage their MS.

“[My role is] making sure they’ve got the support in place either from their families or other people. I suppose more so in the community we sort of try to support the carers as well, the whole family approach rather than just individuals. When I worked in hospital it was more about focusing on the patient.” SN9

Knowledge of family and home dynamics provided the opportunity to put a person “in context (GP 10)” and often was linked to a wider awareness of their patients’ personal circumstances, including employment and living arrangements. This was felt to be of particular importance when dealing with a highly variable and fluctuating condition like MS, as it was possible to see where circumstances could be improved to increase a patient’s quality of life, or conversely to see where a person’s MS was starting to impact on a given area of their life.

“I think what would be hard if it was a new patient with MS that just came and registered, it would be getting to know her and getting to know her normal. Like this lady, I know her whole lifestyle, you know, what she does, what she works as, what her husband does.” PN12

This awareness of what was “normal (PN,12)” for a particular person with MS allowed professionals to make adjudications or judgments regarding patients’ abilities to cope with both emotional and physical difficulties related to their MS, and to identify when they
needed increased support. This knowledge therefore allowed a better appreciation of when the individual became a candidate for service intervention. SNs and GPs could improve situations directly by intervening in employment, financial benefits, or DVLA applications by giving their written support.

Managing physical comorbidity and multimorbidity were seen as key goals for treating people with MS in primary care. Whilst clearly defined MS symptoms and MS specialist medication were viewed as the role of specialist care services, non-MS symptoms and a more holistic approach to wellbeing were viewed as within the remit of primary care, supporting patients’ candidacy for these services.

“Things not specific to MS so I’m referring to treating their psychological support, social support, treatment of other medical flare ups, coughs, colds, chest infections, things like that, so it’s treatment but, not for the MS specifically.” – GP12

In relation to this, all professionals emphasised the need to explore all possible causes of symptoms, and not attribute symptoms to MS, in order to establish whether a patient was a candidate for care, and if so, which service.

“All three of my patients with MS tend to blame a lot of the other things that are going on all down to the MS. So it’s trying to make sure that we’re not missing that, you know, the lady’s tiredness isn’t because she’s got some other medical problem going on and going over the basics as we do for patients that didn’t have MS.” – GP2

Professionals’ accounts of symptom attributions differed. The majority of GPs reported that they took a careful history and did not assume that symptoms were always due to MS. Conversely the majority of SNs suggested that both patients and GPs attributed all symptoms to MS, thus assuming candidacy for specialist care that may be incorrect and unnecessary. Where this impacts on navigation it was suggested this may have negative consequences for coordination of care and patient trust.

“I think sometimes some GPs put everything down to their MS and sometimes even stupid things down to their MS and I think that is wrong, because it destroys the patient’s confidence in them and so when they ring us and we say that’s not your MS, you need to go to your GP, their own GP – “That’s your MS”, and often the patients feel like a ping pong ball because we’re not experts in other things.” – SN2
Professionals also spoke of the need to make sure people with MS did not miss out on any of the services available to all patients, e.g. health promotion activities such as screening and vaccinations, as all patients were viewed as candidates for these services.

**Psychological problems in MS**

All professionals discussed the high levels of depression and anxiety they regularly saw in people with chronic conditions, and SNs highlighted this in MS (“up to 90% of my caseload”, SN7). All professionals discussed social and biological factors that may cause low mood, e.g. relationship breakdowns or symptoms such as incontinence. In addition, all SNs and a minority of GPs discussed this within the context of the UK’s current financial and socio-economic climate, where financial and employment worries were common.

“I’ve got a lady who it’s taken over her entire life, she is so stressed about her benefits being cut and how she’s going to survive. We’ve had patients whose benefits have been stopped over-night. It’s dire.” SN7

SNs and GPs commonly normalised psychological problems in MS by highlighting the logical explanations of why people experienced psychological problems in this condition. SNs emphasised certain time points at which patients were most likely to experience these problems.

“There’s an understandable element to certain parts of it, when they’re just diagnosed you’d expect them to go through the gambit of emotions. If they’ve not relapsed for quite a few years and they’ve forgotten they’ve got MS and then it comes back to bite them on the bum, when they change from relapsing remitting to a more progressive type and also when they, I suppose in their mind, have to make life or death decisions with respect to the treatment. So sometimes they do need extra support to talk through that.” SN2

All professionals discussed the psychological impact of MS relapses and disability progression. The majority of GPs and SNs dismissed pathological explanations in favour of social justifications and resisted medicalising or pathologising symptoms of low mood in people with MS. This could lead to not viewing patients as candidates for psychological care if the cause of their symptoms was not viewed as due to psychological conditions or of a severity requiring psychological support.

“That’s not necessarily just true of people with MS. Any long term condition or any sort of shit life [sic] syndrome, which most of our patients have, I think that also affects it as well. When most of your patients are depressed, some extent
will have rubbish lives or are down. At what point do you medicalise them or is it just something that we should be trying to improve people's lives and quality of life.” GP6

Despite this emphasis on social explanations, management did not always seek to address these difficulties, instead favouring the use of pharmacological or psychological management to address symptoms of low mood, or less commonly, anxiety. In addition, the majority of SNs referred to research suggesting a specific brain pathology in MS, or MS treatment, may cause depression.

“A lot of them get very low in mood and we don’t know whether that’s because they’ve been diagnosed with a long term condition or whether it’s something in the brain, specifically with MS or one of the medications they’re on.” SN7

For professionals this pathological explanation did not appear to alter their perceptions of identification of candidacy or navigation to GP or psychological services for support. All professionals were confident about their abilities to elicit symptoms of depression in people with MS. PNs and SNs suggested that GPs were central to the management of psychological problems such as depression. Both PNs and SNs reported that they would contact the GP immediately if they suspected depression in any patient with MS, and would rely on the GP for ongoing psychological management.

“We’d ask the GP to see them, because they are the ones that would do the prescribing in that case.” SN1

SNs reported relying on the GP to manage the situation and patient needs, as they were unaware and unwilling to perform the role of a mental health professional. People with MS were therefore candidates for GP care as soon as they demonstrated a severity of depression that SNs felt unable or unwilling to manage. All PNs and SNs highlighted their lack of training in psychological needs and SNs, and to a lesser extent PNs, felt very strongly that managing psychological needs should not be within their remit.

Nurses felt that where support for people with MS experiencing psychological symptoms was not available then they were left working outside of their professional remit. This was emphasised more strongly by SNs who felt that both professionals and people with MS expected them to be knowledgeable on psychological issues, due to the nature of their role in helping people to adapt and adjust to life with MS. However, both SNs and PNs felt untrained and unsupported to deal with these problems.
“The patients come to us and expect us to have the knowledge, because we deal with a lot of depression, low mood, as you would with any long term condition but it’s really just out of our depth.” SN3

Problems caused by unfounded expectations were expounded by the judgement of other health care professionals who overestimated SNs’ remit in managing psychological symptoms, and their responsibility for managing these.

“The problem lies, sometimes in the community they think well we are MS nurses, this person is low in mood, sort it out and we can only do a certain degree of it, but if they really need a course of counselling or something that’s a bit more intense it really needs to be done by properly supported counsellors I guess, the ones who are educated to doing it.” SN8

The threshold at which patients need referral for more intense support did not appear to be clearly defined in any professional group, and appeared to differ by individual confidence and experience, suggesting that perceptions of candidacy were subjective.

When all three groups of health care professionals were asked about “psychological needs of people with MS” they interpreted this differently. Some discussed conditions such as schizophrenia or bipolar that may require the care of a Community Psychiatric Nurse (CPN). Others discussed low mood that may or may not require intervention. When discussing their level of comfort in managing psychological symptoms, most participants said they were confident in managing psychological problems such as anxiety or depression without suicidality, but required support of mental health services when managing people whose psychological problems were potentially risky to themselves or others. In some cases of people with MS, SNs and GPs felt that their psychological needs were more pressing than their physical health needs, and therefore the emphasis of their care should be shifted to mental-health services as they were more candidates for psychological care than physical care.

“We’ve got a few patients with mental health issues as well, so that can often over shadow the physical symptoms, and I’m absolutely rubbish at mental illness. I just haven’t got enough knowledge or insight, so I’m really out of my comfort zone and completely out of my depth, so I find that quite traumatising actually.” SN3

Both SNs and PNs commonly referred to “Pandora’s box” or a “can of worms”, whereby exploring an individual’s psychological problems revealed more than they had the time or
capability to manage without a quick and guaranteed referral to psychological services. Due to the perceived risks, some nurses would chose to not address psychological issues in their consultations.

“If we open that can of worms and we’ve got nothing to support them with, are we actually doing them a favour? Yes, it’s ignoring them [psychological problems] in one sense, or talking about things more generically. Because you could actually take away all their boundaries and that concerns me with the lack of back up available”. SN2

All SNs and the majority of PNs reported that their main fear in managing people with psychological needs was a risk of suicide that they could have prevented, or did not document or refer on (thus putting themselves at risk professionally). Sometimes SNs were not sure as to the cause of psychological symptoms e.g. mania or suicidality, as these could potentially be a reaction to DMTs or steroids administered to treat relapses. In these instances SNs required support from colleagues trained in mental health. SNs perceived that as they wished to turn to mental health services for support, so their role was to be able to offer mental health professionals support on physical symptoms.

“My role really is to be there for the mental health professionals that deal with her [patient with MS] a lot of the time, because if we can guide them, I've given the staff my name and direct number and said if she gets any more physical issues they know how to ring me for advice.” SN3

Whilst psychological issues such as depression were commonly mentioned, only SNs and one PN mentioned the cognitive difficulties experienced by people with MS, despite this being a highly frequent symptom in MS (40 to 65%; Amato, Zipoli & Portaccio, 2006), and despite GPs being perceived as the key lead for psychological problems.

“You’ve also got to look at the patients themselves and a lot of them have got cognitive memory problems and they might well forget that they haven’t seen us for a while and they might forget to phone us.” SN4

Awareness of cognitive impairment is important, as cognition was potentially an access and management continuity barrier to care, where it prevented patients from remembering to make appointments, or caused difficulties remembering information given in consultations. In this respect it could impact on the “appearances at health care”
component of the candidacy framework, as even when a person has navigated the health care system, it may prevent attendance.

“I found that we used to write things down in the end, because I used to always ask him to bring his letters in for when his next review was at the hospital. He’d say it was next week and it was actually next month. But again, I was relying on him to bring back the stuff, and often he didn’t. He would often miss his appointment. And in the end it got to the point where I just kept ringing on the days that I knew I needed to see him, because there was no point in giving him a time and an appointment, because he’d forget.”

PN13

This suggests that in a minority of people with MS cognitive impairments may potentially have an impact on patients’ access to, and use of services. This may be under acknowledged by professionals in primary care who may not consider the candidacy of patients with cognitive impairments.

6.3.2 Time

The ability to provide holistic care was perceived to be limited by time, as it could be difficult to address all problems of relevance to the patient in a limited time consultation. Despite having longer appointment times than GPs, this was primarily an issue for PNs who felt their consultation times were set externally. GPs (especially partners in more senior positions) felt (within limits) that they had the autonomy to set time as they chose. SNs had longer appointments than both GPs and PNs (approximately 30 minutes) but felt they could struggle to address multiple complex issues in a holistic manner during this limited time. SNs viewed newly diagnosed patients as candidates for home visits irrespective of disability and arranged one hour home visits to address concerns and answer any questions. This was felt to be a very valuable and efficient use of time, as it was perceived to lessen use of services later on and improve wellbeing.

“The investiture of time when they first are diagnosed, if you go and spend two to three hours with them at home, it reaps benefits all the way through generally, because if they feel as if they’ve had enough time, had things explained, asked lots of questions and you get rid of all the myth busting that you’re having to do and all the rubbish that goes with that.” SN3
SNs perceived that their role was not simply to provide patients with information, but to provide them with credible information and expel any misconceptions learnt through the internet or the media. Limited time led to prioritisation of issues, and some PNs felt that it was difficult or impossible to address psychological issues, when the 20 minute consultation centred on the assessment and measurement of physical symptoms.

“So yeah we ask about depression. But it’s difficult because of the time frames we have for appointments.” PN1

This was echoed by SNs who felt that even if psychological needs were within their remit, it would not be possible to address both mental and physical needs in a 30 minute consultation. A perceived lack of time also meant that PNs reported being unwilling to address additional physical comorbidities in consultations, unless there was a clear abundance of time. In addition to a lack of specialist knowledge (discussed further below), this was given as a main reason for not addressing MS in PN consultations, i.e. MS was viewed as the comorbidity not the index condition. This suggests that patients with MS may not be viewed as candidates for PN support for either psychological or physical concerns.

“I probably wouldn’t mention it because there’s enough to talk about with their asthma. So if the asthma was quite straightforward and the boxes were ticked and they were all happy with their asthma then I might say your MS seems to be ok at the moment is that right? Just give them an opening. But that’s only if I have time.” PN1

Home visits were used by all professionals to manage complex cases with multiple issues where time was perceived as limiting. Home visits were felt to provide more time, which in turn allowed the opportunity to address more aspects of the patient’s wellbeing. For PNs home visits offered the opportunity to address additional issues that would not be viewed as central in their more formal consultations.

“We’re not under pressure quite as much on our home visits as we are in the surgery. In the surgery you always know that there’s another patient out in the waiting room. But when we’re on home visits then we manage our own time, so we can spend a little bit longer with people with MS, and give them the opportunity to talk about any issues or any problems that they have.” PN3
GPs valued the ability of longer consultations and home visits where they deemed them necessary to manage people’s multimorbidity, perceiving this to be the most effective use of time and resources by addressing many issues contemporaneously.

“It’s continuity, we can deal with all the problems for more complex patients in one session, in a good, longer consultation that’s a home visit, rather than sort of, bitty telephone triage and things with different GPs.” GP2

Using home visits with longer consultation times was felt to improve the relational, informational and management continuity of care provided, in comparison to discussing and addressing issues in separate consultations, potentially by different professionals.

“I think two things would make a difference to MS patients; more time and continuity of care, and again that’s about having rather more time and being able to schedule your follow-up patients and so on.” GP1

Greater time was also provided through the use of scheduled follow-up appointments, which all professionals would use to address additional issues and monitor progress or decline.

6.3.3 Continuity of care and the professional-patient relationship

Relational continuity of care was essential to all participants. Relational continuity of care between a patient and one health care professional over a long period of time allowed professionals to gain knowledge of participants’ functioning. It subsequently made it easier to identify when maximum health and wellbeing was not being maintained and to identify areas for intervention. In effect, continuity of care allowed professionals to judge criteria for candidacy of care at an individual level.

“If we stay in a practice long enough we do get to know the patients quite well and we can see they’re not walking as well, or they’re out of their chair and walking in. You can see the difference sometimes.” PN6

Awareness of normality and difference allowed all participants to use their familiarity with a patient to judge differences in body language that may indicate a worsening of physical or psychological symptoms. This familiarity worked on knowledge of participants’ physical demeanour such as their body language or tone of voice, or psychological constructs such as personality or mood.

“I mean I think the whole thing about general practice is you work a lot on cues and what people aren’t saying and what their body language is saying and their facial expression, and that can be burdened or low in mood.” GP5
Relational continuity of care also attempted to ensure that one professional was familiar with a patient’s medical history, including previous symptom exacerbations or progression (increasing informational continuity). This was seen as beneficial for both patients and professionals as it increased professional knowledge, sped up the process of dealing with exacerbations and was viewed as a method of increasing patients’ confidence in their health care professional. Having the same GP for a prolonged period of time could potentially ensure that judgments regarding candidacy and recursivity were made faster, if the professional was quicker at recognizing ambiguous signs of a relapse and may ensure advantageous knowledge of treatments and service navigation.

“I think if you’ve had the same GP who’s always been involved every time there’s been deterioration or a rise in symptoms, then it makes it a lot easier clinically to manage what’s going on.” GP13

Relational continuity of care facilitated a positive professional-patient relationship, ensuring trust and that patients felt listened to, which was perceived as improving patient experiences of care.

“I would imagine patients probably see the benefit of just having the same person so they’re not re-telling the same story again and they feel that someone is actually responsible for their care and that someone is listening to what’s going on.” GP9

All participants mentioned the exhaustion patients felt at reliving their life story and medical history to many professionals. The concept of personal responsibility was also important to both professionals and patients, where responsibility signalled that not only was the patient a clear candidate for care, but care coordinated by a named individual. Due to the nature of their role, PNs often had to aim to change health behaviour, and reported that this could be quite contentious for some patients. They therefore saw long term partnership with the patient as a method of overcoming resistance to lifestyle changes and working in collaboration and partnership.

“I’m not saying I befriend them but I like them to see me as their...I like to help them along the way and say we’re not going to do everything overnight. We’re going to work at it with them.” PN4

By using this longitudinal collaborative approach, professionals aimed to ensure that goals and services were relevant to patient-centred care and patient chosen goals, and therefore had a higher likelihood of being adhered to. Getting to know and trust one
professional also enabled discussion of sensitive issues that could be physical or psychological in nature.

“They often come back to the same person because they like that continuity, and it often takes a long time for people to trust you and to get to know you, and to feel comfortable with telling you this information. And often patients with MS might have urinary incontinence or something, and they might not want to tell the person that they’ve just met for the first time.” GP4

Gaining a patient’s trust was viewed as central for the honest discussion of sensitive issues, and health care professionals reported that patients were more likely to bring up sensitive issues with a professional who had earned their trust, over a prolonged period of time in some cases.

Long term continuity with a patient allowed GPs and SNs to judge the frequency of that patients’ help seeking, through an ongoing awareness of how often the patient was presenting to primary care or specialist services. This affected GPs perceptions of candidacy, as where infrequent health care users presented with symptoms, GPs were able to factor this information into their assessment of presenting problems and patient needs. In some cases these patients were viewed as having more serious needs when they did present at health care services, than frequent attenders commonly presenting for minor issues.

“My lady with MS that I see regularly, she’ll actually ring up and book a home visit herself, she's quite good, usually every couple of months. But when she's got a problem, I know that if she's on the list, she needs to be seen.” GP2

It was acknowledged that this extra level of awareness would not be possible with new patients, or patients who did not see the same GP regularly, thus limiting GPs’ ability to judge candidacy in these situations.

Whilst frequency of attendance was less relevant to PNs (due to their focus on routine follow-ups or infrequent tasks such as vaccinations) PNs learnt about their patients’ preferences for symptom management through long term continuity. Long term involvement with patients meant that all health care professionals had been involved with past treatment decisions and could therefore comment on the patient’s individual responses to past treatment and their preferences for future care.

“In the past I’ve persuaded her to take antidepressants for two months and she did quite well. But she profoundly doesn’t believe in depression as a thing; she
thinks depression is for weaklings, so she says “I’m not depressed, why do you always go on about antidepressants”. There’s no way that she’s going to accept any therapy, so I just have to be kind of supportive.” GP1

This aided a partnership approach to care and ensured that professionals were aware of patient’s goals and important values. In addition to their knowledge of their patients’ preferences, all participants referenced the expert patients they worked with. This could refer to patients having lived experience, resulting in knowledge of their own body, or patients who were very knowledgeable on MS physiology and treatments.

“The patient is the expert in their disease, we’re the expert in medicine and treatment but they’re the expert in their experience. Because they’ve had the disease for a long time and they know what’s going on, how their body reacts. So you’d be a fool not to take into account what they’re saying.” GP7

In addition to utilising patient experiences to ensure relevant and tailored care, the majority of GPs found that working with expert patients with MS changed the dynamic of the doctor-patient relationship. This meant that GPs viewed themselves and the patient as mutual experts, with a more equal approach to responsibility for management. For some GPs this involved playing a less central role for MS management, and focusing instead on comorbidities.

“I’m more in a supportive role with her being the expert patient really, and me, sort of, looking after the other things, the COPD, the stroke and the blood pressure.” GP2

Expert patients could cause difficulties when patients expressed the feeling that GPs were not knowledgeable enough on MS to meet their needs. This caused difficulties in the doctor-patient relationship, especially for younger GPs who had less experience working with people with MS in primary care.

“The patient may not come and see me as much because they may feel, you know, there’s that thing of do they value you less because you can’t deal with MS. I got that impression from him, he thought that because I wasn’t the expert on MS, I wouldn’t understand him properly, so my role was to just give him a prescription.” GP6

All PNs and SNs described how they aimed to provide information and support at a level that was tailored to the patient’s individual requirements, to prevent overloading patients with complex medical information.
“Each one’s different really, because some people want to know more or less everything about MS, and other people just want to know the basics, so you’ve got to pitch it at their level.” SN6

A combination of information and signposting was viewed as the best way to ensure person-centred support that addressed a range of issues including service navigation, practical management strategies and support for those needing emotional reassurance. The key to person-centred information for patients with MS was emphasised by SNs as the timeliness of “being ready with the right information at the right time (SN3)”. This referred to providing information as it was needed for a particular question, but also judging the appropriate time to provide information on MS and future prognosis and management options.

SNs could experience problems where patients were very knowledgeable on MS but their expectations were not feasible within current systems.

“Obviously quite rightly patients are better informed, there’s no qualms with that, but it’s the realistic expectations of what can be delivered within the health service, and that is an increasing challenge.” SN2

A minority of SNs discussed how their patients had learnt to play the system and play professionals against each other to gain access to services or pharmacological treatments. This could cause difficulties where communication between professionals was lacking and SNs were not aware of what was being provided or prescribed by colleagues elsewhere. An example of this was steroids being administered incorrectly in primary care, when patients were not experiencing relapse. Playing the system was viewed negatively when it caused inequity or unnecessary treatment through the incorrect identification of candidacy.

The varied experiences of professionals suggest that the candidacy, access and responsiveness needs of every patient with MS may be different, depending on how they view their status as an expert patient, and services may need to be flexibly tailored around the patient’s preferences.
6.4 Access
6.4.1 Access to primary care
Both GPs and PNs reported surgery level access protocols that had a subsequent impact on access to primary care for people with MS. These protocols correspond with the ‘operating conditions’ aspect of the Dixon-Woods et al. (2006) candidacy framework. There was an appreciation of growing demand from patients who were not satisfied with lengthy waiting times to access primary care, and many surgeries reported a nurse or doctor led triage system to increase the timeliness of access.

“A lot of patients now want urgent access or on the day access, so we do a triage system. So if you ring up in the morning, you can get to speak to a GP or an advanced nurse practitioner on the day.” GP2

Whilst it was felt that access through triage systems was highly permeable and equitable for all patients, both GPs and PNs acknowledged the differences in access to care for QOF conditions and non-QOF conditions. It was felt that patients with QOF conditions received more proactive care as they were invited for follow ups by the GP or the PN on a regular basis and given an opportunity to discuss any unmet needs. The majority of PNs reported they felt that GPs also fulfilled this role for people with MS, but this was only mentioned in a minority of GP interviews.

“Basically, with neurological conditions, it would probably be the GP that asks them to come along, or sometimes patients will self-refer. But it’s not something, I’m sure you’ve heard of the QOF indicators we use in general practice? Because neurological conditions other than epilepsy aren’t sort of annually checked, they’re not invited in regularly. So either they come along because they want a health check, or because the GP has asked them to come in.” PN3

The majority of GPs (with the exception of one) were aware that MS was not a QOF condition (thus a more limited candidacy for proactive GP care) and therefore they were not responsible for arranging reviews or follow ups.

“So, you know, MS isn’t on QOF, so I’m not going to be calling them in.” GP6

This suggested a discrepancy in the data where PNs believed that GPs played an active role for monitoring patients with MS, whilst GPs believed that this was the remit of secondary care services.
The issue of not proactively calling in patients with MS corresponded with a larger issue regarding personal responsibility for people with MS, and the predominant role of specialist MS services in managing and coordinating care. This was not presented by GPs as deference to expert patient status, more as an understanding that the overall management of people with MS primarily resided with secondary care. Where patients required clearly defined primary care input, but experienced physical access barriers to attending primary care (due to mobility issues, for example), most GPs were able and willing to undertake home visits for those deemed suitable candidates. Home visits for patients with restricted mobility, overall ill-health or multimorbidity, were commonly mentioned by all participants as a method of ensuring equity of service provision to all patients.

In addition to clinical characteristics, individual professionals made decisions about the appropriateness of home visits, so potentially their judgment of candidacy impacted on access. Both GPs and PNs perceived good equity of care provision in primary care, through the roles of both GPs and PNs. PNs primarily conducted home visits for flu vaccinations to ensure that this service was available to all patients, irrespective of mobility difficulties. This was considered especially valuable for patients who experienced multimorbidity and those with weakened immune systems e.g. MS.

“We have 3 nurses that do home visits for vaccinations, so at this time of year we’re busy going out doing that for people who are too unwell to come in or too infirm to come in.” PN1

In addition to vaccinations, an equitable approach was taken to providing general health checks and lifestyle advice to people with chronic conditions. PNs reported that home visits provided the opportunity to offer the same services as more mobile patients received.

“If they need a health check we’ll arrange to go and see them at home. Probably do pretty similar sort of things that they do in the surgery, we’ll just talk to them about their lifestyle, check all the other things that I’ve mentioned to you, the height, weight, blood pressure, take bloods.” PN3

The local operating procedures varied on this however, as not all PNs felt they had the time to conduct home visits. In comparison to this, no GP mentioned that they would have difficulty in conducting a home visit, although the time intensive nature of home visits was mentioned by one GP. This corroborated with PN and GP perceptions of their own
autonomy, whereby GPs perceived they worked to their own timetabling, whilst PNs felt restricted by time. Both GPs and PNs referred to the useful additional information that could be gathered from home visits, regarding patients’ living arrangements, condition management and available support.

“It happens sometimes that they can’t come in, so we have to go and visit them at home. It is good to see because you really get a sense of how they’re coping, what’s happening, who’s around and that’s useful.” GP8

Although home visits were primarily viewed in a positive manner by GPs, one GP raised concerns about solely seeing patients in a home environment and another raised the difficulties of completing screening tests with limited equipment.

“You can see people’s functional disabilities when they come into your surgery but people over estimate what you can do in people’s homes and they over estimate your ability to measure risk.” GP11

This suggested that solely providing home visits may not provide access to the same quality of care as consultations in a GP surgery. The minority of GPs also discussed how seeing people in their home environment could lead to a false sense of security regarding their ability to manage independently, as they may have developed compensation strategies at home that could not be utilised outside of this environment e.g. in hospital. This could potentially lead to incorrect conclusions regarding candidacy for care. They perceived that it was therefore necessary to get a balanced and realistic view of ability through combined home visits and consultations in the surgery or hospital. Several GPs had only worked with people with MS when providing out-of-hours access, resulting in a limited awareness and knowledge of the needs of people with more mild to moderate MS symptoms.

“The only patients I’ve seen with MS actually have been when I’ve been doing out of hours. So they tend to be the patients that are quite severe.” GP7

Out-of-hours visits were frequently related to exacerbations of symptoms that may be indirectly related to MS, such as urinary tract infections or catheters. Out of hours GPs were felt to experience disadvantages in judging the severity of symptoms and candidacy for urgent or specialist care, due to a lack of prior awareness of the patient’s normal or stable level of functioning.
“If someone had never met her [patient with MS] before, an out of hours doctor saw her with marked contractures and a weakness, they may worry that this was a newer thing. Someone who knows her will know that this has been stable for many, many years.” GP12

GPs suggested that where they were providing out of hours care, their primary aim was to deal with the immediate presenting issue, before referring the patient back to their primary care provider (who was assumed to have a continuous relationship with the patient), for more connected follow up and referral to services.

GPs commonly referred people with chronic conditions to IAPT; however IAPT services were only mentioned by 3 SNs out of a sample of 9, suggesting that they may not be utilised by SNs.

“IAPT is a good service, if patients have been talking to us and they feel really down, they feel they’re depressed or they feel they’re struggling getting their head around the diagnosis. But there’s quite a waiting list.” SN4

Those who had utilised IAPT services for MS reported positive experiences of these services, but found that waiting times could be prohibitive. Knowledge of local IAPT services differed by FT suggesting that SNs utilization of this service may rely on local links and communication.

“We've recently got to know the local IAPT services. We can't refer directly, so we rely on the GPs to do it. It depends on the GPs if they listen to us and say, yes we’ll refer on, but if we write to the GPs, they might just look at a letter; it could be sat there for ages.” SN8

Similarly to PNs however, where patients could not self-refer, SNs perceived that once they had made the referral to a GP the process was out of their hands, and access was therefore very reliant on GP adjudications.

In addition to facilitating access for individual services, SNs saw GPs role in access at a higher level, through their role in commissioning services for people with MS.

“The area that doesn’t have physio, I’ve noticed that me and the rehab consultant almost write the same letter to GPs now saying “they will have to be admitted as an inpatient as you’ve got no physio”. It’s like you’re writing them insulting letters all the time, because if they don’t purchase services, they’re not there for people.” SN1
GPs did not discuss their perceived role in commissioning services, and this was not explored further, therefore it is unclear if GPs perceive they have the same level of responsibility as SNs perceive they do.

6.4.2 Access to community and specialist care

Cross-boundary continuity, where care was consistently managed and coordinated across primary, specialist and community settings was seen as integral to the care of people with MS. However, continuity depended on access, and varying permeability of access to community and specialist care was reported. Professionals reported access requirements for themselves (i.e. to be able to access services for advice or further information) and their ability to ensure access to services for their patients. Access was perceived as closely linked to responsiveness, as to be a responsive service professionals had to ensure access was as fast as possible, whilst ensuring appropriate support.

“Moving forwards we’re looking at what we can do different for the patients in the centre to be more responsive. We specialise clinics, so for newly diagnosed we actually see them a lot quicker. We offer a specialist relapse service, so hopefully a quicker response to that or advice to GPs.” SN2

This access was especially important where patients required certain interventions at specific time points to prevent further disability accruing. This point was raised most commonly by SNs who highlighted the need for fast intervention for relapses to prevent disability where possible. Frustrations were expressed where regulations or eligibility criteria (commonly perceived as being created by non-clinicians for financial gain) had a severe and negative impact on the wellbeing of patients, despite the best intentions of the professionals attempting to ensure fast intervention.

“It’s like in the area where we don’t have physio, you can have physio if you’re housebound. Well it’s a bit late then right? If you’d actually given them physio before they became housebound...that’s very stupid.” SN1

Once this disability had accrued then it was often difficult or impossible to reverse, leaving patients in what SNs perceived as unnecessarily poor health with a reduced quality of life. Some GPs found SNs were difficult for professionals to access in a timely manner, and this impacted on their ability to provide a responsive and continuous service for their patients.

“The only thing I would like is to always be able to access the MS specialist when I want to access her. Not that minute, but knowing that they’d get back
to you within a reasonable [time period], within 24 hours would be really good.” GP10

Difficulties in accessing SNs were also discussed by SNs, who described how this was a current problem within their service, but one which they could not currently address due to the technological infrastructure utilised in their place of employment. There was a sense of exasperation at criticisms of both patient and professionals’ telephone calls being sent to an answer machine, but a perception of no foreseeable solution as all SNs worked in the community and conducted a large number of home visits or MS clinics in community settings.

“We are probably not as responsive as we would like to be, but in part that is because the nurses are employed centrally but cover the geographical area, so the phones are central. So obviously if we’re out doing clinics in other areas we’re not sitting by the phone.” SN2

In addition to the problems of not being located by the central telephone system, SNs from all Foundation Trusts (FTs) discussed the volume of active patients they had and the difficulties that could ensue in managing high volumes of calls (one SN reported 70-90 calls a day with no administration support or triage service). There was a feeling by SNs in the majority of FTs, that systems such as this were unsustainable but no solution was imminent. It was felt by SNs from the majority of FTs that financial cutbacks caused increased, and often inappropriate, work for SNs, especially administration.

“I guess the other thing is the cuts in the administration that’s going on in the NHS at the moment, that’s having a lot of impact on our service. We appear to be having to do more paperwork, if you like, to keep things running. We sometimes do what feels like other people’s jobs and that takes us away from the care aspect.” SN8

This perception of overwork resulted in SNs feeling overburdened with their workload and frustrated that it prevented them fulfilling their remit, resulting in a less responsive service for patients with MS. Some SNs felt it created a culture where the most responsive care went to those patients who “shouted loudest (SN2)” which was perceived as a negative system for providing care.

The pressure described by SNs in some ways mirrored that shown by PNs. As autonomy was felt to have decreased and a target driven culture increased within recent years,
nurses felt that there was less provision for them to act as nurses and complete the important but less quantifiable caring activities that they viewed as central to their role. All SNs were very concerned about increasing pressure to discharge patients from services, as it was felt that this would prevent patients from accessing services rapidly upon relapse, which could not be predicted, even in those who had been relapse free for many years. Different FTs had different management strategies for discharge. One FT used an archiving strategy to ensure that whilst patients were not on their current case load they were able to access care immediately by contacting the service, who would then move their records back to the active case load.

“The trust are very keen on discharging in general, I think that’s for the doctors, that kind of situation, so it’s different from us, but what we do is we archive patients, so we keep them downstairs in a set of drawers if they haven’t had any contact with us over two years, which means they can reactivate themselves at any point, it’s just that we don’t actively contact them to see how they’re doing.” SN3

Whilst this was viewed as the most efficient use of resources, it did not prevent the problem of high caseloads, as whilst “100 a year are archived, we get a 150 referrals a year (SN3)”, highlighting that increasing referrals to services may still need addressing. A barrier to access reported by SNs across FTs was that they were prohibited from providing care to patients who had not been assessed by a neurologist within the last 2 years.

“The only thing that stops us is if they haven’t seen a neurologist and the rules are very clear, if they haven’t seen a neurologist for two years, we can’t see them.” SN3

This was viewed as preventing patients from accessing SN care, where they had not had a recent neurologist appointment. SNs had mixed reactions to this, whilst some believed this was purely due to financial motives, and therefore an unnecessary barrier to access, others believed it was necessary to protect nurses from any legal or professional ramifications. Both PNs and SNs discussed their perceptions of a working environment where they felt vulnerable to litigation proceedings and aware of the lack of support available from their professional body or medical colleagues if their conduct was questioned. For the majority of PNs and SNs this was corroborated by perceptions of a lack
of support and integration in teams and a feeling of separation between nurses and medical colleagues.

“I don’t think neurologists would necessarily stand up in court for us and they have so much legal protection because they’re doctors, we don’t have any litigation cover whatsoever. I mean, we have the Nursing and Midwifery Council, they would support us, but if we’d done anything outside the code of conduct, then we would be literally on our own, so we have to make sure that we just cover what we can really without getting too paranoid about it to be honest.” SN3

PNs reported that they addressed this issue by referring patients to the GP whenever there was any doubt and thoroughly documenting all information. They referred to these litigation worries most frequently on the topic of suicidality and managing psychological issues with MS.

“I put down appointment made with the doctor, just in case anything did happen and it got back… Because you’ve got to cover your back in case there’s a problem. You want to do your best for your patients but you’ve also got to cover your own back.” PN10

GPs reported that they were more likely to contact SNs than MS Specialist neurologists. This was due to better perceived access of nurses (even with an appreciation that access may be slow), and an understanding that primary care and specialist nursing had shared goals in managing daily wellbeing of patients, whilst consultants dealt primarily with diagnosis and specialist medication. SNs were also perceived as being more approachable, and more knowledgeable of individual patients than neurologists.

“MS nurses are more approachable. So if I’m uncertain, then I would probably get in touch with the MS nurse. If I’m worried about a patient, I think they’re deteriorating and I think they need treatment, then I’d try and get in touch with the consultant.” GP6

The majority of GPs had not experienced direct contact with an SN or MS specialist neurologist, only copying them into written reports, and therefore could not comment on available access or experiences of working with these professionals.

SNs in some FTs felt that the expansion of disease modifying treatments had created a hierarchical care service, where those patients receiving DMTs received more specialist input and therefore a more responsive service than patients who were not eligible.
“My concern is that there’s a potential for so many tiers of different services, because I do feel that people who are under the care of a centre and are receiving modifying treatment from specialists get a much better service than those who aren’t and actually it’s those people that make up the majority.”

SN2

This led to SN concerns of unfairness and inequity in specialist services, where patients with MS not on MDTs saw general neurologists, and patients on MDTs saw specialist neurologists, which was perceived as denying them the right to the most responsive care. The increased focus on specialist services and medication was described as occurring at the same time that community services were felt to be under supported by budget holders and policymakers. The decreased role and decreased involvement of district nurses with both professionals and patients was felt to limit access to high quality community care.

“I don’t think district nurses have the role they used to have with people with MS, making sure they are in appropriate beds, and the appropriate equipment, because I think they literally fly in and out again. They don’t have that relationship they used to have. Because the ones with good district nurses, they have everything they should have in the house.” SN1

District nurses were viewed as the key to the successful assessment of need in the home and the organisers of adaptive medical equipment. The continuous and highly involved role of district nurses meant that they were also viewed by GPs and SNs as a potential professional to highlight problems that patients might be experiencing at home.

“The district nurses are going in, because we have weekly meetings, if they’ve got any problems, they’ll bring them up and they’ll ring us directly but it’ll be flagged up maybe through a different route, if they’re struggling, you know, with coming to terms with anything or problems. So there’s other ways round it, you know, if they don’t necessarily contact us directly.” GP2

The more limited role of district nurses, and their limited contact and coordination with the majority of primary care teams, was seen as a deficit with negative ramifications for care of patients with MS. Their role constituted an access point to both community care and primary care, through their ability to inform other professionals of patients’ needs.

6.4.2.1 Access to psychological services

Whilst the minority of SNs and GPs had good experiences of accessing psychological services, the majority found the waiting lists in their local area were prohibitive (up to
eight months) and available services were patchy and inequitable across geographical areas. SN and GP’s positive experiences of psychological care seemed to be based on the use of services within their local team, whether that was in primary care or secondary care.

“In the practice, once a week, we have a counsellor and they have four or six appointments a week that we can book patients into.” GP4

Inequity of services was reported for community based mental health care, as few PCTs had services for people who required psychological support in a home visit format.

“There is a difficulty in accessing psychological services with her obviously with her being housebound, with most of my patients I get them started on medication and I get them seeing psychological services. I can’t quite see how that would work because we don’t have any community-based, home visiting psychological services.” GP9

This could lead to a perceived inequity of care for psychological symptoms in the patients who were perceived to need it the most, due to isolation or severity of MS symptoms. GPs reported the difficulty in accessing secondary psychological services, and faced a conflict between ensuring fast access, but also appropriate service referrals, when the most specialist services had the longest waiting lists. This recursively influenced referrals as GPs aimed to get the best balance for their patients based on current knowledge and past experiences of services.

“The difficulty is that we’re trying to manage these patients very often in a timely manner and I’m conscious of the fact that the [secondary care] services have a huge waiting time. If you have someone who has more severe symptoms then asking them to wait for months on end just to see someone seems slightly difficult for me as a GP to say to someone.” GP9

Similarly to care for physical symptoms, SNs and GPs reported the timeliness and responsiveness needed for psychological symptoms.

“Neuropsychology, the wait because it’s such a specialised service is pretty bad, and often these people need interventions quicker before they get to crisis. But due to CPN workloads, unless a person is expressing suicidal tendencies, they won’t get referred through. Well if they had early intervention they may not get to that point.” SN2
When faced with a lack of services or an extensive wait for a service many GPs took on personal responsibility for patients experiencing psychological issues (i.e. booking in regular telephone or face to face consultations) to ensure they received regular follow up in this period.

Psychological services were not the only service that was perceived as difficult to access, with an awareness of increasing delays for social services and physical rehabilitation services.

“I think social services is very stretched in general, and sometimes I can’t get assessments as quickly as I would like. But, for people who need extra care packages at home, or I feel they might benefit from occupational therapy or home physio, sometimes there’s quite a waiting list for those kind of services.”

GP3

This was not seen as a problem specifically for people with MS, but a wider delay for patients with all physical disabilities. These access difficulties were perceived as disrupting cross-boundary continuity and creating unmet patient need. Equitable access for these more general services was felt to have been further prevented with the recent movement from PCTs to CCGs.

“We tried to arrange services with the commissioners just before the PCT split into CCGs. We thought we’d sorted it out and then they decided to do the CCGs and the PCT split into three. So two bits of the PCT have some physiotherapy provision and one bit has none, so it’s very unfair.” SN1

SNs discussed eligibility criteria for physical care services more than GPs or PNs, suggesting a different aspect to their identification of candidacy for community services. Additional eligibility criteria reported by SNs were eligibility for disease modifying treatments, eligibility based on disability status, and eligibility based on age with either minimum or maximum age limits (i.e. no under 18s and no over 65s). Both SNs and GPs reported the role of eligibility criteria in facilitating or restricting access to psychological services.

Differing eligibility for services was felt to cause inequalities and fragmented care.

“The physio department won’t see people from outside the CCG. The psychology department have a waiting list but have said they will see anyone who doesn’t have access locally. Psychiatry will see anybody because there isn’t any other, so they will see the whole of the city.” SN1
An extra barrier to inclusivity was reported when psychology teams (outside of IAPT) wouldn’t accept people with a physical health problem, although this barrier was reported by SNs but not reported by GPs.

“I had one lady get diagnosed after she had been treated for anxiety and she was being treated for anxiety by the proper teams and then just happened to get diagnosed with MS and they couldn’t get rid of her. Her anxiety was just managed so much better than anyone else’s I’ve seen and I think it was because she just happened to be in the mental health system before they gave her an organic diagnosis.” SN1

Both responsiveness and continuity of care were perceived to be better when patients with MS had a premorbid psychological condition before the confirmed onset of MS.

6.4.3 Facilitating access to care

SNs viewed their role as being a central point for people with MS to access health care services and the first aim of their role post diagnosis was to ensure that patients knew who their SN was and how they could access this service when needed: “The essential part is a contact number at that point (SN2)” . Once this access was established then they felt they could work on providing long term person-centred care, but access was the primary goal.

All health care professionals were aware of patients’ access requirements and facilitated these where possible (in addition to home visits). One example included booking a patient’s appointments around their daily fatigue, thus demonstrating person-centred knowledge to ensure a responsive and accessible service. Other professionals made adjustments to accommodate patients who were in employment, thus ensuring that access was equitable and they were not deprived of services. Flexibility was viewed as key to providing equitable access to all patients.

“If somebody is working and newly diagnosed and they request to come to clinic, we’ll give them an hour and then an option of another hour at a time, instead of 2 or 3 hours at home... usually it’s the patient that dictates, we’ve got flexibility with that.” SN3

Whilst SNs focussed on access as an aspect of service delivery, all PNs discussed the physical characteristics of their surgery building and equipment.
“We’re very lucky downstairs. If they couldn’t climb onto the bed, we have a bed that goes up and down. We have a lift. You know, we’re quite…it’s a friendly surgery where people of all disabilities can access.” PNS

This was not specific to MS but useful for all patients with disabilities or mobility impairment. In addition to ensuring access within their practice, GPs also aimed to facilitate access for patients in other services by acting as facilitators, coordinators and advocates (as outlined in the section on coordination above). Direct professional to professional communication could also be used to speed up appointments for patients and improve the continuity of care.

“Neurologists generally, I find, are quite amenable. I’ve definitely phoned them for advice before, or written for advice, or asked them to expedite an appointment, and I’ve never had problems, they’ve always been amenable to that.” GP3

In this way GPs facilitated their patient’s access to secondary care, and endeavoured to ensure more timely access. PNs also aimed to ensure this but their involvement was limited to asking GPs to make referrals or advocate on the patient’s behalf. SNs perceived good professional to professional communication as a method of improving the responsiveness and timeliness of access to services.

“I think if we could have a better working relationship with the Community Mental Health teams it would be so, so much better. We could do a lot of early intervention, whether it’s group work, individual work, coping mechanisms, anxiety management, nothing to do with MS, just general things.” SN2

Not being able to directly contact health care professionals was therefore felt to limit continuity, and care became reactive not proactive, which was felt to limit potential benefits to the patient. Where direct professional to professional communication was not used, or not used in a timely manner, then this could have a negative impact on patients’ access to services. One example of this was SNs dependency on neurologists to refer new patients with MS to them.

“A lot of the time we’re not in there at diagnosis with the consultant, so then it’s reliant on a letter being dictated, being sent to the nurse and then the nurse contacting the patient. The problem is we’re still not referred everyone from the varying consultants. It’s getting better, but there’s still odd little pockets where it isn’t.” SN2
This corresponded to a wider issue of inconsistent geographical access to services, based on the actions of individual health care professionals.

6.5 Management of MS

6.5.1 Unpredictability

Both PNs and GPs compared the unpredictability of MS to the more predictable nature of most of the chronic QOF conditions they worked with. This unpredictability created problems with long-term planning for both patients and professionals.

“I don’t think they can plan as well as people with either COPD, asthma, diabetes. They can’t plan that well because they just don’t know. Their future’s very uncertain. They can be well for a long, long time but they never know that. I think that’s the sad part of that condition.” PN6

All professionals described the variability of symptoms and the speed with which symptoms could change, and the problems this caused for both professionals and patients in managing the condition.

“Because it’s a changing condition, and it can change from day to day or month to month or year to year and sometimes it’s up, sometimes it’s down. So I think it takes a lot for patients to plan and manage.” PN1

GPs also reported uncertainty over the differential diagnosis of MS symptoms, when the cause or prognosis of symptoms was not clear, causing difficulties in identifying candidacy for care. This caused problems in management and advanced care planning.

“We’ve got one person who’s had one episode of optic neuritis so we don’t know what’s going to happen to them.” GP11

Lack of knowledge of common presentations of MS could add to this uncertainty, making diagnosis and management harder.

“So it’s that uncertainty with MS, because you’re not sure whether this is a common thing, because MS can be...you can have so many different symptoms. So is this MS or is this something else?” GP6

Therefore, with limited experience and knowledge of MS, making clinical judgments could be difficult, and in turn it was difficult to identify candidacy for care. Unpredictability was a huge issue for SNs who felt they managed patients’ emotional reactions to this situation.

“People naturally usually want black and white answers, because they need to plan their life. They need to know, well where am I going to be in five years’ time, what am I going to be like? Are there tablets to make me better; is there
a pill that makes me walk? And the trouble with MS is it’s all woolly and vague and shades of grey and that’s really hard to get over to people, because we sort of sit there and say, well this may happen, but it may not and you may be like this for a number of years and we don’t know.” SN8

SNs were aware of, and shared, patients’ frustration and sadness at this lack of certainty, but stated that their role was to focus on the positives and motivate patients to live a full live, in spite of the lack of prediction.

6.5.2 Rarity and lack of specialist knowledge

GPs and PNs commented on the rarity of MS, its status as a non-QOF condition and how few people they had encountered recently with MS in clinical practice, compared to more common chronic conditions. This rarity in general practice was also acknowledged by SNs.

“Most practices have got very few MS patients, so to them, their MS caseload isn’t really what worries them. The practices that speak to us are the ones where most of our cohort of patients go. But I can understand from a GP’s point of view, if they’ve only got one or two people with MS, they don’t really want to get too involved.” SN1

The small numbers of patients seen meant that both GPs and PNs reported little specialist knowledge on this topic.

“Well things like diabetes, hypertension, because that is linked to QOF I think we’re all up to date and knowledgeable of the chronic diseases. But I suppose like MS we don’t see a lot of patients, it’s quite a speciality so it’s probably an area we don’t have training in.” PN12

Most GPs and PNs did not perceive this lack of specialist knowledge as a negative issue, or one that impacted on the care they provided. This was because they felt their role to be more general, relying on more general skills such as signposting, rather than the application of specialist knowledge.

“I think like all minority conditions that you see in the practice my knowledge is probably not that good, but I do feel confident offering a level of support to MS patients.” GP10

An area where both PNs and GPs reported they could feel better supported was information and resources regarding navigating specialist MS services in the community. Not knowing the local services made signposting difficult, especially for PNs who felt they were very knowledgeable on this area in other chronic conditions.
“I have to say, because we’ve only got a small number of patients with MS, compared to our list size, probably, I don’t feel I need to develop my skills any further. But I suppose what it is is knowing what resources are available and where to feed on to, if somebody’s struggling. I think that would perhaps be more beneficial, in having support numbers that you can pass on or get hold of”. PN9

This lack of information also made referrals difficult for GPs when they were not aware of available or relevant services.

“I think the GP definitely is, in a lot of conditions it’s coordinator and sort of adviser and advocate really. It’s really working out what hasn’t been done and knowing what’s on offer and I think that’s probably why it’s a bit more frustrating with MS, because you’re not actually quite sure which services are appropriate and available to them.” GP5

Information resources were valued more highly than training or Continuing Professional Development (CPD) by GPs and PNs, as most participants reported that they did not see an identifiable need to improve their limited knowledge on MS. For PNs this was because MS was not a QOF condition, and therefore was not perceived as being in their daily role remit. There was also a perception of struggling to complete training, and stay up to date, with highly prevalent conditions such as COPD that were in their key remit.

“Not unless it was QOF because, it’s hard enough for us to get training as it is for the things we are doing presently. So MS being a low number of patients would be a low priority.” PN1

GPs did not feel that they needed to improve their knowledge, as when they lacked knowledge in more specialist areas they contacted specialist MS services for advice or referrals.

“If I thought the patient was having an acute exacerbation we would all benefit from some specialist advice and I’d say ‘this is what I think’s going on, what are our options, how good is the evidence for that particular option in this particular type of situation?’” GP1

Most GPs felt that using this consultation model (described in the quote above) they could provide a responsive service to people with MS within primary care, without the need for advanced knowledge and training. Some GPs felt that they needed to improve their knowledge of MS when working continuously with one patient with MS. In this situation
they reported using general information searching techniques to keep up to date with frequently changing information.

“My knowledge of MS is very very poor at the moment. What frequently happens when I end up taking on more of their care I go and do a read up on it, that’s how I keep up-to-date because it changes so quickly and my knowledge, what I was taught at medical school is meaningless now.” GP8

The above participant’s acknowledgement of outdated knowledge from medical school was echoed by older GPs. The lessening relevance was sometimes perceived as a positive, when GPs reflected on the negative perceptions they were taught about MS, and the limited potential they expected for people with this condition.

“My knowledge of MS then was really the advanced progressive, which is what we’d learned at medical school, this terrible thing and then you end up in a wheelchair. And that hasn't been the case, she’s had a completely normal life with a few exacerbations. So yes, I think it’s made me more positive about MS, that it's not necessarily what I thought, which was the severe end of the spectrum.” GP10

By working with people with milder MS GPs challenged these preconceptions. However, some GPs who had only worked with people with fast progressing MS in the palliative care stages maintained negative perceptions of the condition.

6.5.3 Role of specialist MS services

SNs described their role as working with people with MS from newly diagnosed through to advanced diseased, incorporating disease modifying treatment, active MS with frequent relapses, and benign MS, along with the full range of physical and psychological symptoms presented in MS.

Both PNs and GPs reported very strong views that MS management for people with active symptoms, or those taking DMTs, should be managed in specialist MS services in secondary care and that in this respect these patients were not suitable candidates for primary care management.

GPs and PNs made distinctions between MS symptoms and non-MS symptoms, and both groups perceived that MS symptoms were not part of their remit, unless they interacted with a comorbidity.

“I don’t really feel I have a role in looking after his MS symptoms. That is mainly in secondary care. In primary care we just look after his regular
injections, his blood pressure and weight, and just lifestyle issues really. But
his actual MS symptoms isn’t something that we tend to deal with here. If he
has any problems round his MS, we will contact the hospital and the MS
specialist nurses.” PN3

This was frequently explained by the perceptions of good access, and good quality of care,
provided by MS specialist services to patients with MS. SNs in particular were viewed as
highly involved and supportive to patients.

Patients have really good contacts with the MS specialist nurses at [district
hospital] and I think they feel quite supported from them regarding the MS. So
I suppose we’re, sort of, managing all the other things because, like, my older
lady, she’s got hypertension and had a previous stroke, so it’s, sort of, more all
the other co-morbidities that go with the MS.” GP2

For most GPs, the responsibility of care (and candidacy for care) for people with MS lay
with secondary care services; unless the patient had a comorbidity or multimorbidity that
was being managed in primary care.

“My experience of MS patients is that they should all be at least on the books
of secondary care. So we re-referred her really because at the end of the day
she had symptoms that we couldn’t deal with in primary care. So what else is
secondary care there for really except to take on that and tackle those issues.”
GP7

The role of secondary care was seen as managing MS symptoms that could not be
managed in primary care, and required specialist knowledge, pharmacological treatment
or ongoing specialist management. SNs acknowledged this role, however also mentioned
that sometimes there were patients for whom they could do nothing more, other than
minimise the daily impact of symptoms.

“We call them general patients, patients who have more progressive forms of
MS that there isn’t really anything much to offer them other than symptom
management and treatment of symptoms. But they usually want a cure.” SN5

This could lead to frustration for both primary and secondary care professionals were it
was felt that specialist MS services were not being responsive to patient’s needs, when
patients were clearly identified candidates for this care.
GPs and PNs rarely mentioned DMTs, whilst for SNs it was a frequent and emotive theme. SNs highlighted the complexity of DMTs for both patients and professionals, and emphasised the difficulties experienced by patients in selecting or maintain DMTs.

“People are really struggling with having to go on treatment straight off. We put these treatment choices in front of them, some with potential very bad side effects and you’re talking to an 18 year old with limited life experience and you think how the hell are they going to get their head around that? And I’m not surprised sometimes people say ‘I don’t want to know’.” SN2

Neurologists took the lead in the implementation and management of DMTs, whilst SNs educated patients on their medications and everyday tasks such as self-injecting. This more hands on approach was reflected more broadly, as SNs reported that neurologists were rarely involved in direct contact with patients outside of diagnosis, treatment or management of complications.

6.6 Chapter summary

The data presented in this chapter covered four key themes of health care professionals’ experiences of MS care: the role of primary care, person-centred care, access to services and management of MS. These themes were discussed in relation to aspects of the Dixon-Woods et al. (2006) candidacy framework and recursivity.

MS was described as an unpredictable and difficult condition to manage, especially where professionals felt they lacked specialist knowledge and expertise due to its rarity. GPs and PNs expressed the desire for more knowledge on local services available for MS, but not for further knowledge or training on MS itself, even if they currently experienced difficulties in identifying candidacy for care due to the ambiguity of MS symptoms. While GPs could potentially be very involved in the health care of people with MS, experiences of involvement varied based on patient need and GP experience and confidence in managing MS symptoms. PNs were perceived by themselves and others as having a limited role for people with MS, with the exception of regular injections. The perceived central role of primary care for MS care provision was seen as managing comorbidities, providing support for emotional and physical needs and coordinating care services. These findings suggested that professionals view people with MS as clearly defined candidates for some aspects of primary care, but not all.

Patient-centred care was viewed as essential when managing an unpredictable and variable condition and was achieved through providing holistic care that managed all of a
patients’ social, psychological and physical factors in consultations not limited by time. A strong professional-patient relationship developed through a long-term continuity of care was central to providing ongoing person-centred care to people with MS and could improve health care professionals’ abilities to judge candidacy of care and navigate services for the best outcome for the patient. GPs and PNs reported that access to primary care services was overall easy and timely, with the exception of primary care psychological services where access was reported to often not be timely. In comparison, all professionals reported that access to secondary services was reported to be poorer and varied by geographical area. Untimely access and nonresponsive services were thought to lead to negative physical and psychological outcomes for patients. Individual professionals described how they could facilitate access, depending on their practice and relationships with other professionals.
Chapter 7: Discussion

7.1 Introduction

In this chapter I examine my findings of people with MS experiences of utilising, and health care professionals’ experiences of providing, health care for MS, in comparison to the existing literature and my chosen theoretical framework. For ease of presentation I present my findings within the individual components of the candidacy framework, as outlined in chapter 4. I then present implications for future research and clinical practice, before presenting judgements about the relevance of candidacy to experiences of health care for MS. Finally, I discuss the strengths and limitations of my study and conclude with my reflections of this doctoral research. Key points from the discussion chapter are presented in Table 21 below.

<table>
<thead>
<tr>
<th>Table 21. Key points presented in the discussion chapter.</th>
</tr>
</thead>
<tbody>
<tr>
<td>• My research offers unique knowledge of people with MS and professionals’ experiences of health care services for MS</td>
</tr>
<tr>
<td>• People with MS’ experiences of health care services for MS comprised the experience of living with MS, managing self-care, access to care, continuity of care and interactions with health care professionals</td>
</tr>
<tr>
<td>• Professionals’ experiences comprised the role of primary care, person-centred care, access to services and management of MS</td>
</tr>
<tr>
<td>• Identification of candidacy and adjudication are central to people with MS accessing responsive care for both physical and psychological symptoms</td>
</tr>
<tr>
<td>• However, candidacy may not fully account for psychological and sociological processes in the stage before formal health-care use, or for the role of effective self-management</td>
</tr>
<tr>
<td>• Becoming expert patients through lived experience and knowledge of appropriate health care services may influence people with MS’ access to, and utilisation of, health care services</td>
</tr>
<tr>
<td>• Responsive access to services and relational continuity are central to positive experiences of care for both people with MS and professionals</td>
</tr>
<tr>
<td>• Difficulties accessing services are reported by people with MS and professionals due to a variety of issues including professionals’ adjudications, perceived permeability of services and local operating conditions</td>
</tr>
<tr>
<td>• Whilst MS is a legitimate medical condition, initial symptoms of MS and ongoing ambiguous symptoms may be treated as lacking credibility or legitimacy</td>
</tr>
<tr>
<td>• Future research in this area will require more innovative recruitment and methodology to ensure participation from younger people with MS, men, people from ethnic minority backgrounds and people experiencing more severe disability due to MS</td>
</tr>
<tr>
<td>• Implications of this research are the need to provide education to people with MS and GPs on identification of candidacy and the significance of adjudications, increasing specialist knowledge and collaboration between primary and secondary care where necessary</td>
</tr>
</tbody>
</table>
7.2 Summary of main findings

Through this research I addressed the identified gap in literature regarding the experiences of people with MS and health care professionals of health care services for MS. As illustrated by my systematic review (chapter 3), previous UK research has focussed on diagnosis and palliative care needs, neglecting experiences of the majority of people with MS, and perspectives of health care professionals.

My research addressed this gap using a qualitative approach, specifically employing in-depth interview methods. It offers the first perspectives of PN experiences on this topic, unique knowledge of GP experiences, and furthers knowledge of people with MS’ experiences of ongoing care, including primary care services. Finally, it contributes to the existing literature by providing unique knowledge of SNs experiences of managing psychological needs, in a time of rapid service change and uncertainty of support provision.

These findings illustrate the complexity of care provision for MS, but also highlight areas in which difficulties experienced are similar to more common, higher prevalence chronic conditions, suggesting generic needs and service improvements for both patients and professionals.

7.2.1 Summary of findings from people with MS

From my data I identified five themes of patient experiences of health care services for MS:

- The experience of living with MS
- Managing self-care
- Access to care
- Continuity of care
- Interactions with health care professionals

These themes derived for both people with MS and professionals are discussed in relation to corresponding aspects of the Dixon-Woods et al. (2006) candidacy framework and recursivity (Rogers, Hassell & Nicolaas, 1999) (as outlined in chapter 4). Candidacy explains how access to health care services is negotiated by patients and professionals based on factors including their identification of symptoms, navigation of services, ease of access to services and health care professionals’ decisions. The concept of recursivity explains how decisions regarding health care are made based on past experiences and knowledge.
Experiences of living with MS and managing MS symptoms (as reported by people with MS) were varied. To cope with uncertain progression of their condition many participants described how they become more knowledgable and how they utilised a variety of both self-management methods and support from health and social care providers to proactively manage their condition, dependent on individual preferences. Participants reported the need for increased timeliness of access to services in both secondary and community settings, combined with better coordination of care services. Participants’ also wanted to be valued as a person in consultations, achieved through empathic and person-centred care from professionals with whom they experience relational continuity, and who responsively meet participants’ needs, whilst maintaining participants’ self-worth and positive identity.

7.2.2 Summary of findings from health care professionals
Analysis of health care professionals’ experiences of MS care resulted in four themes:

- The role of primary care,
- Person-centred care
- Access to services
- Management of MS

While GPs reported they could potentially be very involved in the health care of people with MS, experiences of involvement varied based on GP perceptions of patients’ needs and GP experience and confidence in managing MS symptoms. PNs perceived they have a limited role in the management of people with MS, with the exception of tasks such as regular injections including Vitamin B12, which may or may not be related to MS. The perceived central role of primary care for MS care provision was seen by all professionals as managing comorbidities, providing support for emotional and physical needs and coordinating care services. These findings suggested that professionals view people with MS as clearly defined candidates for some aspects of primary care but not for symptoms or treatment needs clearly identified as requiring specialist MS services.

Patient-centred care in this study was defined by professionals as providing “holistic care” that managed all of a patient’s social, psychological and physical factors in consultations, through knowledge of the patient as an individual and a strong patient-professional relationship. This is in keeping with previous literature on patient-centredness (Mead & Bower, 2000) which highlighted how patient-centredness takes a biopsychosocial approach and utilises a strong therapeutic alliance. Although it was emphasised by primary
care professionals that person-centred care was the aim for all patients, patient-centredness was described as essential when managing an unpredictable and variable condition such as MS. Person-centred care was felt to potentially improve health care professionals’ abilities to judge candidacy of care for a given patient and increase their knowledge on relevant services and how best to navigate them. GPs and PNs perceived access to primary care as responsive and timely, with the exception of untimely access to primary care psychological services. All professionals reported that access to secondary and community services was poorer than access to primary care, and varied by geographical area. Professionals reported their perceptions that untimely access and unresponsive services could potentially cause decreased psychological and physical wellbeing for patients. Individual professionals (from all professional groups) felt they could facilitate or block access, depending on their practice and relationships with other professionals.

7.2.3 Similarities and differences between people with MS and professionals’ experiences of care for MS

Both people with MS and health care professionals discussed the impact of the uncertainty of MS progression. GPs and PNs suggested that uncertainty was problematic due to difficulties in managing a rare and unpredictable condition, where they were not supported with necessary specialist knowledge. Both people with MS and professionals referenced ‘expert patients’ but with different connotations. People with MS reported how ‘expert patient’ status influenced their perceptions and use of services, but did not use the terminology ‘expert patients’ (DH, 2001). All professionals described how they addressed the “expert” nature of their patients within the professional-patient relationship by tailoring their communication style to patients’ preferences and information needs; however people with MS reported that this was not always the case in their consultations.

Access to health care services was the most comparable theme for people with MS and professionals. Both groups reported the positive and negative experiences they had had accessing a range of services. People with MS reported their limited knowledge of available services, creating difficulties in navigation and access. Difficulties identifying and navigating services were also experienced by health care professionals, however they reported fewer difficulties as they had the resources to identify relevant services or contacts to assist with signposting. Both groups of participants discussed how they
facilitated access; professionals reported how they facilitated access to both their own and other services, whilst people with MS reported how they “stayed in the loop” to ensure continuing knowledge and access. Barriers to timeliness of care were reported by people with MS but less so by primary care professionals. Some GPs and all SNs mentioned the difficulties of ensuring quick and responsive access to specialist MS services and community services such as physiotherapy and psychological services, which were felt by both people with MS and professionals to have the longest waiting times. This lack of timely access was felt to be detrimental to the physical and psychological wellbeing of people with MS.

People with MS described their experiences of communication and responsiveness with health care professionals, whilst professionals described the more general concept of patient-centred care. People with MS discussed a lack of personhood and stigmatising judgements made by professionals; professionals did not mention these negative issues but instead discussed the individualised, holistic and respectful care that they aimed to provide to all patients (not just people with MS). The concept of responsiveness reported by people with MS incorporated the results achieved by individual professionals and health care systems more generally. Where professionals discussed responsiveness, they primarily referred to the professional-patient relationship and responsiveness on an individual level. Professionals’ perceptions of responsiveness were linked to the rarity of MS and a lack of specialist knowledge, requiring more coordination with, and access to, specialist services than other chronic conditions.

The category of coordination of care was described by both people with MS and professionals. For people with MS, coordination of care was viewed as management and information continuity, ensuring continuous care over multiple health care professionals. Professionals described coordination in terms of their role coordinating other health care services, as part of their ongoing professional-patient relationship (relational continuity), and only mentioned information continuity when discussing communication between primary and secondary care.

In summary, these findings suggest that people with MS and professionals experience many similar challenges and opportunities in receiving and delivering MS care. Findings will now be compared to previous research and the theoretical framework of candidacy.
Figure 9. The extended concept of candidacy

Recursivity was central to all aspects of the candidacy framework as both people with MS and professionals’ past experiences determined future decisions.

Pre-identification of candidacy:
As described in the work of Rogers, Hassell & Nicolaas (1999) the identification of candidacy for care and formal help seeking may be a small part of an individual’s health experience. Many decisions about service use and self-care are made before the identification of candidacy.

1/Identification of candidacy:
Patients must identify themselves as a suitable candidate for care

2/Navigation:
Patients must be aware of the services available to them and have the necessary resources to access them

3/Permeability of services:
Services that are easier to utilise e.g. through direct access are preferable to those which require referrals

4/Appearances at health care:
Patients have to assert their need for health care (sometimes repeatedly) in order to receive appropriate services

5/Adjudications:
How health care professionals perceive symptoms influences how they respond

6/ Offers and resistance:
Patients chose to accept or reject medical offers based on their experiences and perceptions of treatments

7/ Operating conditions:
Experiences of health care commonly depend on local influences such as resources and local finance arrangements
7.3 Comparison with the literature

In this section I will compare my findings to previous research and policy, and explain my findings in relation to candidacy (as in Figure 9).

7.3.1 Identification of candidacy

The first stage of Dixon-Woods et al.’s (2006) candidacy framework is the point at which the patient identifies him/herself as a candidate for care. In this section I will explain how people with MS identified themselves as candidates for care for both physical and psychological symptoms.

7.3.1.1 Identification of candidacy for physical symptoms

The candidacy framework was designed to investigate facilitators and barriers to access of health care services (Dixon-Woods et al., 2006). As such, my findings suggest it may not always address the issue of agency and why people may choose not to identify themselves as candidates for care. Not identifying oneself as a candidate for care is conceptually different to choosing to not appear at health care services, or refusing services later on (as described in the candidacy model).

Historically, societal influences ensured that people experiencing illness were labelled with the ‘sick role’ (which is constructed by society and imposed on an individual; Parsons, 1951), defining people as different from healthy individuals in society, and ensuring dependency on medical professionals. However, this may not be applicable to chronic illness, which challenges Parsons’ concept of illness as a temporary state in which the sick person should not be expected to achieve normal daily activities (Parsons, 1951). In addition, Parsons (1951) states that the sick person must try to get well, a concept that may be impossible in an incurable chronic condition such as MS. It is not surprising therefore, that the majority of my participants with MS viewed themselves as functioning members of society without emphasising a sick role; the minority of people that did acknowledge an ongoing sick role experienced high levels of residual disability.

The sick role is positioned within the medical model of illness which relies on diseases “[being] defined and treated within a framework that assumes unique causality, consistent and recognisable symptoms, and scientifically determined treatment (Sulik, 2009, p.1060)”. This may not be applicable to a condition such as MS where participants reported their symptoms may be transient or ambiguous in nature and not always eligible for disease modifying treatments. The sick role may be appropriate for
people with relapsing-remitting MS during periods of acute disability, but not their primary identity the majority of the time (Bury, 1982). In parallel with the sick role, the role of health care services and identification of candidacy may fluctuate with symptom severity and urgency, suggesting varying perceptions of candidacy in association with symptoms and perceived sick role.

The concept of illness identity may be more applicable to lifelong conditions such as MS (Vaughan, Morrison & Miller, 2003). Illness identity explains how individuals incorporate meaningful aspects of their illness into their lives and perceptions of self (Sulik, 2009). Unlike the sick role, illness identities allow for the concept of autonomy and patient choice, suggesting that how people attach meaning to their illness identity may translate into roles and attitudes towards illness (Yanos, Roe & Lysaker, 2010) and influence their perceptions of candidacy for care and help seeking (Sulik, 2009). People with MS in my qualitative study expressed a variety of views about their MS identity. For some of my participants with MS their diagnosis was central to their identity and informal support networks. As explained in chapter 5, those who attended MS society groups (often older people with progressive MS) appeared to have a stronger illness identity. The severity of disability in MS may be the crucial factor, where strength of an illness identity is judged on the number of symptoms experienced (as in Vaughan, Morrison & Miller, 2003). People who experience fewer MS symptoms on a daily basis may not develop a strong illness identity, but simply focus on day to day symptom management and getting on with a life which they perceive to be as normal as possible. In my findings these individuals wished to use services when needed, but did view themselves as constantly in need of services.

Service use preferences may change over time for people living with rare conditions, moving from the need to obtain a diagnosis to learning to live with the condition on a daily basis (Daker-White et al. 2011). This suggests perceptions of candidacy may also change over time; for some of my participants with MS they shifted from being a candidate for specialist neurology services, to candidacy for symptom management within ‘normal’ life, which may come from a variety of primary, secondary and community services.

Data from my interviews corresponded with the two concepts of normalisation suggested by Bury (2001); individuals either tried to keep their pre-illness lifestyle and identity intact, or incorporated their MS into their lifestyle to create a new normal. The
level of preferred involvement from health care services, and perceived candidacy for care therefore varies by people with MS’ individual stances on normality and meaningful roles.

Rogers and Nicolaas (1998) suggest that the majority of symptoms in chronic disease are managed by individuals themselves, and the use of formal health care services is rare in comparison to self-care. There is therefore a significant amount of symptom management and decision making made before formal help seeking and the identification of candidacy.

Before people begin the help seeking pathway there may be an additional stage of self-monitoring, requiring judgements to be made incorporating knowledge of the body, recognition that a problem exists, and awareness that an individual cannot manage it alone (Smith et al., 2008). There are several ways that this self-monitoring stage may integrate with the candidacy model; it may precede identification of candidacy, as people cannot identify themselves as candidates for care until they recognise that a health problem exists. Alternatively, it may be a factor that precedes appearances at health care, even when identification of candidacy is accepted. Aspects of the candidacy framework may also act recursively; where people are aware that services are difficult to navigate and access as there may be a longer period of self-monitoring before help seeking.

Self-monitoring was commonly reported by respondents due to the fluctuating nature of MS, with symptoms that could sometimes resolve with no intervention. In my findings, where people with MS had experienced transient symptoms in the past, they reported they were more likely to delay help seeking behaviour. My findings reflect Skovgaard, Pedersen and Verhoef (2014) by showing that people with MS used the assessment of bodily sensations and symptoms to identify their responses to medication and whether they were experiencing symptom exacerbations warranting medical intervention. Whilst some people experienced daily symptoms due to MS, or disability that would never be recoverable (e.g. mobility impairments), others were only symptomatic at times of relapse. The fluctuating nature of MS symptoms meant that some participants did not see themselves continuously as candidates for care and fits with the shifting-perspectives model of chronic illness, where participants moved from periods of illness to periods of wellness and vice versa (Patterson, 2001).
Kelly et al. (2011) reported that delayed time to presenting with MS symptoms at health care services was most common in people with a primary progressive onset. This may be because identification of candidacy for care appeared more straightforward for people with relapsing-remitting MS, who experience clearly identifiable relapse symptoms (such as vision or mobility impairments), than for people with progressive MS, for whom there may be less delineation between illness and wellness. Where people experienced new and unpredictable symptoms that were perceived to be serious or long lasting, then immediate help was likely to be sought. Some symptoms such as pain, or fast onset changes to mobility or vision necessitated immediate candidacy for care. However, a minority of my participants reported minimising their symptoms in the hope that they would resolve themselves or stay at a tolerable level. Kelly et al. (2011) observed that many of their participants with MS had been symptomatic for months before presenting to GPs or non-neurology services (mean time 13.6 months) with initial MS symptoms. Potentially delays in diagnosis may be due to people with MS not identifying themselves immediately as candidates for care, possibly due to not recognizing the symptoms of MS. Alternatively, it may be due to a period of self-monitoring as people attempt to judge and make sense on their symptoms.

Smith, Pope and Botha (2005) discussed the concept of "sanctioning" whereby help-seeking is potentially influenced by the actions and perceptions of significant others such as family and friends, or contact with others with the same condition either in person or online (Daker-White et al., 2011). Previous studies have shown that people feel more justified or sanctioned to use services where symptoms reached crisis point or where people were visiting primary care services for a comorbid symptom (Smith, Pope & Botha, 2005). A potential limitation of the candidacy model is focussing solely on adjudications of health care professionals, without explaining how the actions, or sanctioning of significant others may impact on an individual’s identification of their candidacy for care.

7.3.1.2 Identification of candidacy for psychological symptoms

Both physical and psychological needs in MS could be overlooked or not interpreted as justifying candidacy, potentially leading to under-diagnosis of symptoms. Under-diagnosis of depression has been reported in previous studies of people with MS Marrie et al. (2009b), suggesting that there are many people with MS experiencing
depressive symptoms that are undiagnosed and therefore untreated. My findings may potentially explain this by suggesting that people with MS are aware of their low mood but normalise this in the context of the impact of MS on their lives and of their ongoing physical disabilities. These narratives described biographical disruption (Bury, 1982), and explained the impact MS had on participants’ self-concept and biography, including how they used available resources and support to manage this disruption. Life stories may be central to the explanations of the depression narrative in people with LTCs and impossible to discretely separate (Alderson et al., 2014). Therefore, participants presented stories describing their low mood but did not relate this low mood to their perception and understanding of depression. My participants with MS commonly explained or ‘normalised’ their depression as a result of loss and change, such as unemployment and relationship breakdowns, and this was a potential barrier to help seeking and to diagnosis of depression (Coventry et al., 2011). An additional barrier to help-seeking may be poor mental health literacy, where a lack of knowledge prevents the identification of psychological symptoms and therefore prevents help seeking (Gulliver et al., 2010).

Previous research has criticised the paucity of studies allowing individuals who described low mood to define what the experience and definition of depression meant to them (Maxwell, 2005). My research addressed this problem by asking people with MS to describe and explain their own experiences. Several participants reported long term use of antidepressants, initiated after a severe depressive episode (which may have been linked to MS or unrelated life events such as bereavement). These participants reported that they did not believe they were currently depressed but continued with medication due to a fear of future depressive relapses. This demonstrated a potential disconnect between how participants view themselves as a candidate for care (not experiencing depression), and how they act as a candidate for care (utilising medication and medication reviews due to depression). Conversely, where people are aware of their psychological needs but prefer to manage them independently, use of services may be low (Mojetabai et al., 2011), and my data reflected this where participants discussed the need to “get on with life” and “overcome” low mood. Prior experiences (recursivity) have been shown to influence help-seeking and navigation for psychological needs (Gulliver et al., 2010) and my data
reflected this where people made future service use decisions based on previous communication and responsiveness.

Participants with MS in my study reported help-seeking for both initial and later symptoms, when their symptoms left them feeling unable to continue with the demands of daily life, similarly to research into depression suggesting identification of candidacy occurs when symptoms start to interfere with everyday roles or family relationships (Maxwell, 2005). These crisis periods may be a key point for intervention, if a health care professional is aware of this situation and adjudicates accordingly.

Diagnosis was a crucial point in all narratives, as similarly to interviews investigating rheumatoid arthritis (Bury, 1982) and medically unexplained symptoms (Nettleton et al., 2005), the search for the cause of illness was also felt to be a search for the meaning behind this life changing event (Bury, 1982). Experiences of diagnosis have been thoroughly investigated in MS and therefore were not the main focus of my interviews (Johnson, 2003; Methley et al., 2014). I was however, interested in experiences of diagnosis for the insight this provided into experiences of health care, and the way this recursively had an impact on future service use.

The pre-diagnostic period was a very anxious and confusing time for participants who hoped that diagnosis would be “an objective fixed point on a terrain of uncertainty (Bury, 1982, p.179)”. However for many people this did not automatically ensure effective explanations and treatments for their MS, meaning that confusion regarding candidacy could extend past diagnosis. Previous research has suggested that diagnosis is easier to accept if it leads to treatment (e.g. Parkinson’s Disease; Pinder, 1992).

However, whilst the minority of people with MS disease may be eligible for disease modifying treatments, for the majority there is no treatment available and they must rely on symptom management strategies.

Daker-White et al. (2011) commenting on Balint (1957) suggest that the role of medicine is to turn ‘unorganized illness’ into ‘organized illness’. However similarly to rare conditions such as ataxia (Daker-White et al., 2011), this organized illness may never be possible for people with MS and ambiguity regarding candidacy for care and navigation of services may be prolonged.
7.3.2 Navigation

In the Dixon-Woods et al. (2006) candidacy framework, the concept of navigation explains how service users must be aware of the services available to them and have the necessary resources to access them. Over time, navigation of services may result in people with MS becoming expert patients and this will now be discussed. The resources needed to navigate services may require adjudication or assistance by health care professionals and the role of relational continuity will be discussed later in this section.

7.3.2.1 Information as a tool for navigation: the rise of the expert patient

For both physical and psychological symptoms, access to and interpretation of, information and knowledge may be central to the identification of candidacy and navigation of services. Health literacy refers to an individual’s ability to gather, process and understand information about available health services, and subsequently to communicate with others about their needs and potential options (Baker, 2006). Cognitive impairment is highly prevalent in people with MS (Amato, Zipoli & Portaccio, 2006), and inefficiencies in information processing are the most prevalent symptom, suggesting that there may potentially be difficulties in processing information relating to services and treatment choices. Additional difficulties include impairments in long-term memory and planning, and the added impact of depression and fatigue on cognitive functioning (Chiaravalloti & DeLuca, 2008). Overall, these indicate that people with MS may require assistance with planning and utilising health care services.

Research into MS and health literacy has suggested that participants with lower health literacy had an increased risk of smoking, obesity, comorbidity and use of emergency services, suggesting that use of health related information may be related to preventing negative health behaviours and unnecessary use of emergency care.

Navigating health care services through skills, information, technology and resources, has been posited as a form of self-care needed to manage a chronic condition (Rogers, 2009) and identified as a key area of support provided through continuity of care in UK General Practice (Hill & Freeman, 2011).

Research has highlighted a problematic area of MS care, where people with MS want to be active and involved in their own care, but may be limited by poor knowledge of MS (Köpke et al., 2012). Lack of information provision was a criticism of health care services from my participants with MS, as in previous UK research (Edwards, Barlow & Turner, 2007; Edmonds et al., 2007a; Johnson, 2003; Laidlaw & Henwood, 2003;
Malcolmson, Lowe-Strong & Dunwoody, 2008; Somerset et al., 2001), and in the last RCGP national audit (2011), showing that it is a major and current concern.

Clarke (2000) investigated the experiences of people with chronic fatigue syndrome, and found that where people face conflicting advice or lack of specialist knowledge or information from health care professionals, they undergo “expertization”. Through this process they become experts about their condition, treatments and research, and find doctors who are sympathetic to their suffering and believe their condition is legitimate. Although expertization could be viewed by some participants as a response to a negative situation (i.e. lack of health care knowledge and support), positives were that it allowed people who perceived their identity as intelligent and self-sufficient to regain this identity in the face of severe and limiting disability. In the narratives of many participants, it was presented as the turning point where they started to regain control of their condition and their life.

Participants in my study went through a similar process to the expertization described by Clarke (2000) to manage the lack of knowledge, uncertainty and anxiety in the early stages of their MS, and symptom management later on. They researched their condition online, made contact with knowledgeable others at organisations such as the MS Society (either in person or online), and identified health care professionals with relevant knowledge and how to access them. As MS symptoms present in a personal and variable manner, both people with MS and professionals placed high value on familiarity or knowing one’s body and therefore being able to judge normality or symptom progression. Although awareness that something was wrong was reported by individuals from the earliest days of their MS symptoms; this MS specific knowledge grew exponentially with the length of time lived with MS. Therefore older participants, typically with progressive MS, voiced the strongest feelings of expert knowledge and lived experience. This may also have been because it is widely acknowledged that there are very few effective interventions for either type of progressive MS (Comi, 2013), therefore people with these subtypes of MS have to manage the best they can. The lived experiences and personal knowledge of people with MS were reported as valued and respected by people with MS, GPs and SNs as a resource for monitoring health and managing life with MS.

Nelson et al. investigated experiences of Canadian primary care patients. Their participants discussed a concept entitled “working the system” which was defined as
“not viewed as circumventing the system; patients were simply using tools available to them to expedite or facilitate access to health care services (2014, p.40)”. Within this concept they described the strategies used by participants to work the system, namely: mobilising personal resources, having connections and contacts, acquiring knowledge of the system, and advocacy. These reflect the concept my participants with MS described as “staying in the loop”, including using the knowledge and support of others, whether professionals, family or MS Society group members to increase their knowledge of MS services and navigate services more effectively. In both my study and Nelson et al.’s study, the majority of participants highlighted that this was not gaining access through unfair means, but simply necessary to ensure access to the health care that was entitled to them and relevant for them. The autonomy and agency described in these concepts fits with the concept of expert patients taking responsibility for their own health care use and condition management (Rogers, 2009). The difference between my findings and those of Nelson et al. (2014) is the level of this autonomy. People with MS in my findings reported the difficulties and distress experienced before they became “in the loop” and the way they fought to stay in it, to ensure best access and wellbeing. In Nelson et al. (2014) however, whilst participants described a parallel experience of getting better at working the system through experience, the fear of being out of the loop, and potential implied dependency on health care services, was not portrayed. This may be because participants in their study did not have chronic or relapsing conditions; however no clinical information is presented making this impossible to judge. The need to stay in the loop for people with MS is in part because specific services may be the ones perceived to guarantee a timely response to a relapse.

7.3.2.2 The choice between continuity of care, access and specialist knowledge
Continuity of care is important on a service delivery level as it is associated with better patient outcomes, higher patient satisfaction, improved preventative care and lower hospital admission rates (Cabana & Jee, 2004; Saultz & Albedaiwi, 2004; Van Walraven et al., 2010).
The relational continuity and therapeutic relationship GPs have with their patients have been described as central to the work of primary care (Hill & Freeman, 2011). My findings showed that continuity of care was very important on a personal level to both people with MS and professionals, but was increasingly threatened by political and
socio-demographic changes (as discussed in Hill & Freeman, 2011). Relational continuity with one professional was valued highly by all participants, as in previous research investigating other chronic conditions (Infante et al., 2004). Relational continuity may be of greater importance in a fluctuating condition such as MS, as the inherent flexibility of relational continuity (Hill & Freeman, 2011) may allow it to respond to changes over time which require significant trust in a health care professional (e.g. relapses). Knowledge of an individual’s medical history was felt by both people with MS and professionals to better enable professionals to make decisions regarding the progression of symptoms, by understanding what constituted normality of functioning for that individual for both medical and non-medical factors. This matches the view of continuity of care outlined by Hill and Freeman who stated “patients want their care to be personal (focused on their individual needs and circumstances) and want to feel that the clinician knows them and their cases, so that they can trust their judgement and advice (2011, p. 5).” Conversely, where continuity of care did not exist, people with MS reported they often did not feel their care was personal, and were unable to trust advice from professionals who lacked a basic understanding of their situation, preferences and needs. GPs reported that where they lacked specialist knowledge on MS this was built up during multiple consultations with someone with MS. A lack of continuity may therefore prevent the aggregation of this knowledge, thus resulting in professionals who are less responsive and less knowledgeable, causing difficulties for both the professional and patient (as discussed in Rhodes et al., in press). Variations in relational continuity were reported, with GPs most frequently providing relational continuity, SNs providing variable relational continuity and PNs and neurologists reported to provide overall limited relational continuity.

Where people with MS had relational continuity with one SN their experiences were also very positive, supporting the literature on the key role played by SNs (De Broe, Christopher & Waugh, 2001). Relational continuity was therefore felt to ensure easier identification of candidacy, a better patient-professional relationship, more responsive adjudications, greater reassurance and improved navigation and access. Reassurance for people with MS comprised two aspects (as discussed by Pincus et al., 2013); affective reassurance and cognitive reassurance. In my findings all professionals and people with MS spoke of the need to demonstrate affective reassurance such as
rapport and empathy; this was viewed as part of a wider professional-patient relationship and central to patient-centred care. Similarly, GPs and SNs viewed themselves as core professionals to provide cognitive reassurance, by providing explanations of information at an appropriate level for the person with MS, although GPs provided less specialist knowledge.

Participants with MS discussed the conflict between ensuring relational continuity and ensuring fast access to care, which has been suggested in previous research on chronic conditions (Cheraghi-Sohi et al., 2008; Rhodes et al., in press; Waibel et al., 2012). Whilst relational continuity of care was viewed by people with MS and professionals as improving access to ongoing care services, in emergency situations people with MS reported preferring faster access to care (e.g. Accident and Emergency departments) to routine relational care (such as GPs). In these situations the perceived risks outweighed the perceived benefits of relational continuity.

Previous research has identified that improved relational continuity and management continuity is a central need for people with MS (Edmonds et al., 2007a; Finlayson, Denend & Shevil, 2003; Johnson, 2003; NICE, 2003; Royal College of Physicians, 2011; Smithson, Hukins & Jones, 2006), and neurological conditions more widely (Peters et al., 2013; Sixsmith et al., 2014; Thomas, Davies & Peel, 2010). My findings corroborated these by highlighting the poor coordination and communication between multiple service providers, based in primary, secondary, community and private sectors. People with MS required knowledge of services and their entitlements to coordinate them and required the confidence to communicate where coordination was not sufficient.

Participants with MS frequently sought the help of GPs and SNs to assist with this coordination and navigate services, although professionals could also report frustration and powerlessness when coordinating on people with MS’ behalf.

In my findings, people with MS navigated to their GP when they were unsure of the cause of a symptom, where the service was easily accessible and where they had a long standing relationship with a named GP. They reported preferring to see specialists where they believed that specialist knowledge was needed to manage their MS more effectively, but were aware that these services may be slower and harder to access. Information needs reported by people with MS in my study included signposting to available options of care (such as community services), education on what constituted
an MS symptom or relapse and how to manage these, and information on long term issues and ongoing progression in MS.

In my research, GPs were viewed as valuable by people with MS even where they did not demonstrate specialist knowledge, provided they were a reassuring and comforting doctor. Previous research suggests patients may be satisfied with services where GPs display limited specialist knowledge, if they perceive the GP as willing to listen, treating symptoms credibly and referring where necessary (Denny & Mann, 2008). As in my study, what was perceived by patients to be unacceptable were GPs who “fobbed off” or “dismissed” individuals, resulting in individuals having to “battle” to be taken seriously and receive appropriate care (Denny & Mann, 2008). Where this dismissal is long term it was reported to result in patients feeling “discarded” (Nettleton et al., 2005) or “abandoned” (as described by a participant in my study). This summarises patients’ perceptions that doctors are no longer interested in pursuing the problems or managing symptoms experienced by people with chronic conditions. In my study this led to both people with MS and professionals feeling like they had nowhere to turn to for support when a professional had demonstrated that they were not willing to engage with a person with MS.

Finally, decisions regarding navigation and support may also be dependent on the stage or subtype of MS someone is experiencing. Research has shown that priorities of people with MS change over time; whilst vision and gait are the two most important symptoms at any stage, pain is the third most important symptom in early MS, whilst cognition is the third most important symptom for people with progressed MS (Heesen et al., 2008). This highlights that information provision by health care services should be an ongoing process, as navigation to different generalist and specialist skills may be needed at different points of a person’s life with MS.

7.3.3 Permeability (access) and operating conditions

The candidacy model was conceptualised to explain experiences of access to health care. The permeability aspect of the candidacy framework explains how services that are easier to utilise (more permeable) are preferable to those which require more effort, such as those reliant on referral by a professional.

Within the candidacy model the final aspect is the impact of operating conditions. This explains how experiences of health care commonly depend on local influences and operating conditions, such as resources and local finance arrangements. Within my
findings access to services was heavily dependent on local and national operating systems and therefore findings from these two aspects are presented together in this section.

Access to specialist health care services has been frequently cited as problematic by people with MS (Johnson, 2003; NICE, 2003; Royal College of Physicians, 2011) and people with neurological conditions more generally (Peters et al. 2013; Sixsmith et al., 2014; Thomas, Davies & Peel, 2010). PCTs transformed to CCGs during my data collection, and both professionals and people with MS reported that this created confusion regarding finance and authorisation arrangements, which in turn were reported to lessen the responsiveness of care for people with MS. Differences were reported between the different PCTs and Foundation Trusts that I researched within, highlighting the varying availability of services, both for MS and more generally. The inequity of availability of treatment for MS, has been previously described as a ‘postcode lottery’ (Harrison, 2004) and the variance in financial procedures and authorisation lead to inequity within my sample.

People with MS, GPs, and SNs in my study reported difficulties accessing long-term community physiotherapy and specialist MS services. The difficulties experienced in accessing psychological support were discussed by people with MS and all three professional groups. Whilst SNs mentioned exclusion restrictions of psychological services specific to people with physical conditions, and some GPs mentioned the paucity of home based psychological support, in general primary care professionals discussed this poor access to psychological support as a much broader issue regarding IAPT and community psychology team waiting lists. People with MS’s frustrations regarding timeliness of access were compounded by the knowledge that during these delays a potentially irreversible decline in physical functioning may occur (RCGP 2010) while they are waiting for steroid treatment, rehabilitative therapy or the onset of DMTs.

Difficulties accessing SNs were reported by people with MS, GPs and SNs themselves. This was felt by SNs to be due to increasing prevalence rates of MS, decreasing administration support and the removal of additional funding for SN posts. Where people with MS were able to access SNs they were a source of tailored and specialist information, emotional support and increased permeability of access to other services, as has been shown in other SN roles such as oncology SNs (Hall et al., 2012). They also
acted as a point of consultation and information for GPs, although the delay in responding led to decreased responsiveness for both people with MS and professionals.

Unlike in previous literature (Becker & Stuifbergen, 2004; Bombardier, Wadhwni & LaRotonda, 2005) people with MS did not report difficulties accessing health promotion activities such as exercise, smoking cessation and nutritional advice. There are two potential reasons for this; firstly people with MS may not have been aware of their entitlement to certain health promotion and disease prevention services, alternatively they may simply not have experienced difficulties accessing these services. GPs, SNs and PNs reported the measures taken to ensure that people with MS had access to preventative care, suggesting that primary and specialist services have adapted where possible to meet these needs and those of people with physical disabilities more widely.

The candidacy framework’s concept of “permeability” was applicable to my findings, where people with MS preferred the more permeable access to GP surgeries than those which required a referral from a GP. Whilst access to SNs was more permeable as it did not require a referral (where people with MS remained “in the loop”), the use of answer phones and lack of immediate contact was felt by people with MS to lessen perceived permeability and responsiveness of this service.

Previous experiences of access recursively influenced people with MS’s navigation to services, as participants were more likely to return to a knowledgeable service that provided fast access to treatment, whether this was a primary or secondary care setting. Similarly, professionals were recursively influenced and were more likely to contact professionals they were confident they could access. Professionals also demonstrated recursivity with people with MS, where prior experience and knowledge of an individual influenced their decision making and adjudications. This could result in expedited access to care where previous experience had taught GPs that a particular individual was unlikely to help seek without due cause.

Access to services did not equate to access to effective symptom management. All professional groups in my study reported the impact short consultations had on their ability to holistically address all the needs of people with MS. In particular, professionals discussed how imposed targets prevented them from addressing what they and a person with MS may view as the primary health care need. My findings
resonate with those of Blakeman et al. (2011) as where PNs felt that checklist items were their priority, this did not leave time in restricted consultations for flexibility or autonomy regarding patient led priorities, such as self-management of symptoms. Previous research has suggested that QOF has altered consultations to focus on a pre-determined biomedical agenda (Campbell et al., 2008; Chew-Graham et al., 2013). In routine GP and PN consultations it has been suggested that QOF does not reward the demonstration of empathy or compassion, and may “prevail over the ethos of ‘holistic person-centred care’” (Chew-Graham et al., 2013, p.5). In my study nurses felt this prevented them from providing the unquantifiable aspects of nursing care, that are central to a good quality of care for people with long term conditions. PNs suggested that longer consultations and more time could ease these restrictions and increase person-centredness, especially for complex consultations such as those addressing comorbidity (as in Kadam, 2012).

Walshe et al. (2008) suggest that lack of time may be an explanation used to justify avoiding topics which professionals are not comfortable addressing, e.g. mental health or emotional distress. This corresponds with my findings of PNs where whilst time was a limiting factor, they voiced concerns in their ability to manage psychological concerns without extended training or support (discussed further in section 7.3.5 entitled “adjudication”). Together these findings from professionals suggest that due to national and service level restrictions, access to holistic support including psychological symptoms may go beyond simply accessing health care services.

7.3.4. Appearances at health care

The candidacy framework states that when an individual navigates to an accessible service, they must assert their need for care (sometimes repeatedly) in order to receive appropriate care.

My findings, combined with the candidacy framework, supported the assumptions of Zola (1973) that people make rational decisions regarding whether to seek help, in line with their personal beliefs about illnesses and treatments, and their personal values. However, my findings both agree and contradict with another of Zola’s assumptions, namely that people with MS may experience symptoms frequently but severity may be the driver to seeking help. This may potentially be due to the high risk and residual nature of serious MS disability when left untreated. However people with MS may also make health care decisions due to a more complex set of sociological, biological and
psychological factors, as outlined in previous research, including their previous illness experiences, the impact of their condition on their daily lives and a subjective view of their illness severity (Smith et al., 2008).

My participants who were older people with progressive MS, discussed their perceived ‘expert patient’ status and the limited knowledge of their doctors. This was presented as an explanation for why they chose not to appear at health care services, even with the necessary knowledge to navigate and facilities to access services. My findings corroborate those of Kroll et al. (2005) who found that in a sample of people with mixed disabilities, individuals felt that they knew more about their disability than their health care provider. This highlights the importance of person-centred care, tailored to people with MS’ knowledge and preference for autonomy.

Daker-White et al. (2012) found that people with ataxia accessed health care services expecting answers and treatment but were instead told to “go away and live with it (p.5)”. This echoes my findings regarding people with progressive MS (but less so those with R-R MS) who perceived a similar lack of support and involvement from secondary care, possibly due to perceptions of progressive MS as rare and untreatable. The frustration felt by people with MS was therefore caused by this dissonance between actions. These frustrations suggest that people with MS predominantly thought the role of these appointments should be to ‘get something out of them’ or ‘get something done’, suggesting some type of intervention whether referral, treatment or advice. The inability of medicine to meet these expectations was summarised by Bury in 1982, when he suggested that whilst medicine could be an important resource whilst able to assist, it could also be a constraint where it was not able to assist people with chronic conditions to find meaning or suitable management strategies.

Appearances at health care appeared less central to my sample than to Dixon-Woods et al. (2006) who investigated access in people from vulnerable groups, with well-established difficulties preceding appearances at health care services. In this respect they may differ from people with MS who appear to choose not to make appearances due to the belief that services are not of value to them personally. Unlike the studies cited by Dixon-Woods et al. (2006), the majority of my sample of people with MS did not appear to experience difficulties in asserting their claim for candidacy for physical health care (as described in Edmonds et al., 2007a), and many were active with campaigning activities such as the MS society. This may potentially due to the self-
selected nature of the sample, as these individuals were verbally articulate (Somerset, 1999), described themselves as middle class (Dixon, 2003), and did not appear intimidated by power differentials (Sword, 1999) or social distance from health care professionals, as highlighted in Dixon-Woods et al. (2006).

However, the findings on identification of candidacy for psychological needs suggested a different pattern. People with MS expressed a variety of beliefs that may present them appearing at health care services. These included concepts discussed in the section 7.3.1 on “identification of candidacy” including normalising emotional distress and not having the health literacy to identify psychological symptoms and navigate care. In addition, even where people identified their feelings as psychological symptoms and knew that help was available, some participants expressed the belief that lessening psychological symptoms was a choice dependent on willpower and distraction (as discussed in Alderson et al., 2014).

7.3.5 Adjudication

The candidacy framework expands past people with MS’ beliefs and actions, by encompassing the role of health care professionals. It states that how health care professionals perceive symptoms influences how they respond when people with MS present at consultations.

This aspect of candidacy was central to my findings. How professionals perceived people with MS’s presenting symptoms, their own abilities to manage the situation and their options for support, all had an impact on their reported responses and actions. Adjudication for MS is not straightforward due to both ambiguous MS symptoms and complications with comorbid medical conditions. In an American sample of 8983 participants with MS, diagnostic delay increased if smoking, obesity or mental or physical comorbidities were present (Marrie et al., 2009a), suggesting that differential diagnosis may be difficult with such complex presentations.

Where access to diagnosis and treatment are reliant on the judgement of health care professionals, adjudication becomes central to access. In doing so, any biases may facilitate or prevent people with MS accessing services or treatments (Owens Evangelou & Whynes, 2013). Owens, Evangelou and Whynes’s (2013) study investigated neurologist’s adjudications for initiation of DMTs, and found that a significantly higher proportion of people with MS on DMTs had had direct written correspondence with their neurologist, including letters of complaint, requests for
explanations and reports on health status. This suggests that the aspect of candidacy known as “appearances of health care” (asserting need to receive appropriate care) may not solely involve physical appearances, but instead may be achieved through written communication. For those with lower literacy skills and potential deference to hierarchy, this may affect their access to treatment through the adjudications of neurologists, showing the importance of the candidacy theoretical framework in addressing disparities in access to health care services.

Whilst the adjudications of neurologists may be central to accessing DMTs, adjudication of GPs is central to both starting the diagnostic pathway (through referrals to neurologists) and the diagnosis of symptoms once a diagnosis of MS is confirmed. GPs potential adjudications are made more valuable as they are the gatekeepers to further treatment, and the initial step for help-seeking in people with MS. Therefore GPs can make the difference between being responsive or dismissive of symptoms. Adjudications may also prevent access in a less targeted manner. Becker and Stuifbergen (2004) suggest that attitudes of health care professionals towards people with disabilities may create a barrier to preventative services, where professionals focus on an individual’s disability, not their holistic wellbeing including good overall health. Professionals in my study reported prioritising individuals’ holistic wellbeing. However, as people with MS and some SNs reported that GPs attribute many symptoms to MS, and some GPs described difficulties in managing MS symptoms, it is possible that additional symptoms may be overlooked where any change is attributed to MS symptoms.

Kroll et al. (2006) described two types of barriers to preventative services for people with disabilities; structural environmental barriers and process barriers. Structural environmental barriers referred to topics related to the physical and social environment in which services are offered. The majority of people with MS did not report experiencing these barriers, and PNs especially were keen to emphasise that they did not believe these were barriers at their practices, although time limitations resulted in difficulties with home visits. Process barriers related to issues in the encounters between patients and professionals during service delivery. These included provider knowledge and skills, professional flexibility and courtesy. My findings suggest that process barriers, not structural environmental barriers are the key priority for
improving MS care more generally, including improving professional knowledge on MS, improving responsiveness of services and improving interpersonal communication. People with MS’ reports of positive experiences with professionals mirrored available literature by focussing on interpersonal communication and rapport (Roush, 1995). This focus on the importance of communication and interaction between two people (‘micro-level’), fits with Dixon-Woods et al.’s (2005) observation that understanding micro-level interactions is central to understanding referral and retention patterns. Participants with MS in this study described in detail the lack of professional behaviour and sensitivity they experienced, which has been discussed in previous research (Kroll et al., 2006) and how this recursively impacted on their future use of services.

7.3.5.1 Referral thresholds

Walshe et al. (2008) explained that the concept of recursivity is appropriate to professionals as well as patients, and health care professionals make decisions based on their previous interactions with individual professionals and services, which in turn bias their future decisions for care. This highlights the vital nature of good intra-professional communication, as my findings support Walshe et al. (2008) by showing that health care professionals’ referrals for MS relied on judgements of ‘good’ or ‘bad’ professionals based on their responsiveness, communication skills and demonstration of mutual respect, in addition to judgements regarding capability. My findings support previous research suggesting professionals would prefer to refer to professionals with whom they have an existing relationship and trust, although this may be difficult in increasingly fragmented health care systems (Somerset et al., 1999; Walshe et al. 2008).

Reduced doctor to doctor communication has been noted between primary care and specialist services (Chew-Graham et al., 2008). GPs in my sample reported believing that if consultants in secondary care were more aware of the wide range of support for ongoing symptom management provided by GPs, then consultants would be more supportive of managing people with MS in primary care. This suggests that greater communication is needed between primary care and specialist services to clarify the roles of individual professionals and services, and identify an acceptable threshold at which to refer people, although without direct access to a named clinician, and with limited alternative options this may not effect much change.
Findings from people with MS and SNs, and to a lesser extent GPs, in my study suggest that where GPs experience low knowledge and low perceived ability to manage ambiguous or difficult to treat symptoms in MS, they may also chose to refer. Added pressure may be patient expectations, as my participants with MS reported that where they were not satisfied with a GP’s knowledge or expertise they expected referrals to a community or specialist service.

An integral part of GP care is using their expertise to manage uncertainty at the pre-diagnostic stage, by acting as gatekeepers to specialist care (Hill & Freeman, 2011). Similarly to previous research (Kelly et al. 2011) my findings indicate that most people with MS were referred to specialist neurology services by their GP, suggesting a key role for GPs in identifying potential MS.

GPs in my study viewed themselves in line with Hill and Freeman’s definition of GPs as “expert generalists who value their role in co-ordinating and integrating care designed around the needs and circumstances of each patient (2011, p.10)”.

GP

GPs in my study did not see specialist knowledge of MS as integral to this role. People with MS differed on the level of knowledge they expected from their GP, suggesting that dialogue between GPs and people with MS should clarify the role and level of knowledge provided by GPs, and provide options for alternative navigation of services for additional specialist knowledge.

The adjudications and level of specialist knowledge of GPs may become of greater importance through the work of clinical commissioning groups. Access to medications is controversial in MS as many treatments including DMTs are not considered cost-effective (NICE, 2002), and CCG funding of several treatments may be withdrawn as recommended in the draft 2014 clinical guideline for MS (NICE, 2014). Where NICE evidence on a drug is not available then a decision on providing the drug is made locally, leading to national variation based on professional adjudications.

The perceived threshold at which people with MS’ needs met the requirement of a referral for more intense support did not appear to be clearly defined in any professional group in my research, and appeared to differ by individual confidence and experience, suggesting that perceptions of candidacy and adjudication were subjective.

This applied to both psychological and physical symptoms. The nature of varying referral thresholds is not a new concept (Cummins, Jarman & White, 1981). However, my work expands on such previous work by showing that professionals other than GPs

230
(namely PNs and SNs) also experience thresholds in relation to referrals, and for physical and psychological symptoms their thresholds may be substantially lower. Previous research suggests GPs make referrals due to medical necessity, to avoid overlooking anything and to reassure the patient (Ringberg, Fleten & Forde, 2014).

Reassurance has been noted as a key function of the GP relationship for people with MS in both prior research (Thorne et al., 2004) and my findings. Where GPs in my study reported feeling they lacked specialist knowledge they were willing to refer after discussion with a specialist colleague, or where specialist advice was not available. Previous research into hospital referrals from GP out-of-hours care has suggested that referral rates are based on GPs’ level of confidence, where GPs with low confidence referred more (Calnan et al., 2007). Similarly to Calnan et al. (2007) less experienced GPs in my study reported feeling less confident and therefore more likely to refer, whilst more experienced GPs voiced greater confidence in their decisions and were more likely to report managing people with MS’ needs themselves. More experienced GPs in my study discussed the need to manage people with MS more in the community than frequently referring them to specialist care. Previous research suggests varied motivations behind referrals to specialist services, as in Walshe et al. (2008) my findings suggest that GPs referred to neurologists or SNs when they felt they could not offer responsive care to people with MS. Where there was no clearly identified responsibility for people with MS or shared responsibility of people with MS, then it could become difficult to identify who was the lead for care coordination.

Referral thresholds for psychological symptoms were also demonstrated in my study. As in Chew-Graham et al. (2007) GPs, and in my study SNs, discussed the value of being able to contact a named individual for specialist knowledge and how this was now nearly impossible due to service restrictions. They highlighted their concerns about the sustainability of current psychological services, and the negative impact poor responsiveness had on people with MS in need of care. People with MS also detailed the responsiveness and timeliness required to address their needs, without their psychological wellbeing deteriorating unnecessarily.

The need for improved responsiveness as described by GPs and PNs in my study reflect factors identified for successful collaboration between primary care and specialist palliative care services, namely: good communication between professionals,
opportunities for education, good access to specialist care, well-coordinated continuing support and clear role and responsibility definition (Gardiner, Gott & Ingleton, 2012). My findings suggest that people with MS did not always feel that they had a named professional who was responsible for overseeing their care. In professional interviews this was illuminated where GPs discussed their perceptions that specialist care coordinated services, whilst SNs reported that due to increasing workloads they would only coordinate people with MS who actively needed input from specialist services, suggesting that certain individuals in MS may experience limited care coordination.

7.3.5.2 Medically unexplained symptoms and legitimacy

The ambiguous and fluctuating nature of MS symptoms may cause questions regarding legitimacy, as in studies of medically unexplained symptoms (Nettleton et al., 2005) or contested medical conditions such as chronic fatigue syndrome (Clarke, 2000). Kelly et al., (2011) reported that 45% of their n = 119 sample of people with MS were initially referred to specialist neurology services for medically unexplained symptoms, suggesting that there may be significant overlap between these symptoms and MS. My participants shared narratives where their perceived real and sincere medical needs were treated as false or not warranting of care. These perceptions of not being believed regarding credible medical symptoms is part of a much wider literature on patients’ needs to demonstrate authenticity and legitimacy of candidacy for care (Brown, 1995; Koehn 2009). Rhodes et al. (in press) describe how patients require “psychosocial safety” which includes the belief that a GP will treat their concerns seriously and credibly. Believing that professionals would not uphold their legitimate claim to candidacy could have a detrimental impact on help-seeking, and my findings suggested that participants with MS were unlikely to seek help for mental health or ‘invisible’ physical symptoms if they did not believe they would be taken seriously, and their candidacy viewed as credible (as in Rhodes et al., in press). This reflects previous literature such as Smith, Pope and Botha where people with cancer reported delayed help-seeking where they believed they would be viewed as a "time-waster" or "neurotic" (2005, p. 827).

Diagnosis is the start of a legitimate and credible candidacy for services (Brown, 1995). Before diagnosis my participants with MS reported varied experiences of perceived legitimacy; some presented to GPs who immediately perceived their claims as legitimate, resulting in fast access to diagnosis. Others were treated as making
illegal claims to care, resulting in prolonged delay before diagnosis. However, despite MS being a relatively uncontested illness once diagnosed, participants continued to experience perceptions of illegitimate claims for candidacy in their ongoing symptoms. This appeared to be because symptoms were not objectively perceivable or measurable in the way that initial symptoms could be attributed to findings on an MRI scan or lumbar puncture. This meant that participants could find themselves in the contradictory position of having an uncontested condition with frequently contested symptoms, where these symptoms did not match professionals’ perceptions of MS.

As in previous studies of MS my participants reacted to these interpretations with anger, frustration and a loss of confidence in both themselves and the professional (Thorne et al., 2004). Nettleton et al. (2005) explains how people need appropriate terms to describe medical symptoms, and where this vocabulary does not exist a medical discourse is substituted, creating the explanation of symptoms as psychological with no physical basis. In this respect they explain a lack of credible language equates to a lack of credible symptoms; in this situation people are vulnerable to the language and labels attributed to them by doctors, in what has been described as “the dominant patriarchal and medical discourse” (Coyne, 1999, p.114).

Daker-White et al. (2011) found that dismissal of symptoms as psychological was more likely when people with ataxia experienced fluctuating symptoms, which is very relevant to MS were many symptoms such as pain and fatigue may be both transient and invisible. Medically unexplained symptoms are commonly perceived by GPs as psychological in nature (Wileman, May & Chew-Graham, 2002). People with chronic conditions’ experiences of being told that symptoms are “all in the mind” have been discussed in relation to ambiguous or medically unexplained symptoms (Daker-White et al., 2011; Nettleton et al., 2005) and people with MS in my sample felt that their medical concerns were being dismissed when they were attributed to psychological causes. Many of my participants with MS did not feel that psychological explanations of physical symptoms were a credible differential diagnosis, but instead, a stigmatising judgement by professionals regarding the person with MS’s personality and character. This may be due to the history of multiple sclerosis, in which MS was traditionally associated with psychiatric symptoms such as hysteria and euphoria (Blatt & Hecht, 1951), leading to the interpretation of MS as a psychiatric not neurological disorder.
Indeed, previous research on MS has focussed on the “personality disorder” of MS, presenting people with MS as overly neurotic, emotionally irritable and lacking in empathy, even when these symptoms be may be indicative of an underlying depression or dementia (Benedict et al., 2001). Where people with MS refute psychological explanations of symptoms, it may be that they are refuting the stigma associated with the history of psychiatry (Gray, 2002), not the possible interrelation of physical and psychological wellbeing, which was a topic commonly discussed by participants. A key finding of my study was that where people with MS had negative experiences or felt they were not listened to or valued, this could lead to feelings of a loss of personhood which challenged their identity and psychological integrity. This concept has been outlined by Coyne (1999) who investigated dissatisfaction in the general population and concluded that dissatisfaction was too narrow a concept to incorporate the complexity of participants’ experiences of poor health care. She suggests that the concept of “personal identity threat” is of greater value, defined as: “Threats to personal identity included perceptions of being dehumanised, objectified, stereotyped, disempowered and devalued” (p. 107). This concept was highly relevant to my participants with MS, and like in Coyne (1999) was present across the whole sample irrespective of age, gender, or level of perceived expert status of knowledge or experience. The majority of my participants with MS reported their most negative experiences with neurologists in hospitals, especially being treated as “non-persons” as reported in Coyne (1999). The invasiveness and emotional nature of diagnostic testing in MS, made the comparison with the depersonalisation of being treated as an object or number even more stark. Feeling objectified was a direct contrast to feeling valued for individuality, personal knowledge and experience, and precluded the importance of individual’s feelings and wellbeing. In addition, objectification revolves around the concept of a normative case (Coyne, 1999) displaying medical norms. Whilst for any patient this would prevent appreciation of their individuality and unique needs, this created further distress in an ambiguous condition such as MS were variance between individuals may prevent a clear cut normative case, particularly in the case of medically unexplained symptoms pre-diagnosis. In negative experiences of care professionals dismissed symptoms that did not fit with their perceptions of these idealised norms, in
some cases delaying diagnosis and preventing symptom management. This dismissal in turn was perceived as indicating a lack of candidacy.

As reported in Coyne (1999; who interpreted Garfinkel (1967) and Goffman [1959, 1963, 1971]) all participants had pre-existing expectations of what social interactions with professionals comprised, and in all negative interactions these expectations were not met. For example, the most extreme emotional reactions were reported when professionals did not listen, interrupted abruptly, shouted or acted aggressively or brusquely (as described in Coyne, 1999).

Patients who perceived stigma from health care professionals use health care services less (Earnshaw & Quinn, 2012) and stigma within health care settings may act as a barrier to regular health care access, in turn decreasing symptom management and quality of life (Earnshaw & Quinn, 2012). It is therefore essential to prevent stigma and address perceptions of stigma or personal identity threat within consultations to ensure that people with MS do not experience these barriers to care.

7.3.5.3 Adjudication of psychological needs

The majority of depression management and antidepressant prescription in the UK is managed within primary care (NICE, 2009, CG91). My study confirmed the key role of GPs in managing psychological care of people with MS, both where nurses felt psychological issues were outside of their remit, and when local psychological services were not available for referrals (as discussed in Macdonald et al., 2009).

Professionals’ judgements on depression are key to understanding the mental health referral decisions they make. GPs in my study reported that their patients (with and without MS) faced a range of social and environmental difficulties. As in previous research (Macdonald et al., 2009; Pratt, Halliday & Maxwell, 2009), GPs and PNs in my study who self-reported working in more deprived areas reported difficulties in managing depression resulting from social and environmental factors. Macdonald et al. (2009) explain that at the “coal face” of general practice, where the causes of depression cannot be fixed by individual GPs i.e. social deprivation, then the only practicable option is to treat the symptoms of depression, commonly with medication. This “medicalization” of unhappiness or sadness (Dowrick & Frances, 2013) related to contradictory data in my study, where both participants with MS and professionals reported both the medicalisation of sadness and the normalisation of potentially significant low mood. Depression was viewed as a highly prevalent part of GP practice,
as acknowledged in literature suggesting psychological conditions account for nearly 25% of general practice consultations (Joint Commissioning Panel for Mental Health, 2012). Individual GPs discussed the varying thresholds at which they would give the diagnostic label of depression (Maxwell, 2005). When referring to mental health needs for people with MS all groups of professionals referred to this as “a can of worms” or “Pandora’s box”. This feeling that discussing mental health may lead to problems that cannot be contained within a given consultation has been discussed elsewhere when dealing with both mental health and multimorbidity in primary care (Alderson et al., 2014; Maxwell et al., 2013; Pratt, Halliday & Maxwell, 2009; Smith et al., 2010). In my study it was prevalent in PNs who associated it with a lack of training and knowledge on mental health and the perception that PNs had only recently started to see mental health as part of their remit (as reported in Maxwell et al., 2013). PNs in my study who reported feeling most comfortable in addressing both psychological and physical needs had prior experience working with people with psychological conditions and/or had attended advanced training. This may have also explained why PNs interpreted the phrase “psychological needs” differently. To many PNs psychology referred to psychiatry and they discussed conditions such as bipolar disorder or schizophrenia, which they reported lack of knowledge of, and in some cases fear. Conversely however, on some occasions PNs referred to situations where people with MS discussed low mood related to their chronic condition and normalised this as “having a chat” which felt within their remit and manageable.

SNs were familiar with the history of cognitive and psychological symptoms of MS and research focussing on psychiatric symptoms caused by brain atrophy and lesions (e.g. Benedict et al., 2004). However, they were quick to state that whilst they had a number of people with bipolar disorder or personality disorder on their caseload, the majority of people with MS they provided services for experienced mild to moderate depression and anxiety, which they perceived as explained by the biographical disruption and challenges of daily life they faced.

It is necessary to address the discomfort experienced by nurses for multiple reasons. Discomfort may cause tension in the nurse-patient relationship, and where PNs are not comfortable discussing psychological needs they may deliberately or inadvertently prevent people with MS from raising concerns (Maxwell et al., 2013), thus preventing detection of symptoms or provision of psychological support. In comparison to nurses,
the majority of GPs reported feeling comfortable managing psychological symptoms but some felt they lacked the time and available avenues of support, leading to reluctance addressing these issues (Pratt, Halliday & Maxwell, 2009), thus creating a potential barrier to care and reducing holism.

7.3.6 Offers and resistance

In Dixon-Woods et al. (2006) the category of “offers and resistance” explains how even when individuals are offered services they have the autonomy and the potential to refuse them. Acceptance and refusal are based on their recursive experiences and perceptions of treatments and services. For example, people with MS may be eligible for DMTs but may reject or discontinue them due to side-effects, perceived lack of efficacy or fear of administration procedure (i.e. self-injection; Costello et al., 2008).

Whilst none of the people with MS in my study reported being eligible for DMTs and rejecting them, the majority of participants reported discontinuing or not initiating medication for symptom management due to a perceived imbalance between side effects and efficacy.

The decision to accept or reject a treatment has been found to rely on the perceived difference between the benefits and the cost of various options (Singer et al., 2014), including the use of anti-depressants (Wouters et al., 2014). As this weighting is highly subjective, it is crucial that the decision making process is communicated between professionals and people with MS.

This process is also related to the concept of identification of candidacy, as where participants do not view themselves as candidates they may not accept a service, in the same way that they would not seek help. For example, in my study participants with MS reported turning down psychological support where they felt their needs were not severe enough (as in Mojtabai et al., 2011).

Refusal is a key part of the stepped care model, and is viewed as providing information about progress and necessary intervention, rather than simply withdrawal from treatment (Bower & Gillbody, 2005) due to a lack of motivation. In this it differs from the candidacy model which views resistance as an act of withdrawing from a given option. Where people with MS reported rejecting a proffered option, it was usually presented in a manner that provided information on a key illness belief or a core part of their self-concept (e.g. medication that interfered with employment). Therefore my findings suggest that offers and rejections should not be accepted at face value but
utilised as a contribution of knowledge and an opportunity to further strengthen the professional-patient relationship.

7.4 Beyond candidacy

7.4.1 Self-management and multimorbidity

A flaw of the candidacy model is that it does not always account for the role of effective self-management of health care needs. Where people with MS effectively managed their physical and psychological needs independently, they were less reliant on health care services and less likely to identify themselves as a candidate for care. Self-management emerged early on in the findings of people with MS and corresponded with the theoretical concept of recursivity (Rogers, Hassell & Nicolaas, 1999). Addressing past experiences and beliefs regarding health care services may identify barriers to effective management of symptoms and utilisation of services. Additionally, candidacy can’t coherently explain the processes behind health care for multiple conditions as it addresses a sequential care pathway for a single condition, although this has yet to be explored. It has been suggested that recursivity is key for health care decision making in multimorbidity (Morris et al., 2011).

Morris et al. (2011) found that support for self-management was dynamic and could change based on key transition points including exacerbations, work overload or significant events such as bereavement. This would suggest that after an MS relapse or significant life event, there may be a need for people with MS to discuss self-management needs and how they may have changed. Similarly, where a person with MS develops an additional comorbidity this should be addressed by the relevant professional to ensure appropriate support. Experiencing multiple medical conditions may have an additive effect which facilitates help seeking (Aikens & Rouse, 2005). If this is the case with people with MS, then GPs may be in a particularly pivotal role for individuals to seek help when they attend with other health needs. The holistic appraisal that GPs and PNs may have in this situation suggests they could play a key role in this self-management support, if MS specific knowledge was not problematic.

Participants in Morris et al. (2011) reported difficulties in accessing information explaining multiple chronic conditions (for example diabetes and depression). It may be harder to access information on managing multiple conditions including a rarer condition such as MS, as accessing relevant information for MS is already reported to be problematic. Tailored information is crucial, as where self-management support is
not targeted at patient specified priorities people may disengage, and symptom priorities may change depending on which conditions is impacting most at a given time (Morris et al., 2011). For people with MS there may be a dilemma where SNs can provide MS specific knowledge but may not be able to advise on comorbidities, and vice versa for PNs. Similarly, whilst GPs may be unfamiliar with specific MS medications, neurologists may not be aware of all medications taken to manage multimorbidity, leaving patients’ lacking confidence (Morris et al., 2011) or at risk of potential drug-drug interactions. Collaboration between primary and secondary services may therefore be the key to successful, tailored, safe and dynamic self-management. Self-management was not just reported for physical symptoms in my study; people with MS also referred to self-help for psychological symptoms, although this was less commonly mentioned by professionals. The reported self-help strategies included using the support of relationships with family and friends, positive thinking and hobbies (as reported in Faulkner & Layzell, 2000). This suggests the utility of self-care for psychological symptoms may be under-recognised by professionals working with people with MS.

7.4.2 Patient-centredness

Chew-Graham et al. (2013) in discussing Stewart’s (2001) definition of patient centred care, suggested that patient-centredness is “not technology-centered, not doctor-centered, not hospital-centered or disease centered (p.2)”. My data suggests contradictions as to how MS care may relate to this definition. Where patients and professionals focussed on annual reviews, they referred to MS specific care provided through hospital based secondary care services and initiated by clinicians, which would match three of the negative aspects outlined above. However, where people with MS, SNs and GPs discussed the role of SNs they referred to a service that could be initiated by patients (albeit with poor responsiveness), involved home visits where possible and provided a service that got to know patients’ whole lives, including factors additional to MS such as social or environmental factors. Input from GPs improved the person-centredness of their overall health care still further, by addressing multimorbidity through patient initiated consultations in a community setting. This suggests that the patient-centredness of care is not static, but dependent on the type of professionals involved in a person with MS’ care and the extent to which each professional is involved. My findings suggest the biggest risk to patient-centredness appears to be
where people with MS only attend MS specialist clinics without intermittent health care use (or those who use no services at all) whilst the best appears to be from those utilising services from a wider MDT including SNs and one consistent GP.

7.5 Strengths and limitations of my study

7.5.1 Critique of recruitment

The sample of people with MS for this study was recruited from primary care and community settings (as discussed in chapters 4 & 5). Due to the lack of response from primary care, despite the significant time invested, only one participant with MS was recruited from primary care. It may be that people recently using primary care have a better recollection of their last primary care consultation, or may experience more comorbidities resulting in more frequent use of primary care (Glynn et al., 2011), than people recruited from community samples whose MS was long term and relatively stable.

Somerset et al. (2001) attempted to recruit participants with MS through GP surgeries. They found that 66 people in participating practices were excluded by their GP as they considered it inappropriate to invite them to the research study due to either ill health, or alternatively very good health, where people with MS were not aware of their condition on a daily basis (Somerset et al., 2001). Research on recruitment more generally has shown that GPs may exclude participants from research if they incorrectly assume comorbidities make them ineligible (Jenkinson et al., 2014). Only one GP responded to my study invite to explain their choices for not participating; they cited lack of time. Overall however, I was not aware of GPs reasons for not including participants in this research, or the numbers of GPs who did invite participants who then declined to participate.

Despite a large recruitment campaign, few invited GPs participated in this study. PNs and SNs had a much higher participation rate, a pattern reflecting previous research (e.g. Walshe et al., 2008). Of the GPs and PNs recruited many had never had direct contact with an MS specialist team. There is therefore a need for future research to proactively recruit participants with experience of working with specialist teams. Additionally, only one GP in my study was employed full time, potentially due to the recruitment of academic GPs who may be more likely to work part time. Although academic GPs may be more aware of current issues in research, none of my participants were currently researching MS thus limiting potential bias.
There may be potential biases of both professionals with an interest in this health care area (as discussed in While et al., 2009) and people with MS who have a particular interest in health care or a story to tell. They may be people who have had negative experiences and therefore wanted to participate to rectify these experiences; many participants discussed how they hoped participating would prevent others experiencing negative aspects of care. However, the majority of participants were keen to discuss both the positive and negative aspects of their health care. Previous research has suggested that feeling a research project has matched an unmet health need, wanting the opportunity to help others in similar situations and wanting to feel your voice is being heard are significant reasons for participating in health care research (Kneipp, Lutz & Means, 2009) matching the motivations of my participants.

In future research there is a need for more proactive recruitment of younger people, men and people from ethnic minority backgrounds. By advertising through online forums and contacting shift.ms I attempted to reach people with MS under the age of 30 years, but was unsuccessful. A participant in my study expanded on the difficulties of meeting younger people with MS and suggested contacting a group for people with MS who were in employment; however no response was received from this group. Also they suggested attending patient information days for recruitment purposes, and with prior ethical approval this could be an effective route of recruitment in future research. By contacting groups that identified themselves as providing services for people from minority ethnic backgrounds (such as Asian MS and specific carers’ and community groups) I hoped to engage with people with MS from minority ethnic backgrounds, as previous research suggests cultural differences in disease progression and psychosocial concerns in people with MS (Koffman et al., 2013). However, as in similar research, this was not achieved, resulting in a primarily Caucasian sample (DalMonte, Finlayson & Helfrich 2003; Edwards, Barlow & Turner, 2007; Edmonds et al., 2007a; Russell, White & White, 2006).

Most participants with MS were female, in keeping with other literature which suggests it is difficult to recruit men (Patel, Doku & Tennakoon, 2003) and samples are usually weighted heavily to women (Edwards, Barlow & Turner, 2007; Malcomson, Lowe-Strong & Dunwoody, 2008). However, as men, especially men of an older age, are significantly more likely to experience comorbidity in MS (Marrie et al., 2008) it is vital that they are recruited into future research.
Somerset et al. (2001) found that participants in their study on health care experiences for MS were equally divided into those who did or did not find MS social groups helpful, which supports the findings of this PhD research and the mixed benefit perceived by participants. Recruiting participants through the MS society may therefore have biased the sample towards people with a particular health care utilization style. No participants in this study were unable to perform any independent activities of daily living at the time of interview. This may have skewed the sample towards a group with similar health care needs, which did not require palliative or residential care. Similarly, the experiences of hospitalisation were only briefly touched on in this study, as topics were led by participants, and few had recently experienced hospitalisation for MS (as this was commonly related to emergency care for relapses). Ghafari et al. (2014) investigated experiences of hospitalization for people with MS in Iran and identified hospitalisation as a period of intense emotional distress and worry. Future research in the UK is needed to compare these experiences with needs of people with MS in the UK health care system.

Strupp et al. (2014) concluded that people severely affected by MS (defined as individuals requiring a minimum of two walking aids to walk 100m, through to people confined to bed and totally dependent) have significantly different care needs than those less severely affected. These included a greater need for home visits, more frequent and continuous neurology input and advanced emotional support for both people with MS and their families. Previous research has found that people with severe ill health may withdraw from interviews if they don’t feel well enough to participate (Nettleton et al., 1995), similarly ill health may be a reason for not participating initially (Patel, Doku & Tennakoon, 2003). Only one participant with severe ill health participated in my study, and we had developed a strong rapport after attending several MS society meetings together. This interview was very short and included multiple breaks, however without meeting in an informal situation and gaining trust and interest it is possible this participant would not have volunteered to participate. Future research is needed to investigate the role of primary care for people severely affected by MS but more proactive recruitment and altered data collection methods will be required.

It has been suggested that people with speech difficulties may be more likely to communicate online, suggesting the utility of online forums for data collection (Daker-
White et al., 2011). As speech problems (dysarthrias) are common in MS, the prospect of an interview may have been off-putting for some people. Offering email interviews may empower people to participate with either speech problems or those experiencing extreme fatigue or cognitive impairments (Egan, Chenoweth & McAuliffe, 2006; Ison, 2009), by allowing people increased time to respond and control over the timing and pace of the interview. Overall, this may increase the variety of experiences investigated and contribute important knowledge (Egan, Chenoweth & McAuliffe, 2006; Ison, 2009), as speech difficulties could potentially impact on communication in consultations, which have already been identified as problematic (Methley et al., 2014).

7.5.2 Critique of methods

This qualitative study was designed to address the gaps identified in the limited literature on people with MS and professionals’ experiences of UK health care services for MS. Using an interactionism approach, including elements of phenomenology and social constructionism, allowed the linking of experiences and meaning across three levels described by Brown (1995, p.37) as:

“The microlevel (such as self-awareness, individual action, and interpersonal communication), mesolevel (such as hospitals and medical education), and macrolevel (such as the nation’s health status, the structure and political economy of the health care system, and national health policy)”. In addition, this epistemology allowed an understanding of shared meaning created by both people with MS and professionals. Narrative analysis was a possible methodology for this PhD. However, MS has been extensively studied with narrative analysis (Robinson, 1990; Reissman, 2003; Olsson, Lexell & Söderberg, 2005) and I felt that investigating the narrative as a whole was not the most effective way of addressing my research questions regarding experiences of health care. Many interviews were limited by participant’s physical and cognitive fatigue so to gain imperative information in a limited time period I used a more structured approach.

Personal resources such as financial situation were not objectively investigated in this study. One disconfirming case in my findings was a participant who felt they needed to buy in private services to ensure good quality care. This raises the issue of personal financial resources as a support strategy (Bury, 1982) and their interaction with self-management and candidacy for care. As I did not formally classify participants by social class, income or type of employment, it was not possible to address this issue in my
research; instead I used information provided by participants as necessary context when interpreting their experiences of services.

As experiences of symptoms and symptom management were based on people with MS or professional’s experiences, the interpretation was based on their perception of reality. It was therefore not possible to discuss or judge an objective perspective of ‘appropriate’ candidacy, use of health care services or treatment in this study. Future research could utilise analysis of case notes or observations of consultations to investigate the appropriateness of particular service use and provision in MS.

My study highlighted that there are different perspectives and priorities between people with MS, primary care and secondary care professionals for MS management. For the purposes of this study participants and professionals’ experiences were taken at face value. To investigate these complex differing perspectives further, ethnography could have been used. This would have allowed the opportunity to investigate patient and professional experiences simultaneously and identified problematic areas in context (Savage, 2000). Observations not audits or investigations of clinical records would be needed, as it has been suggested that it may be impossible to objectively measure the process of offers and resistance through these methods. This is because offers of health care services are often made in private during negotiation in consultations and not necessarily formally recorded (Dixon-Woods et al., 2005). By utilising the method used in Chew-Graham et al. (2013) of audio recorded consultations followed by tape-assisted recall interviews, it would be possible to gain an understanding of identification and adjudication within a specific consultation, instead of general concepts which may suffer from selective remembering.

Due to initial difficulties with recruitment the planned method of longitudinal interviews could not be completed within the allocated PhD time period. All data were therefore collected from single interviews with participants. For both patients and professionals it could be a significant amount of time since their last health care experience for MS and potentially important information may not have been recalled.

Previous longitudinal qualitative studies of health care services for long term conditions (Boyd et al., 2009; Murray et al., 2009) have shown this to be an effective, if time intensive, method of: obtaining individual’s current experiences and opinions of their health care services and staff, providing context to themes and identifying changes in priorities for care over time (Murray et al., 2009). Changes in time are important for
progressive conditions such as MS, as longitudinal interviews may have identified relationships between changing MS subtype and symptoms, and changing experiences and needs of services (Bury, 1982). In addition, longitudinal qualitative research can provide a continuous relationship between researcher and participant that may assist in discussion of sensitive topics (Murray et al., 2009), making it relevant to the study of potentially distressing topics in MS such as potentially stigmatised symptoms, or negative experiences of consultations.

In future an anonymous format such as an email interview or questionnaire with no face to face contact may encourage reflection on all available services and health care needs, including sensitive issues. Having more than one researcher, such as researchers of different genders, may enable participants to feel more comfortable discussing sensitive issues including issues that involve perceptions of masculinity (Sallee & Harris, 2011), however this was not possible within the confines of this PhD research.

7.6 Reflections on the study

I originally intended to interview neurologists and IAPT workers about their role in psychological support. However, preliminary data from both patients and professionals did not identify IAPT workers or neurologists as fundamental sources of psychological support; therefore time and resources were prioritised for GPs, PNs and SNs as outlined in chapter 2. My findings regarding the limited role played by neurologists was corroborated by a study showing that whilst 90% of neurologists provided the diagnosis of MS, only 50% of people with MS reported them as their biggest support in understanding the disease (Heesen et al., 2003).

Previous literature suggests that carers and family members are heavily involved in the health care of people with MS, and have additional health care needs themselves (Forbes, While & Mathes, 2007). A limitation of my research is that carer’s experiences and needs were not explored. This was because a compromise had to be made between the available time for data collection and the lack of knowledge regarding potentially key individuals for MS. As the lack of knowledge on GPs and PNs was profound and a large amount of available knowledge exists investigating carer wellbeing in MS (Benito-Leon et al., 2011; McKeown, Porter-Armstrong & Baxter, 2003) I prioritised GP and PN experiences. Previous research has suggested that carers may be more critical of services than service users (who may perceive stigma or negative consequences to voicing criticism; Coyle, 1999). Therefore, interviewing carers may
provide further information on the role of health care services for MS and triangulation on the experiences of care for people with MS. It has also been suggested that GPs are key to supporting carers (MS Society, 2009) and therefore further investigation of carer’s experiences may shed light on the role of GPs for the holistic care of families living with MS.

In conclusion, future research should prioritise increasing the knowledge of health care services for MS by recruiting more diverse samples of people with MS using more innovative methods, investigating the knowledge of professionals working with specialist MS teams, and including the perspectives of additional health care professionals and carers.

7.7 The role of the researcher and reflexivity

For the first two years of my PhD I was employed as an assistant psychologist in the NHS. As described by previous researchers this dual clinician-researcher role has been both a benefit and a challenge (Yanos & Ziedonis, 2006). Many of the participants with MS had experienced negative encounters within the NHS and others were unwilling to appear critical of NHS care. As such I did not disclose my identity as NHS staff unless participants directly asked. This was to try and ensure that participants were as open as possible about experiences, given that interviews are negotiated between individuals based on their and the others perceived role (Briggs, 1986) and it has been suggested that where health care professionals lead qualitative research participants do not feel they are able to criticise health care services (Smithson, Hukins & Jones, 2006). Only seeing participants once made analysis both easier and more difficult. It prevented me getting too immersed in participants’ lives, making analysis easier and less subjective (Hughes, 1994). I was also not native to the research in that I do not have MS, allowing me to prevent over-identifying with participants (Corbin Dwyer & Buckle, 2009).

With regards to health care professionals I did not disclose this additional role to GPs and PNs; however I knew the SNs through my NHS role so they were aware of my experience and knowledge.

I did not interview anyone who was employed in the same role as me, making it easier to maintain distance from the findings and interpretative analysis. As the geographical areas of my clinical employment and research were totally separate I ensured that I did not interview any of my patients or colleagues from my own NHS Foundation Trust. I was personally aware of the difficulties experienced by professional participants.
working in the changing NHS climate. Analysis was conducted with my supervisory team who included non-clinicians, ensuring that the analysis was not overly sympathetic to these issues and allowed a detached perspective. However the inclusion of a supervisor with a clinical role was vital in integrating technical and clinical knowledge into analytic interpretations around issues such as medications, operations and other treatment procedures, as described by other research teams investigating health care topics (Olesen et al., 1994).

The topic of how MS had affected people physically and emotionally was a very emotive one. Even participants who had been diagnosed with the condition for decades still had strong emotions when describing their experiences. For some participants it was the first time they confronted the progression of their MS or the limitations they now faced. As may be expected therefore, several participants became distressed. In addition, the interview often raised distressing experiences not related to MS e.g. illness or death of a loved one. My experience as an assistant psychologist meant that I was well placed to identify and support people when they were distressed and to judge the level of distress and further actions regarding ceasing the interview and safety-netting before leaving. My service-user consultant offered personal experience when interpreting the data from these interviews and suggesting possible resources to signpost to. Her input to the study design was invaluable in both the design of the research and the creation of a dissemination plan targeting people with MS and their families, clinicians and academic researchers (Appendices J & K).

7.8 Wider implications for research, education, policy and practice

7.8.1 Psychological needs of people with MS

Given the potential normalisation of depression in people with MS it could be suggested that an implemented depression case finding measure is needed. Previous research has established that GPs disliked being asked to work to protocols or standardised measures and valued the professional respect of autonomous flexibility (Alderson et al., 2014; Maxwell et al., 2013; Walshe et al., 2008). In a health care environment where both PNs and GPs feel restricted by tickboxes then it is unlikely that a highly standardised intervention for a rare (non-QOF) population would be adhered to, or of perceived as of value.

In addition, studies from other long term conditions measured under QOF have shown that introducing compulsory screening may actually reduce the effectiveness of
depression screening where it became ‘reductionist’ and prevented the use of established clinical skills (Coventry et al., 2011). What is needed in MS is to increase the awareness of depression amongst people with MS and professionals; but highlight this as a central part of practice and not an additional outcome measure.

Maxwell et al. (2013) investigated case finding for depression in people with diabetes and CHD and found that it was only effective when there were appropriate options for referral and management available after identification. My findings suggest that appropriate options for psychological care for MS may be lacking, as may GP and PN knowledge of relevant services and confidence in appropriate referrals (as detailed previously in other LTCs, e.g. Maxwell et al., 2013). This highlights the need for improved information provision and access to services as more appropriate intervention targets than increased case finding, at this point.

7.8.2 Education of both people with MS and professionals

GPs and PNs in my study did not feel they could justify the time needed for further Continuing Professional Development or education on MS, given their perceived overburdened workloads. It was suggested by all primary care professionals that education on MS would only be seen as worthwhile if the number of patients with MS registered with a specific practice were to increase significantly.

However, the RCGP states as part of the key messages of its curriculum that all GPs should “be competent in the management of neurological emergencies, many neurological conditions can be managed in primary care [and] GPs play an essential role in the management of chronic neurological disability in the community” (RCGP, 2014, p.3). In particular it states that GPs should manage symptoms relevant to MS including numbness, tingling and dizziness, and specifies MS as a condition where GPs should know the epidemiology and indications of a fast referral to prevent permanent disability. Findings from people with MS, GPs and SNs in my study suggest this may not always be the case. Therefore, even where GPs do not feel that they require specialist MS knowledge, it is suggested this should be the minimum level of knowledge, competency and role responsibility when working in general practice in the UK.

To provide education that minimises additional work burden, a free three hour online training resource entitled “Multiple Sclerosis in General Practice” is available from the RCGP website and is targeted at GPs, GP trainees and PNs. In addition the MS Society published “A guide to MS for GPs and primary care professionals” in 2009, which is a
comprehensive guide but will need updating after the implementation of the updated NICE clinical guideline for MS in 2014.

Previous examples of educating GPs on best practice and guidelines for neurological conditions have shown that an education session as short as 2 hours significantly changed clinical practice and improved adherence to best practice guidelines (Minshall, Berry & Smith, 2010). The implementation of the updated NICE clinical guideline for MS in 2014 would seem a key opportunity for increasing GP education on management of MS.

There are also a small number of GPs with Specialist Interest in MS in the UK (Pimenta, 2006) whose knowledge and interest could potentially be used for commissioning or educating other GPs, as demonstrated in GPs with a specialist interest in headache (Kernick, 2012). Further to GPs, there may also be a remit for training practitioners with special interests such as pharmacists (as outlined by the DH, 2007b), given the vital nature of decision making regarding pharmaceutical treatments in MS. The first pharmacist with specialist interest posts were initiated to monitor anticoagulants at GP surgeries, thus moving this testing service from the hospital into a more accessible community setting (National Prescribing Centre, 2008). As people with MS may experience barriers in accessing hospitals, moving investigative services closer to them in the community would be an advantage. Currently MS treatment is monitored by blood tests conducted in primary care and analysed in hospital laboratories, however findings from my study showed that the majority of PNs and people with MS saw this as a procedural task with no discussion of MS or symptom management. This is therefore potentially a missed opportunity for specialist knowledge and person centred care including discussion of MS pharmaceutical treatment, responses to side effects and any concerns the person with MS may be having. This would provide a compromise where GPs did not see the value of improving their specialist knowledge but people with MS required access to specialist knowledge, without the delays encountered with use of specialist services.

Assessing patient knowledge at the onset of MS might assist with identifying needs for signposting and education support. Matti et al. (2010b) investigated patients’ knowledge of optic neuritis, a key symptom of MS, before and after an information session by a neuro-ophthalmologist. They found that patients in their study already had a very high baseline knowledge of optic neuritis, resulting in no significant change after
the information session. However, they did find that people with MS increased their knowledge of available treatments and best practice guidelines for relapse management. This suggests that even for patients with high knowledge early on in their MS there may be a benefit to providing education regarding treatments and management. SNs reported providing patient information days and courses, and the majority of participants in the North West made references to the ‘getting to grips’ course for newly diagnosed people run by the Specialist MS team within Manchester. Köpke et al. (2009) found that a four hour group information intervention on relapse and relapse management led by an SN and peer trainer resulted in more autonomous decision making in people with MS in Germany. In 2012 Köpke et al. trained non-medics (primarily nurses, physiotherapists, psychologists and social workers) to deliver the same intervention session and found that in addition to increased autonomy participants had increased knowledge of relapse definition and the effects and effectiveness of relapse therapy. Together these studies show that education regarding relapse identification, and therefore candidacy for immediate services, can be a concept that is successfully taught to people with MS in a relatively low intensity intervention. In addition, these studies show that such educational interventions may be delivered by most members of the MDT, suggesting that GPs do not have to take the lead on this education.

**Implications for policy: Commissioning new models of care**

As discussed previously in the thesis, the role of GPs and pharmacists with specialist interests in MS could prove innovative to MS care, particularly with the recent increased focus on disease modifying treatments and treatment side effects. This may improve self-management and move the focus of MS care from acute care settings to community settings. In line with the Department of Health (2007c) ‘closer to home’ initiative, this may potentially contribute to gains of decreased waiting times and increased access, without requiring a decrease in the quality and safety of care.

Multiple Sclerosis Specialist Nurses (SNs) need to make commissioners aware of their work within the community, supporting people with MS. This allows primary care to access specialist advice and support when needed (one of the ten characteristics of a high-performing chronic care system; Ham, 2010) and is therefore integral to the primary care team. A commissioning priority should be to commission services which enable MS SNs to assist with improving knowledge and confidence of primary care
professionals, through improved access to specialist MS services, resources and knowledge. Where funding permits, the optimal strategy would be to integrate SNs, so patients registered with all GP practices have access to an SN in a community setting. It is hoped this will then improve adjudications (the clinical decisions professionals make) and in turn improve patient’s experiences of the continuity and responsiveness of care and access to services. This focus on integrative care has been established as a local and national health care priority (National Collaboration for Integrated Care and Support, 2013) and may potentially allow people with MS more control over their symptom management and holistic wellbeing.

Continuity and coordination of care may prevent emergency admissions (Purdy, 2010; potentially due to MS relapse or infection) which may have positive implications for both people with MS and service providers. A case study of improvements to the integration of care for people with MS was provided in Islington Primary Care Trust, where an integrated care pathway was established by providing an outreach MS SN to support community matrons, general practitioners, neurologists and local community teams to support people within MS within their homes (Royal College of Nursing, 2006). More recently, the North West London integrated care pathway (NHS, 2015) outlined a pilot project in Harrow involving eight GP practices. It aims to incorporate MS care into an existing integrated care system, providing a primary care-led risk-based care plan (to be updated four times per year), primary care case management and local treatment, including home testing for urinary tract infections, home based IV steroids and local rehabilitation. This move from ‘reactive care planning’ (as described in Newbould et al., 2012) to the proactive personalised care planning pledged by the Department of Health to all people with long term conditions (DH, 2009b), may significantly benefit people with MS in the North West.

Increased funding for psychological therapies in the North West of England was described by all participants and is a key implication for commissioning (Department for Health, 2011a). Where this is not a current possibility however, CCGs should investigate innovative ways to provide psychological support without the need for professionals to resort to the use of antidepressant medication (where it is not indicated by best practice guidance). This could include a greater provision of community psychoeducation or CBT groups (as demonstrated in IAPT services), for people with depression at clinical caseness but low risk and low functional impairment.
from psychological symptoms and/or an increased focus on environmental and societal risk factors.

Practice Nurses (PNs) reported that home visits were becoming scarcer due to Practice targets and increasing caseloads. Home visits were felt by PNs to be central to equity of care for people with MS with mobility impairments and often poor overall health. A commissioning implication should be to consider the potential impact of decreasing home visits, which potentially conflicts with the ethos of community-led care, and ensure that the needs of people with MS are still being met, despite increased Practice targets.

Despite PNs lack of specialist knowledge regarding MS, both people with MS and PNs highlight the skilled work undertaken by PNs with people with physical disabilities and mobility impairments more generally e.g. smear tests. This should be an implication for the broader commissioning of services for people with physical disabilities. Although PNs in this study were not enthusiastic about greater involvement in MS care, case studies from government policy have detailed service improvement strategies that may potentially translate to MS care, including the provision of clinical supervision to PNs and integrated community nursing teams (comprising both practice and district nurses; DH, 2007d).

Placing specialist nurses in primary care is part of the concept of ‘extended primary care’ (Smith et al., 2013) utilised both in the UK and internationally. It has been found to be beneficial for decreasing risk factors for progression of chronic kidney disease and increasing self-management and adherence to lifestyle advice (Walker, Marshall & Polaschek, 2014), and improved clinical management of diabetes (Vrijhoef et al., 2002). It has also been proven to be beneficial to patient satisfaction, but inconclusively effective in improving symptom management in epilepsy (Mills, Campbell and Bachmann, 2002). As discussed previously in the thesis, Quinn (2011) identified that employment of an SN through what was then a PCT saved the trust £60,000 in unnecessary admissions and increased patient satisfaction. Greater collaboration between SN and primary care in the North West may potentially offer multiple benefits to both patients, services and commissioners.

Implications for practice: MS Specialist Nurses

From the study findings it appears that either directly (through the judgements of other professionals) or indirectly (through lack of funding for alternative services) MS SNs
may be faced with managing the psychological needs of people with MS where they do not feel it is appropriate or feasible for them to do so. This is a key priority for change: potentially this is causing increased stress to these professionals by causing them to work outside of their professional remit. In addition, it may also result in inequitable access to services for people with MS with psychological needs. Findings from SN suggest that further training would not be seen as beneficial; the implication for practice should instead focus on improving access to psychological services and increasing links between primary care and IAPT services for supporting the management of people with depression.

Both SNs and GPs described difficulties in liaison between primary and secondary care. A potentially beneficial model of working may be to hold specialist MS clinics within community settings (e.g. GP surgeries), to address inter-professional relationships in the community (which were reported as useful by both GPs and SNs). This may also provide increased access to people with MS with mobility disabilities within the local community, thus being of mutual advantage to professionals and patients.

**Implications for practice: GPs**

These findings demonstrate the variation in the role of GPs for MS, as experienced by both people with Ms and GPs. Two contradictory indications for practice could be suggested from these findings. The first is that a minimum standard of GP involvement in MS management should be formalised (indeed, this is partly done in the RCGP curriculum previously discussed in the thesis) ensuring the highest quality community care for people with MS. However, findings from both GPs and people with MS suggest that differences exist in the level of involvement preferred by people with MS and GPs, therefore mandating involvement may not address patient or professional preference. A compromise may be that GPs commission resources to enable them to play fuller role in MS management whilst appreciating the personal nature of the doctor-patient relationship in MS.

A tension was identified in the data regarding GPs lack of knowledge of MS, and lack of incentive to develop knowledge due to the small numbers of people with MS seen in general practice (and non-QOF status). This suggests that increasing available CPD resources regarding MS (for GPs to utilise if self-appraised as necessary) would not be welcomed or perceived as beneficial. However, minimum standards of knowledge are expected of GPs (RCGP curriculum) and if they are not met it should be an implication
for practice to enable GPs to increase their knowledge through the available CPD resources and links with specialist services.

From these findings, a potential barrier to continuity in MS care may be the lack of a designated professional to coordinate care, i.e. case management (Ross, Curry & Goodwin, 2011) or care coordination. An implication for practice would be the aim of every person with MS knowing who their designated professional lead is; in their 2009 primary care guide to MS, the MS society suggest that GPs are the appropriate candidate for this role. As management of MS appears to centre around an individual’s idiosyncratic presentation, not a specialist knowledge of neurology overall, GPs are key candidates for this role (and many GP participants reported doing so). Lack of specialist knowledge of MS should not be a deterrent to coordinating care as these findings suggest this utilises the generalist skillset, applicable to holistic person-centred care for all long term conditions, as demonstrated by GPs’ role as ‘accountable GP’ for older people and people with complex needs (NHS England, 2014). It is also in line with the development of ‘expert generalist’ skills, which the Royal College of General Practitioners predict is vital for the role of general practice by 2022 (Royal College of General Practitioners, 2013). Improving links with specialist services may help improve GPs confidence where they feel lack of knowledge challenges their role.

**Implications for practice: Practice Nurses**

Findings from this study suggest that it cannot be assumed that the PN role in identifying depression in QOF conditions is transferable to identifying depression in people with MS. All PNs reported that they were not responsible for managing depression, instead transferring this responsibility to GPs, therefore increasing PNs confidence in recognising and referring depression, would not require increased management by them and could potentially be an implication for practice.

Although it may be assumed that PNs see people with MS for management of their comorbidities and lifestyle issues, PNs did not report that management of MS was within their remit. Implications for practice and policy are therefore that PNs do not see themselves as a target group for interventions focussing on increasing the role of primary care services for people with MS. However, PNs were favourable of becoming more informed about available services and resources for people with MS within their local community. Due to the low numbers of people with MS they see, the implication for practice would not be for specific training or CPD events, but for SNs to facilitate
(either directly or indirectly through other services) increased signposting for PNs. Due to the changing nature of services this would require a regularly updated hub for information, or a more proactive outreach approach. PNs were not in direct contact with SNs and some were not aware SNs existed. A potential implication for practice is therefore that where a PN leads the care of comorbidities experienced by someone with MS (e.g. diabetes) they should be made aware of their patient’s SN, the SN role and the support they can expect and access. Greater written correspondence (i.e. cc’ing medical reports) could facilitate this partnership.

7.9 Chapter summary

Using a qualitative method this study has contributed knowledge to the literature on the experiences of people with MS and health care professionals. Using the theoretical concepts of candidacy and recursivity extended this knowledge by explaining issues relevant to navigating and accessing health care and suggesting how these health care experiences may influence future help-seeking and health care use. These findings suggest the importance of knowledge of MS and available services to ensure both people with MS and professionals are aware of health care needs and potential services. In addition they suggest that improving health care experiences for people with MS do not require radical change, but an extension of skills integral to primary care, such as using patient-centredness and relational continuity of care to ensure responsive care capable of supporting self-care for MS and comorbid needs. Future research needs to expand this work to incorporate the experiences of younger people with MS and people from minority ethnic backgrounds. These findings can be used in clinical practice and policy to educate both people with MS and professionals regarding candidacy for both MS care and psychological needs, thus potentially increasing help-seeking and responsive access to services.
References


Brown, E. (2014) Challenging the new draft clinical guideline for MS. Available at: http://www.mssociety.org.uk/get-involved/campaigns/campaigns-


Joint Commissioning Panel for Mental Health. (2012) Guidance for commissioners of primary mental health care services. Available from:


283


Rogers, A., Vassilev, I., Sanders, C., Kirk, S., Chew-Graham, C., Kennedy, A., Protheroe, J., Bower, P., Blickem, C., Reeves, D., Kapadia, D., Brooks, H., Fullwood, C., Richardson,


Royal College of General Practitioners. (2012) Multiple Sclerosis in General Practice. Available at:


Royal College of Physicians. (2011) *The National Audit of Services for People with Multiple Sclerosis.* London: Royal College of Physicians and MS Trust.


general nurses working with people with multiple sclerosis’, Journal of Clinical Nursing,
18(18), pp. 2635-2648.

Wiener, C. ‘Making Teams work in conducting grounded theory’ in Bryant, A. and
Ltd, pp. 293-310.

178-182.

trajectory’, Body and Society, 2, pp. 23-47.


Van Dijk, L. (2014) ‘Antidepressants in primary care: patients’ experiences, perceptions,
self-efficacy beliefs and nonadherence’, Patient Preference and Adherence, 8, pp. 179-
190.

73-93.

advantages and challenges of being a double agent’, Psychiatric Services, 57(2), pp.
249-253.


of the Neurological Sciences, 311(Supplement 1), pp. S48-S52.

Zola, I.K. (1973) ‘Pathways to the doctor- from person to patient’, Social Science and
Medicine, 7, pp. 677-689.
Appendix A: Health expectations research article

REVIEW ARTICLE

Experiences of UK health-care services for people with Multiple Sclerosis: a systematic narrative review

Abigail M. Methley BSc MRes,* Carolyn Chew-Graham MB ChB MD RCGP,†† Stephen Campbell BA (hons) MA (Econ) PhD† and Sudeh Cheraghi-Sohi BSc MRes PhD¶

*PhD Student, University of Manchester, Manchester, ††Professor of General Practice Research Keele University, Keele and University of Manchester, Manchester, †Professor of Primary Care Research, University of Manchester, Manchester, ¶Research Fellow, University of Manchester, Manchester, UK.

Correspondence
Abigail M. Methley BSc, MRes
Centre for Primary Care
University of Manchester
Wilmslow Building
Oxford Road
Manchester, M13 9PT
UK
E-mail: abigail.methley@postgrad.
manchester.ac.uk
Accepted for publication
2 June 2016

Abstract

Background Multiple Sclerosis (MS) is a chronic, degenerative condition with an estimated UK prevalence of 100,000. Contact with health-care services is frequent and long-term; however, little research has investigated the experiences of health care for MS in the UK.

Objective The aim of this systematic narrative review was to critically review qualitative studies reporting patients’ experiences of health-care services in the UK.

Search strategy EMBASE, CINAHL, Medline, psychINFO and MS Society databases were searched with no date restrictions using search terms denoting ‘Multiple Sclerosis’, ‘health-care services’, ‘patient’, ‘experience’ and ‘qualitative research’. Snowballing and hand searching of journals were used.

Inclusion criteria Studies were included if they used qualitative methods of data collection and analysis to investigate adult patient’s experiences of health-care services for MS in the UK.

Data extraction and synthesis Data were extracted independently and analysed jointly by two reviewers. Studies were appraised for the quality of evidence described using the Critical Appraisal Skills Programme’s qualitative tool. Due to the breadth of areas covered, the data were too heterogeneous for a synthesis and are presented as a narrative review.

Main results and discussion Five studies were included. Studies primarily investigated diagnosis or palliative care. Themes of importance were the emotional experience of health care, continuity of care and access to services, and support from health-care professionals. Studies were mainly poor quality and focused on a homogenous sample.
Conclusions This study provides the first review of the UK evidence base of experiences of health care for MS. Future research should investigate experiences of care after diagnosis in a more varied sample of participants.

Introduction

Multiple Sclerosis (MS) is a chronic, degenerative neurological condition with an estimated prevalence of 100,000 people in the UK. A higher proportion of females are diagnosed with MS, with a gender ratio of 4:1. Patients present with a wide variety of symptoms, including visual impairment, mobility impairment or paralysis, incontinence, fatigue, pain, spasms, problems with coordination and cognitive dysfunction.

There are several subtypes of MS including relapsing-remitting and progressive forms; consequently, the healthcare needs of people with MS may differ according to their subtype and symptoms. Thus MS can be a complex and difficult condition to diagnose, to experience and to manage, and the uncertain prognosis may cause difficulties in managing the disease for both doctors and patients, including the creation and maintenance of long-term treatment and rehabilitation plans.

In the UK, management of people with MS should be by a multidisciplinary team (MDT) with the aim of treating relapses, preventing further relapses through disease-modifying treatments, managing symptoms such as pain or incontinence and providing rehabilitation services. Patients may receive both primary care services and specialist Neurology services, often comprising a Consultant Neurologist and an MS Specialist Nurse, although provision varies by locality. Some teams may include allied health professionals such as Occupational Therapists or Physiotherapists. The severity and progressive nature of symptoms of MS may necessitate input from palliative care services.

Although a number of systematic reviews exist on pharmacological treatments and physical rehabilitation for MS, to date no systematic review exists of the literature reporting experience of UK health care by people with MS. An increased importance has been placed on the patient experience by national healthcare policy which outlines plans for increasing patient choice and providing more sensitive, flexible health care, where patients have greater control and involvement in decision making.

Qualitatively investigating patients’ experiences of health-care services allows health-care professionals, commissioners and policy makers to identify areas in need of intervention that may not be identified or explored fully through traditional surveying methods such as questionnaires. The aim of this systematic review was therefore to identify and present the available qualitative literature exploring the experiences of MS patients’ use of health-care services in the UK.

Methods

Inclusion and exclusion criteria

Studies eligible for inclusion were those that qualitatively investigated patients’ experiences, views, attitudes to and perceptions of health-care services for MS in the UK. No time limit was imposed on searches as this was an original review.

Qualitative research, for this purpose, was defined by the Cochrane qualitative methods group as using both a qualitative data collection method and qualitative analysis. Both quantitative and mixed method studies were therefore excluded.

The definition of a patient for this study was adults (aged 18 years and over) with a diagnosis of MS, who had experience of utilizing health-care services at any time point. We chose to specify adults as there are differences in paediatric and adult health care for MS in the UK which may have made comparisons...
difficult. Also, paediatric MS cases are estimated to make up <5% of the total population of people with MS. There were no restrictions on subtype of MS, gender, ethnicity or frequency of use of health care.

We defined experience using a definition from a narrative review investigating experiences of health care for another condition, (Sinfelt et al. p. 30) as ‘Patients’ reports of how care was organised and delivered to meet their needs’. Patients’ reports could refer to either experience of health-care services delivery and organization overall, or their experience of care by specific health-care personnel.

Due to the focus on MS, studies were excluded if they used a mixed sample of various conditions (e.g. a mixed sample of people with neurological conditions or a mixed sample of people with MS and people with Huntington’s disease) or if they used a sample of mixed respondents (i.e. people with MS and their carers) where results of patients with MS could not be clearly separated. If a paper focussed on MS and had a section or subtheme on healthcare services, however this was not the main research area of the paper, then that study was included; however, only data from the relevant subtheme were extracted and included in the findings. Finally, studies investigating quality of life were excluded. Additional exclusion criteria were non-English language papers, papers that only described care or health-care professional experiences not patient experiences, editorials and commentaries.

Search strategy

A list of search terms was created in collaboration with a Specialist Librarian, an Information Scientist and the wider research team. Terms were grouped within the categories: (i) MS, (ii) health care services, (iii) patients/service-users, (iv) experience/opinions/perspectives, and (v) qualitative research.

The search strategy comprised groups of free text and MESH headings divided into the categories of terms described above, which were then searched together using the AND function. A separate search strategy was used for each database to ensure that the terms and MESH headings used were relevant for each particular database. The full search strategy is presented in Table S1.

Databases searched included PsyCINFO, Medline, EMBASE, CINAHL and the MS Society library. Reference lists of included papers were searched for additional relevant references. The Multiple Sclerosis Journal was hand searched from inception in 1995 until August 2012. A further search was also conducted in the British Journal of Neuroscience Nursing using the words ‘Multiple Sclerosis’ and ‘Qualitative’. Grey literature outside that contained within the MS Society library was not searched due to resource constraints. The search was not limited by geographical area to ensure that studies were not missed due to incorrect labelling. However, only studies that reported on UK services were included. An updated search was run on 22nd August 2013 (Figure 1), however new papers were identified.

Data management and quality appraisal

One reviewer (AM) judged titles and abstracts against the inclusion criteria. If a title and abstract met the inclusion criteria then full text copies of all articles were retrieved for further investigation. Two reviewers (AM and SCS) then independently assessed these articles against the inclusion and exclusion criteria. Any disagreements were resolved via discussion. Data from included studies were extracted by both reviewers independently to ensure accuracy and then stored on a Microsoft Excel spreadsheet.

Extracted data were then appraised for quality using an expanded version of the Critical Appraisal Skills Programme (CASP) criteria modified for thematic synthesis with qualitative literature. Quality was independently appraised by two authors who met to decide a consensus. As some questions in this modified CASP tool could be subjective and difficult to grade (e.g. ‘what is your overall view of this
study?7 graded from 1 = Excellent to 6 = Very poor) we followed the process detailed in Masood et al.,7,22 where the percentage of CASP criteria met by each paper was taken as an indicator of quality (Table 1). We therefore removed all questions that required grading and marked remaining questions in terms of whether evidence was present (1 = Yes) or absent (2 = No) (see Table S2 for more information). Studies were not excluded on grounds of quality, instead this information was used to present the quality of evidence available on this topic, for discussion.

Results
The majority of papers were excluded because they did not report qualitative methods, yet contained words that were relevant search terms such as ‘patient’, ‘knowledge’, ‘experience’ which were frequent key words for questionnaire studies on patient experience and satisfaction. Papers that were excluded at the full text stage contained samples of both people with MS and another group, for example, carers that was not explicit in the title and abstract.

The search identified five studies (presented in Figure 1) that fitted the inclusion criteria (two publications reported different results from the same study7,22) as. Information about these studies is presented in Table 1. Although no date restrictions were set, all studies found were published between 2003 and 2008. The majority of the studies were conducted in England (n = 4),18–22 with one in Northern Ireland.23 Levels of demographic reporting varied widely. Discussion of ethnicity was virtually absent with only one study reporting this information.20 Embrey et al.20 only provided information on the number of participants. Similarly, Laidlaw and Henwood22 only provided the sample size and gender of participants. In the other three studies,20,21,23 participants were aged from 34 to 72 years, with a disease duration of between 0.4–37 years. Only one study22 provided an in-depth profile of disease progression, reporting that the majority of their sample were ambulant with aids, an equal number of participants with relapsing-remitting and secondary progressive MS were included and the majority of participants were homemakers or retired. Four studies20,21,23 collected data using interviews (unstructured22) or
<table>
<thead>
<tr>
<th>Source article</th>
<th>Setting (hospital/community)</th>
<th>Sample</th>
<th>Research design</th>
<th>Aims</th>
<th>Word count</th>
<th>Overall quality assessment (% of CASP criteria met)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Edwards et al.</td>
<td>England, Birmingham. Recruited through MS Society and local newspaper</td>
<td>N = 24. Age range 35-72 years. 17 f and 7 m. Disease duration 1-37 years. 23 Caucasian</td>
<td>Semi-structured telephone interviews with thematic content analysis</td>
<td>To examine patients' experiences of being diagnosed with MS, information given at the time, treatment and the impact on their lives</td>
<td>3183 words</td>
<td>59.5%</td>
</tr>
<tr>
<td>Embrey*</td>
<td>England, Staffordshire. Recruited through hospice day care</td>
<td>N = 9</td>
<td>Interviewed using an open-ended question approach and analysed using Giorgi's (1985) framework analysis</td>
<td>To explore the experiences and views of people with moderate and severe MS participating in a palliative day care programme offered at a hospice in North Staffordshire</td>
<td>Paper 1: 3666 words Paper 2: 4180 words</td>
<td>40.5%</td>
</tr>
<tr>
<td>Johnson</td>
<td>England, Southeast. Recruited through hospital database</td>
<td>N = 24. Interviewed in 2 cohorts. Cohort 1: Age range 37-67. Cohort 2: Age range 34-66 years. Cohort 1: 6 m, 6 f. Cohort 2: 4 m, 8 f. Cohort 1: Age of onset 24-59. Illness duration 0.6-26 years. Cohort 2: Age of onset 21-61 years. Illness duration 0.6-33 years</td>
<td>Interviewed one cohort before and one after the implementation of an MS Specialist Nurse. Analysed with thematic analysis</td>
<td>To investigate patient's experiences of receiving a diagnosis of MS</td>
<td>3923 words</td>
<td>48.6%</td>
</tr>
<tr>
<td>Liddle &amp; Henwood (2003)</td>
<td>England, London. Recruited through MS Society</td>
<td>N = 8. 2 m, 6 f.</td>
<td>Unstructured interviews and open thematic analysis</td>
<td>To investigate MS Patients' holistic experience of Magnetic Resonance Imaging (MRI)</td>
<td>3604 words</td>
<td>51.4%</td>
</tr>
<tr>
<td>Malcomson, Law-Stong &amp; Dunwoody</td>
<td>Newtownabbey. Recruited through MS Society</td>
<td>N = 13. Aged 40-69 years. 1 part time, 3 unemployed, 5 homemakers, 4 retired. Group 1: 5 f, 1 m. Group 2: 4 f, 3 m. 6-30 years since diagnosis. 6 relapsing-remitting, 6 secondary progressive, 1 primary progressive. Ambulant with aids (n = 8), Wheelchair (n = 2), Independently mobile (n = 3)</td>
<td>Two focus groups and thematic analysis</td>
<td>To explore personal accounts and experiences of individuals with MS who felt able to cope with the disease in day-to-day life</td>
<td>7997 words</td>
<td>59.5%</td>
</tr>
</tbody>
</table>
semi-structured interviews\textsuperscript{[18–21]} and one study utilized focus groups.\textsuperscript{23} Thematic analysis was the predominant analytic method utilized,\textsuperscript{20–23} although a named method of analysis, Giorgi’s (1985) framework analysis was reportedly used in one study.\textsuperscript{30,31}

Quality appraisals

The overall quality scores attributed to the publications are presented as the percentage of CASP criteria met (see Table 1 and Table S2). The highest scoring studies only scored 59.5% of criteria met, whilst the lowest rated study scored 40.5%. Studies frequently failed to report their justifications of both sample size and the reasons for selecting a particular sample. Whilst studies were usually very clear on how data were collected and recorded, poor reporting of analysis was a major contributor to low scores. For example, four studies\textsuperscript{20–23} reported using a form of thematic analysis but made no reference to an iterative process. Only one study\textsuperscript{8,9,19} reported a theoretical perspective (Phenomenology). Findings were, overall, clearly reported; however, a lack of demographic information made it difficult to assess the transferrability of findings.

Data analysis

Once the data had been extracted, it became clear that the relative paucity of papers identified for inclusion, and the breadth of areas researched in these papers, ensured that resulting data were too heterogeneous to utilise an in-depth qualitative synthesis method such as a meta-ethnography (as proposed by Sandikowski et al.\textsuperscript{24}). Therefore, as outlined in previous studies investigating qualitative research, for example, Lie et al.\textsuperscript{25} it was necessary to utilise a narrative summary approach to present the main findings of all studies in a narrative form. Both authors summarized the findings of the studies and compared them to check for accuracy and consistency. Once this was completed, the aims and topics explored in these studies were compared. The reported aims of these studies could be broadly categorized into two areas, the process and experience of diagnosis (n = 4)\textsuperscript{20–23} and palliative care (n = 1).\textsuperscript{38,39} These findings will now be presented in the form of a narrative summary.

Diagnosis

Studies focussed on the experience of various aspects of diagnosis. Subthemes of information and experiences of access to services and health-care support were found to facilitate emotional reactions and improve the emotional experience of diagnosis. Information was key for the diagnostic process whilst access to services and health-care professional support were highlighted as subthemes for continued care.

Three studies reported a prolonged investigative process, negative experiences of receiving a diagnosis\textsuperscript{20,21,23}, and two studies reported dissatisfaction with the way in which diagnosis was managed.\textsuperscript{22,23} Time taken to reach a definite diagnosis was sometimes lengthy\textsuperscript{20–24}, in two studies patients reported waiting over 17 years for a diagnosis\textsuperscript{20,23} however, one study reported a participant’s confirmation of a diagnosis of MS in <2 years\textsuperscript{21} and another study reported cases diagnosed within 12 months.\textsuperscript{20} In summary, the process of diagnosis was overall a negative and lengthy experience.

Emotional reactions to the diagnostic process were widely reported and transcended all stages of diagnosis.\textsuperscript{20–23} Before diagnosis, reported emotions were an awareness that something was wrong, distress, uncertainty, fear and anxiety.\textsuperscript{21,25} During the diagnostic testing period these emotions continued to be present. After diagnosis, emotional responses were described as devastating or shocking unless MS patients had prior suspicions of MS\textsuperscript{20,23} although feelings of relief at the identification of the condition were also reported.\textsuperscript{21,25}

Information received. Information was described as necessary for participants to understand their MS and a lack of timely information was found to cause increased anxiety and distress.\textsuperscript{22} A lack of advice and information about MS at the
time of diagnosis and difficulties accessing information regarding MS was reported. Ms knowledge at the time of diagnosis was reportedly important for all participants in one study and this involved a process whereby the participants became more informed and were able to identify relevant support services.41

Another study highlighted the provision of information on the MS society at the time of diagnosis would have been beneficial.42 The only study reporting the experiences of MRI scanning, revealed a lack of information at all stages of the MRI scan before scanning, at the time of the scan and when the results were ready.43 One study reported conflicting findings; a small number of participants were happy with the information provided, however many more reported that they had not had adequate information or advice on MS.44 Disatisfaction with health-care services was commonly linked to lack of information provision and understanding.22,23

This reported lack of information caused anxiety and fear among patient perceptions of control of both the scanning experience and MS in general.22 Frustrating encounters were reported with health-care professionals, including General Practitioners (GPs), who could not provide information on MS and relevant support services, in comparison to occupational therapists, physiotherapists and community nurses who were felt to be more knowledgeable.7 In one study, participants reported that their GPs were 

informed and not knowledgeable on MS.45

Timeliness and access to information is therefore of great importance, and variation was found in the level of knowledge of MS demonstrated by health-care professionals.

The post-diagnostic phase: access to services and experiences of health-care professional support. Difficulties were also reported in accessing treatments for their MS later on in the disease course46 and a focus on physical health needs at the exclusion of psychosocial support.47 One study reported mixed findings, as whilst a small number of participants were happy with the care they received. Overall, most of the participants in this study received little or no treatment for MS and were often refused funding for treatment by the National Health Service (NHS).40

Continuity of care was an issue at the time of diagnosis, and later on bridging diagnosis and subsequent care. Neurologists were reported as trying to solve the puzzle of MS and then withdrawing when that was achieved.48 In one study, participants reported feeling abandoned and isolated by the health-care system, unless they received support from another health-care professional, such as a GP or MS Nurse.49

Two studies discussed unsatisfactory health-care professional support.50 Communication with health-care professionals was perceived negatively by participants in one study who reported that their professionals had been off-hand, casual and unsympathetic.51 Participants in another study recalled their diagnosis being given in a manner that lacked sensitivity, empathy and understanding.22

Participants in one study reported difficulties in initiating symptom investigation as they felt they were not believed by health-care professionals.20 This study also reported that although a suspicion of MS was noted in their medical records they were not informed of this.29 Access to health care and the professional manner and communication demonstrated by health-care professionals has a large impact on patients' experiences of continuing health-care services for MS.50 Continuity of care, and specifically poor experiences of continuity, between different health-care providers and services is therefore a key factor in the experiences of MS patients.

Palliative care

Embrey48,49 was the only study (reported across two publications) to report on the experiences of palliative care for MS patients. Therapeutic interventions were found to improve symptom relief, provide a sense of achievement and fun, improved optimism and provide an opportunity for health promotion, although a downside was the infrequency of therapeutic

© 2011 John Wiley & Sons Ltd
Health Expectations
interventions and worries over continuity of this palliative care service. Group support provided friendships based on common conditions and problems, allowed an awareness of each others’ problems, provided positive experiences with hospice staff and reduced carer burden by providing time off for carers. Participants reported being initially fearful and worried about using a hospice but appreciated the relaxed environment which improved their self-confidence.

Further analysis

Once this was completed, it was felt it would be of value to see whether there were any tentative commonalities between these two areas of care. Whilst a full meta-ethnography was not possible, the initial elements of a basic thematic synthesis were conducted. As outlined in Thomas and Harden,²⁶ line-by-line coding was completed for all sentences in the findings sections of the six included studies. Next, two authors (AM and SCS) jointly compared these codes to create overarching themes.

Despite the very different aims of diagnostic care services and palliative care, some themes of experiences emerged which transcended the care pathway (Figure 2), namely, the emotional experience of care, perceived support from healthcare professionals and the importance of continued care and access to services. Two themes were developed which were unique to the particular care setting: experiences of diagnostic procedures and the benefits of palliative care services. These five themes were then discussed within the larger research team (all four authors) to check consistency of interpretation and ensure that the themes were grounded in the studies and not extrapolated beyond the data. Due to the limited and varied nature of the data, we did not complete the defining stage of a narrative synthesis, which was to ‘go beyond’ the content of the original studies to create an explanation of experiences of healthcare or generate theory on this topic.²⁷

Discussion

Included studies fell broadly into two distinct areas of research: experience of diagnosis and experience of palliative care. However, similarities were identified between the two areas of care in terms of issues with healthcare professional support, access to continued care and the emotional experience of using healthcare services.

Figure 2 Presentation of themes from diagnosis and palliative care studies.
Primarily, descriptions of diagnosis presented mainly negative experiences and poor service provision, suggesting this is still an area in which MS care can be improved, as reported in the included papers by people with MS from across the UK.

Implications for practice and research
Communication with health-care staff has been a key finding in research investigating MS care.28,29 However, as the studies in this review were relatively recent, they suggest that this is still a current and significant issue, despite being noted as a key principle of the 2003 NICE guideline for MS recommendations for clinical practice. A clinical priority should therefore be to improve health-care professionals’ awareness of the emotional impact of ineffective communication, with the provision of medical education and training on appropriate styles of communication if necessary, similarly to those utilized in oncology services.40

This review highlighted the emotional reactions people with MS experience in relation to their symptoms, and the treatment they receive, particularly during diagnosis when uncertainty, fear and anxiety appear at their highest. The NHS has previously acknowledged the need to improve the patient emotional experience in order to improve patient experiences overall and this is evidently necessary for patients with MS.

A lack of timely information on diagnosis, living with MS and treatment was found to directly link to negative emotional states such as anxiety and fear. Providing timely and credible information on these topics should therefore be a priority in improving the patient emotional experience.31

The included studies suggested that the experience of diagnosis could be improved by better responsiveness and increasing the continuity of care between and within primary, community and specialist care and ensuring that relevant emotional and informational support structures are in place for people receiving a diagnosis of MS. Although all studies in this review were published within the last decade, many participants in these studies had been diagnosed for a long period of time before these studies took place. It is possible that a perceived improvement of MS patient experiences occurred due to earlier or more timely diagnosis as a result of the increasing use of technology such as MRI to identify lesions suggestive of MS. It may also possibly be due to the increased support and information provided by MS Specialist Nurses since the increasing implementation of their role throughout the 2000s; however, these assertions cannot be confirmed from the evidence provided by the included studies.

Implications for commissioning
Patient concerns over the continuity and quality of care services in the UK are a pertinent and current issue due to budget restrictions and the cessation of certain National Health Service (NHS) facilities.34 Access difficulties due to funding restrictions, or procedures, may change with changes accompanying the Health and Social Care Act 2012.35 The inclusion of neurological conditions (including MS) in one of the four strategic clinical networks is hoped to improve the continuity of care across primary and secondary care services, and provide expert clinical information to the commissioners of services for this patient group.36 This strategic clinical network also encompasses mental health care, reflecting that the UK now has an increasing focus on prioritizing mental health needs in people with physical health conditions,37 including MS. However, a service audit of MS care in 2011 revealed difficulties accessing relevant services dependent on local funding priorities, referrals and availability of services,38 and further variety may be displayed due to the priorities of clinical commissioning groups.30 It will therefore be necessary for further research to investigate these issues within the new NHS structure.

Strengths and limitations of the study
Due to time and resource restrictions, only the four major databases for this research topic
were searched and only English language papers were included, potentially limiting the number of relevant papers identified.

The conclusions presented are drawn from a limited body of research, some of poor quality methodology or reporting. There is therefore a need to utilise high quality qualitative research to gain a more thorough understanding of the full health-care experience for people with MS, to maintain or improve the health-care experiences provided.

To date, there are few qualitative studies published on the health-care experiences of people with MS and those that exist have been limited to issues around diagnosis and palliative care. Although palliative care was found to provide a positive experience with increased peer support and psychological and physical benefits, little qualitative evidence exists on this aspect of care. Overall, the available body of literature omits many aspects of MS care, as the studies identified only cover the very beginning and the very end of the health-care pathway, with no investigations of rehabilitation and continuing care experiences.

From the limited demographic data provided, it is difficult to assess how well the above findings represent the experiences of a wide variety of people with MS. From the available information, it appears that more participants under the age of 35 should be studied, as MS can be diagnosed from childhood; however, the views of young adults with MS are currently unrepresented in the literature. In addition, only one study reported ethnicity data, leaving a large gap in our knowledge of any differences of experiences between ethnic groups. As MS may affect people from all ethnic groups1 and there are well-established difficulties in help co-creating and barriers to accessing health care reported by people from ethnic minority backgrounds, it would appear pertinent to explore the views of these individuals.

Summary

This review provides an overview of the literature relating to MS patient experiences of health care in the UK and two discrete areas of research into diagnosis and palliative care. Diagnosis was presented as a primarily negative experience whilst the limited evidence on palliative care suggested a positive experience. Themes of importance for both areas were found to be the emotional experience of health care, continuity of care and access to services, and support from health-care professionals. These themes present areas of high importance for the designing, commissioning and delivery of clinical care which require attention and change. However, the empirical evidence is currently limited to a homogeneous group of patients’ experiences of the start and end of the illness trajectory. This therefore leaves a considerable gap in knowledge relating to the majority of the illness management experience and the views of minority groups including young people and those from ethnic minorities. Future research should work to improve patient care in these areas and provide knowledge on the experiences of care across the care pathway.

Acknowledgements

This project was fully funded by a National Institute of Health Research (NIHR) School for Primary Care Research (SPCR) PhD studentship. The views expressed are those of the authors and not necessarily those of the NHS, the NIHR or the Department of Health. The authors would like to thank Dr Gavin Daker-White, Dr Charlotte Garrett, Dr Caroline Sanders and Katie Paddock for their feedback and support. The authors would like to thank Professor Peter Bower for providing advice on the design of the study. The authors would also like to thank Rosalind McNally for assisting the search strategy and providing suggestions for improvements.

Sources of funding

The authors disclosed receipt of the following financial support for the research, authorship, and or publication of this article: National
Institute of Health Research, School for Primary Care Research (NIHR SPCR) studentship.

Conflict of interest

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Supporting Information

Additional Supporting Information may be found in the online version of this article:

Table S1. Search terms for all databases.

Table S2. Quality appraisal of included studies.

References

22. Laidlaw A, Henwood S. Patients with multiple sclerosis: their experiences and perceptions of the


Appendix B: BMC Health Services Research research article (under review)

Title page

PICO, PICOS and SPIDER: A comparison study of specificity and sensitivity in three search tools for qualitative systematic reviews

Abigail M. Methley¹, Stephen Campbell¹, Carolyn Chew-Graham², Rosalind McNally³ and Sudeh Cheraghi-Sohi¹

¹ University of Manchester, United Kingdom
² Keele University, United Kingdom
³ Manchester Mental Health and Social Care Trust

Corresponding author:
Abigail M. Methley, MRes- University of Manchester, Centre for Primary Care, Williamson Building, Oxford Road, Manchester, M13 9PL, United Kingdom.
Email: abigail.methley@postgrad.manchester.ac.uk

Additional authors

Stephen Campbell, PhD- Professor of Primary Care Research
University of Manchester, Greater Manchester Patient Safety Translational Research Centre, Centre for Primary Care, Williamson Building, Oxford Road, Manchester, M13 9PL, United Kingdom.
Email: Stephen.Campbell@manchester.ac.uk

Carolyn Chew-Graham, MD, FRCGP- Professor of General Practice Research at Keele University, Institute of Primary Care and Health Sciences, Keele, United Kingdom and honorary Professor of Primary Care at the University of Manchester, Centre for Primary Care, Williamson Building, Oxford Road, Manchester, M13 9PL, United Kingdom.
Email: c.a.chew-graham@ Keele.ac.uk

Rosalind McNally, MSc- Outreach Librarian, Manchester Mental Health and Social Care Trust, Research and Innovation 3rd Floor, Rawnsley Building, Central Manchester Hospitals site, Hathersage Road, Manchester, M13 9WL, United Kingdom.
Abstract

Background
Qualitative systematic reviews are increasing in popularity in evidence based health care. Difficulties have been reported in conducting literature searches of qualitative research using the PICO search tool. An alternative search tool, entitled SPIDER, was recently developed for more effective searching of qualitative research, but remained untested beyond its development team.

Methods
In this article we tested the SPIDER search tool in a systematic narrative review of qualitative literature investigating the health care experiences of people with Multiple Sclerosis. Identical search terms were combined into the PICO or SPIDER search tool and compared across MEDLINE, EMBASE and CINAHL Plus databases. In addition, we added to this method by comparing initial SPIDER and PICO tools to a modified version of PICO with added qualitative search terms (PICOS).

Results
Results showed a greater number of hits from the PICO searches in comparison to the SPIDER searches, with greater sensitivity. The SPIDER searches showed greatest specificity for every database. The modified PICO demonstrated equal or higher sensitivity than SPIDER searches, and equal or lower specificity than SPIDER searches. The modified PICO demonstrated lower sensitivity and greater specificity than PICO searches.

Conclusions
The recommendations for practice are therefore to use the PICO tool for a fully comprehensive search but the PICOS tool where time and resources are limited. Based on these limited findings the SPIDER tool would not be recommended due to the risk of not identifying relevant papers, but has potential due to its greater specificity.
Keywords
health care, users’ experiences; multiple sclerosis (MS); research evaluation; research, qualitative; systematic reviews

Background
Systematic reviews are a crucial method, underpinning evidence based practice and informing health care decisions [1, 2]. Traditionally systematic reviews are completed using an objective and primarily quantitative approach [3] whereby a comprehensive search is conducted, attempting to identify all relevant articles which are then integrated and assimilated through statistical analysis. The comprehensiveness of the search process has been viewed as a key factor in preventing bias and providing a true representation of available research [4]. Current research investigating the process of quantitative systematic reviews therefore focuses on methods for ensuring the most comprehensive and bias free searches possible [5]. Because of the time and resources required to complete a systematic and comprehensive search, efforts have been made to investigate the sensitivity of searches, and thus lessen the amount of time spent reviewing irrelevant articles with no benefit [6].

However, conducting comprehensive searches also forms the bedrock of qualitative or narrative reviews, now commonly referred to as qualitative evidence syntheses [7]. Qualitative evidence syntheses are now acknowledged as a necessary and valuable type of information to answer health services research questions [8]. However, difficulties in completing a sensitive yet comprehensive search of qualitative literature have been previously noted [9, 10, 11] including: poor indexing and use of key words of qualitative studies, the common use of titles that lack the keywords describing the article, and unstructured abstracts.

Tools have been devised to aid in the structuring of search questions and selection of keywords, especially in teams where there it is not possible to have an experienced information specialist as a member of the review team. The PICO tool focuses on the Population, Intervention, Comparison and Outcomes of a (usually quantitative) article. It is commonly used to identify components of clinical evidence for systematic reviews in evidence based medicine and is endorsed by the Cochrane Collaboration [2]. Due to its target literature base several of these search terms such as “control group” and “intervention” are not relevant to qualitative research which
traditionally does not utilise control groups or interventions, and therefore may not locate qualitative research. However, these terms may become more relevant in the future as more trials and interventions incorporate qualitative research [12].

As the PICO tool does not currently accommodate terms relating to qualitative research or specific qualitative designs, it has often been modified in practice to “PICOS” where the “S” refers to the Study design [4], thus limiting the number of irrelevant articles.

Cooke et al. also addressed this issue of relevance by developing a new search tool entitled “SPIDER” (sample, phenomenon of interest, design, evaluation, research type), designed specifically to identify relevant qualitative and mixed-method studies [9]. The key features and differences of the SPIDER and PICO search tools are shown in Table 1. The addition of the “design” and “research type” categories to the SPIDER tool was intended to further increase the ability of this tool to identify qualitative articles, whilst removing irrelevant PICO categories such as the “comparison” group [9].

Cooke et al. recommended that the SPIDER tool was tested further in qualitative literature searches [9]. Although it has been used previously in a scoping review to investigate gaps in an evidence base on community participation in rural health care [13], SPIDER has not yet been tested and evaluated in a qualitative systematic narrative review context. The authors of this article recently completed a systematic review of the qualitative research investigating experiences of health care services for people with Multiple Sclerosis [14]. On embarking on this review topic we faced many of the difficulties commonly discussed in identifying qualitative literature on a given topic, and identified SPIDER as a potential way of overcoming some of these difficulties. Therefore, the aim of this article was to test SPIDER by replicating the work of Cooke et al. [9], specifically by comparing the two approaches: 1) the traditional PICO method of searching electronic databases with 2) the newly devised SPIDER tool, developed for qualitative and mixed-method research. In addition we wished to build and expand on the work of Cooke et al. [9] and so our third aim was to compare PICO and SPIDER to a modified PICO with qualitative study designs (PICOS, see table 1) by investigating specificity and sensitivity across 3 major databases.
Table 1. Search categories and SPIDER and PICO headings

<table>
<thead>
<tr>
<th>PICO heading</th>
<th>PICOS heading</th>
<th>SPIDER heading</th>
</tr>
</thead>
<tbody>
<tr>
<td>Multiple Sclerosis and patient/service user</td>
<td>Population</td>
<td>Sample</td>
</tr>
<tr>
<td>Health care services</td>
<td>Intervention</td>
<td>Phenomenon of Interest</td>
</tr>
<tr>
<td>Named types of qualitative data collection and analysis</td>
<td>Comparison</td>
<td>Design</td>
</tr>
<tr>
<td>Experiences, perceptions</td>
<td>Outcome</td>
<td>Evaluation</td>
</tr>
<tr>
<td>Qualitative or qualitative method</td>
<td><em>not applicable</em></td>
<td>Study type</td>
</tr>
</tbody>
</table>

Methods

Inclusion and exclusion criteria
Studies eligible for inclusion were those that qualitatively investigated patients’ experiences, views, attitudes to and perceptions of health care services for Multiple Sclerosis. No date restriction was imposed on searches as this was an original review. Qualitative research, for this purpose, was defined by the Cochrane qualitative methods group [7] as using both a qualitative data collection method and qualitative analysis. Quantitative and mixed method studies were therefore excluded.

We define experience as “Patients’ reports of how care was organised and delivered to meet their needs” [15, p.301]. Patients’ reports could refer to either experience of health care services delivery and organisation overall or their experiences of care by specific health care personnel. We included studies that investigated adults (aged 18 years old and older) with a diagnosis of Multiple Sclerosis, who had experience of utilising health care services at any time point. There were no restrictions on subtype of Multiple Sclerosis, gender, ethnicity or frequency of use of health care. Health care in this sense referred to routine clinical care (either state funded or
privately funded) not trial protocols or interventions. Excluded studies included studies that focussed on self-management and studies that investigated quality of life.

Because of the focus on Multiple Sclerosis, studies were excluded if they used a mixed sample of various conditions (e.g. studies reported a mixed sample of people with neurological conditions) or if they used a sample of mixed respondents (i.e. people with Multiple Sclerosis and their carers) where results of patients with Multiple Sclerosis could not be clearly separated. If an article had a section or subtheme on health care services but this was not the main research area of the article, then that article was included; however only data from the relevant subtheme were extracted and included in the findings. Additional exclusion criteria were articles that only described carer or health care professional experiences not patient experiences. Conference abstracts, editorials and commentaries were not included.

Search strategy

For this systematic search we developed a detailed search strategy in collaboration with a specialist librarian and information specialist. This search strategy was tailored to the three largest medical and nursing databases (MEDLINE, EMBASE, and CINAHL Plus) as in Cooke et al.’s study [9] and search terms used a mixture of medical subject headings and keywords. To investigate the benefit of the SPIDER,PICO and PICOS tools we used identical search terms but combined them in different ways as shown in Tables 2, 3 and 4 below.
Table 2. The search terms used in the SPIDER search

<table>
<thead>
<tr>
<th>SPIDER tool</th>
<th>search terms</th>
<th>MEDLINE</th>
<th>EMBASE</th>
</tr>
</thead>
<tbody>
<tr>
<td>S</td>
<td>[MH Multiple Sclerosis OR TX multiple sclerosis] AND MH patients OR TX service user* OR TX service-user*</td>
<td>exp &quot;health care facilities, manpower and services&quot;/ OR health care.tw OR health services.tw OR exp Health Services Administration/ OR exp Therapeutics/ OR exp Diagnosis/ OR organisations.tw OR exp Health Occupations/ OR consultation.tw OR referral.tw OR exp Health Personnel/ OR Health Education/ OR hospital*.tw OR consultant*.tw OR neurologist*.tw OR doctor* OR practice nurse*.tw OR specialist</td>
<td></td>
</tr>
<tr>
<td>P and I</td>
<td>MH (health services needs and demands) OR TX health care OR TX health services OR TX care OR MH patient care OR MH health personnel OR MH health services administration OR MH health services OR MH health facilities OR MH mental health services OR MH therapeutics OR TX specialist care MM &quot;Multiple Sclerosis Psychosocial Factors&quot; OR MM &quot;Multiple sclerosis diagnosis&quot; OR</td>
<td>exp health care/ OR health care.tw OR exp health service/ OR exp health care organisation/ OR exp health care utilization/ OR exp &quot;care and caring&quot;/ OR care.tw OR medical care.tw OR exp health care personnel/ OR health service$.tw OR health care professional$.tw OR exp health care quality/ OR exp terminal care/ OR exp health care management/ OR exp</td>
<td></td>
</tr>
<tr>
<td>MM “Multiple sclerosis drug therapy”</td>
<td>nurse* OR psychologist*.tw OR general practitioner*.tw OR exp &quot;psychiatry and psychology (non mesh)&quot;/ OR exp/Dentistry/ OR exp investigative techniques/ OR exp &quot;health care economics and organisations&quot;/ OR specialist care.tw OR mental health services.tw OR mental health care.tw OR secondary care.tw</td>
<td>medical procedures/ OR exp health care facility/ OR hospital$.tw OR welfare/ or *human needs/ or *social welfare OR exp medical ethics/ OR consultant$.tw OR neurologist$.tw OR doctor$.tw OR practice nurse$.tw OR specialist nurse$.tw OR psychologist$.tw OR general practitioner$.tw OR mental health care.tw OR mental health services.tw OR psycholog$ services.tw OR specialist care.tw OR secondary care.tw OR primary care.tw OR primary health care.tw</td>
<td></td>
</tr>
<tr>
<td>TX qualitative interview OR MH focus groups OR MH content analysis OR MH constant comparative method OR MH thematic analysis OR MH grounded theory OR MH ethnographic research OR MH phenomenological research OR MH</td>
<td>exp interviews as Topic/ OR exp Nursing Methodology Research/ OR content analysis.tw OR constant comparative.tw OR grounded theory.tw OR ethnography.tw OR interpretative phenomenological analysis.tw</td>
<td>exp interview/ OR exp grounded theory/ OR exp ethnography/ OR interpretative phenomenological analysis.tw OR exp phenomenology/ OR focus group$.tw OR exp content analysis/ OR exp thematic analysis/ OR exp constant comparative/</td>
<td></td>
</tr>
<tr>
<td></td>
<td>semantic analysis OR TX interview*</td>
<td></td>
<td></td>
</tr>
<tr>
<td>---</td>
<td>-----------------------------------</td>
<td></td>
<td></td>
</tr>
<tr>
<td>E</td>
<td>TX perception* OR MH patient satisfaction OR TX satisf* OR TX value* OR TX perceive* OR TX perspective* OR TX view* OR TX experience OR MH (health services needs and demand) OR TX opinion* OR MH consumer satisfaction OR TX belie* OR MM “Patient Attitudes” OR MM “Attitude to illness”</td>
<td>perceive*.tw OR perception*.tw OR exp Consumer Participation/ OR <em>personal satisfaction/ OR exp Consumer Satisfaction/ OR satis</em>.tw OR exp Hospital-Patient Relations/ OR exp Professional- Patient Relations/ OR value*.tw OR perspective*.tw OR view*.tw OR experience*.tw OR need*.tw OR exp &quot;Health Services Needs and Demand”/ OR issue*.tw OR exp Attitude/ OR belie*.tw OR opinion*.tw OR feel*.tw OR know*.tw OR understand*.tw</td>
<td></td>
</tr>
<tr>
<td>R</td>
<td>AB qualitative OR MH qualitative studies</td>
<td>exp Qualitative Research/ OR qualitative.tw</td>
<td></td>
</tr>
</tbody>
</table>

[S AND P of I] AND [(D or E) AND R]
<table>
<thead>
<tr>
<th>PICO tool</th>
<th>Search terms</th>
<th>MEDLINE</th>
<th>EMBASE</th>
</tr>
</thead>
<tbody>
<tr>
<td>CINAHL Plus</td>
<td>[MH Multiple Sclerosis OR TX multiple sclerosis] AND MH patients OR TX service user* or TX service-user*</td>
<td>[exp multiple sclerosis/ OR multiple sclerosis.tw]AND [exp Patients/ OR patient*.tw OR service user*.tw OR service-user*.tw OR exp consumer participation/ OR consumer.tw]</td>
<td>[exp multiple sclerosis/ OR multiple sclerosis.tw] AND [exp patient/ patient$.tw OR service user$.tw OR service-user$.tw OR consumer$.tw]</td>
</tr>
<tr>
<td>I</td>
<td>MH (health services needs and demands) OR TX health care OR TX health services OR TX care OR MH patient care OR MH health personnel OR MH health services administration OR MH health services OR MH health facilities OR MH mental health services OR MH therapeutics OR TX specialist care MM &quot;Multiple Sclerosis Psychosocial Factors&quot; OR MM “Multiple sclerosis diagnosis” OR MM “Multiple sclerosis drug therapy”</td>
<td>exp &quot;health care facilities, manpower and services&quot;/ OR health care.tw OR health services.tw OR exp Health Services Administration/ OR exp Therapeutics/ OR exp Diagnosis/ OR organisations.tw OR exp Health Occupations/ OR consultation.tw OR referral.tw OR exp Health Personnel/ OR Health Education/ OR hospital*.tw OR consultant*.tw OR neurologist*.tw OR doctor* OR practice nurse*.tw OR specialist nurse* OR psychologist*.tw OR general</td>
<td>exp health care/ OR health care.tw OR exp health service/ OR exp health care organisation/ OR exp health care utilization/ OR exp &quot;care and caring&quot;/ OR care.tw OR medical care.tw OR exp health care personnel/ OR health service$.tw OR health care professional$.tw OR exp health care quality/ OR exp terminal care/ OR exp health care management/ OR exp medical procedures/ OR exp health care</td>
</tr>
<tr>
<td>C</td>
<td>n/a</td>
<td>n/a</td>
<td>n/a</td>
</tr>
<tr>
<td>---</td>
<td>-----</td>
<td>-----</td>
<td>-----</td>
</tr>
<tr>
<td>O</td>
<td>TX perception* OR MH patient satisfaction OR TX satisf* OR TX value* OR TX perceive* OR TX perspective* OR TX view* OR TX experience OR MH (health services needs and demand) OR TX opinion* OR MH consumer</td>
<td>perceive*.tw OR perception*.tw OR exp Consumer Participation/ OR <em>personal satisfaction/ OR exp Consumer Satisfaction/ OR satis</em>.tw OR exp Hospital-Patient Relations/ OR exp Professional-Patient Relations/ OR value*.tw OR perspective*.tw</td>
<td>Perception$.tw OR exp satisfaction/ OR satis$.tw OR value$.tw OR perceive$.tw OR exp psychological aspect/ OR perspective$.tw OR view$.tw OR exp personal experience/ OR experience$.tw OR exp health care need/ OR need$.tw</td>
</tr>
<tr>
<td>PICO tool</td>
<td>Search terms</td>
<td>CINAHL Plus</td>
<td>MEDLINE</td>
</tr>
<tr>
<td>-----------</td>
<td>--------------</td>
<td>-------------</td>
<td>---------</td>
</tr>
<tr>
<td>P</td>
<td>[MH Multiple Sclerosis OR TX multiple sclerosis] AND MH patients OR TX service user* or TX service-user*</td>
<td>[exp multiple sclerosis/ OR multiple sclerosis.tw] AND [exp Patients/ OR patient*.tw OR service user*.tw OR service-user*.tw OR exp consumer participation/ OR consumer.tw]</td>
<td>[exp multiple sclerosis/ OR multiple sclerosis.tw] AND [exp patient/ patient$.tw OR service user$.tw OR service-user$ OR consumer$.tw]</td>
</tr>
<tr>
<td>I</td>
<td>MH (health services needs and demands) OR TX health care OR TX health services OR TX care OR MH patient care OR MH</td>
<td>exp &quot;health care facilities, manpower and services&quot;/ OR health care.tw OR health services.tw OR exp Health Services</td>
<td>exp health care/ OR health care.tw OR exp health service/ OR exp health care organisation/ OR exp health care</td>
</tr>
</tbody>
</table>

* (P and I and O)

Table 4. The terms used in the PICOS search
<p>| health personnel OR MH health services OR MH health facilities OR MH mental health services OR MH therapeutics OR TX specialist care MM &quot;Multiple Sclerosis Psychosocial Factors&quot; OR MM &quot;Multiple sclerosis diagnosis&quot; OR MM &quot;Multiple sclerosis drug therapy&quot; | Administration/ OR exp Therapeutics/ OR exp Diagnosis/ OR organisations.tw OR exp Health Occupations/ OR consultation.tw OR referral.tw OR exp Health Personnel/ OR Health Education/ OR hospital*.tw OR consultant*.tw OR neurologist*.tw OR doctor* OR practice nurse*.tw OR specialist nurse* OR psychologist*.tw OR general practitioner*.tw OR exp &quot;psychiatry and psychology (non mesh)&quot;/ OR exp/Dentistry/ OR exp investigative techniques/ OR exp &quot;health care economics and organisations&quot;/ OR specialist care.tw OR mental health services.tw OR mental health care.tw OR secondary care.tw | utilization/ OR exp &quot;care and caring&quot;/ OR care.tw OR medical care.tw OR exp health care personnel/ OR health service$.tw OR health care professional$.tw OR exp health care quality/ OR exp terminal care/ OR exp health care management/ OR exp medical procedures/ OR exp health care facility/ OR hospital$.tw OR welfare/ OR *human needs/ or *social welfare OR exp medical ethics/ OR consultant$.tw OR neurologist$.tw OR doctor$.tw OR practice nurse$.tw OR specialist nurse$.tw OR psychologist$.tw OR general practitioner$.tw OR mental health care.tw OR mental health services.tw OR psycholog$ services.tw OR specialist care.tw OR secondary care.tw OR primary care.tw OR primary health |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>C</td>
<td>n/a</td>
<td>n/a</td>
</tr>
<tr>
<td>O</td>
<td>TX perception* OR MH patient satisfaction OR TX satisf* OR TX value* OR TX perceive* OR TX perspective* OR TX view* OR TX experience OR MH (health services needs and demand) OR TX opinion* OR MH consumer satisfaction OR TX belie* OR MM “Patient Attitudes” OR MM “Attitude to illness”</td>
<td>perceive*.tw OR perception*.tw OR exp Consumer Participation/ OR <em>personal satisfaction/ OR exp Consumer Satisfaction/ OR satis</em>.tw OR exp Hospital-Patient Relations/ OR exp Professional- Patient Relations/ OR value*.tw OR perspective*.tw OR view*.tw OR experience*.tw OR need*.tw OR exp &quot;Health Services Needs and Demand”/ OR issue*.tw OR exp Attitude/ OR belie*.tw OR opinion*.tw OR feel*.tw OR know*.tw OR understand*.tw</td>
</tr>
<tr>
<td>S</td>
<td>AB qualitative OR MH qualitative studies</td>
<td>Exp Qualitative Research/ OR qualitative.mp AB qualitative OR MH qualitative studies</td>
</tr>
<tr>
<td></td>
<td></td>
<td>(P AND I AND C AND O AND S)</td>
</tr>
</tbody>
</table>
One reviewer judged titles and abstracts against the inclusion criteria. If a title and abstract met the inclusion criteria then full text copies of all articles were retrieved for further investigation. Two authors reviewed these full text articles independently for relevance to the search aim (i.e. patients/service users with multiple sclerosis, experiences of health care services and qualitative research). Any disagreements were resolved via discussion. Data from included studies were extracted by both reviewers independently to ensure accuracy and then stored on a Microsoft Excel spread sheet. No ethical approval was required for this study.

Results
All searches spanned from database inception until 12\textsuperscript{th} October 2013. As in Cooke et al. [9], we reviewed our findings based on two metrics; the number of hits generated and of these, the number relevant to the search aim (see Table 5).
<table>
<thead>
<tr>
<th>Database</th>
<th>PICO search</th>
<th>PICO S search</th>
<th>SPIDER</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Articles found in initial search</td>
<td>Articles included</td>
<td>Articles found in initial search</td>
</tr>
<tr>
<td>CINAHL plus</td>
<td>1350</td>
<td>After abstract and title = 78</td>
<td>146</td>
</tr>
<tr>
<td></td>
<td>After full review = 14</td>
<td>56</td>
<td>After full review = 12</td>
</tr>
<tr>
<td>EMBASE</td>
<td>14250</td>
<td>After abstract and title = 35</td>
<td>189</td>
</tr>
<tr>
<td></td>
<td>After full review = 14</td>
<td>14</td>
<td>After full review = 7</td>
</tr>
<tr>
<td>MEDLINE</td>
<td>8158</td>
<td>After abstract and title = 34</td>
<td>113</td>
</tr>
<tr>
<td></td>
<td>After full review = 12</td>
<td>12</td>
<td>After full review = 6</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>After full review = 5</td>
</tr>
</tbody>
</table>
Number of articles generated

As found in Cooke et al. [9], PICO created a much greater number of hits compared to SPIDER. A total of 23758 hits were generated using PICO, 448 hits were generated using PICOS and 239 hits were generated using SPIDER. Overall, the average reduction of hits % across all three databases was 98.58% for SPIDER vs. PICO, 97.94% for PICO vs. PICOS and 68.64% for PICOS vs. SPIDER. The time spent screening hits for relevant articles equated to weeks for the PICO hits and hours for the PICOS and SPIDER hits.

Proportion of relevant articles

Articles which met the inclusion criteria after full text review are displayed in Table 6 [16-33]. Examination of the titles and abstracts of the identified articles resulted in the obtainment of 18 full text articles relevant at full text, across all databases and search tools.

PICO tool

For the PICO tool in CINAHL Plus, 5.78% of hits were deemed relevant after the title and abstract stage (78 articles/1350 articles), and 14/78 articles (17.95%) were confirmed to meet the inclusion criteria after full text review. For the PICO tool in MEDLINE, 0.42% of hits were deemed relevant after the title and abstract stage (34 articles/8158 articles) and 12/34 (35.29%) articles were confirmed to meet the inclusion criteria after full text review. For the PICO tool in EMBASE, 0.25% hits were deemed relevant after the title and abstract stage (35 articles/14250 articles) and 14/35 (40%) articles were confirmed to meet the inclusion criteria after full text review.

PICOS tool

For the PICOS tool in CINAHL Plus, 38.36% of articles were relevant after the title and abstract stage (56 articles/146 articles) and 12/56 (21.43%) were confirmed to meet the inclusion criteria after full text review. For the PICOS tool in MEDLINE 14.16% of articles were relevant after the title and abstract stage (16 articles/113 articles) and 6/16 (37.5%) were confirmed to meet the inclusion criteria after full text review. For the PICOS tool in EMBASE 7.94% of articles were deemed relevant after the title and abstract stage (15 articles/189 articles) and 7/15 (46.67%) were confirmed to meet the inclusion criteria after full text review.

SPIDER tool

For the SPIDER tool in CINAHL Plus 38.36% of articles were relevant after the title and abstract stage (56 articles/146 articles) and 12/56 (21.43%) were confirmed to
meet the inclusion criteria after full text review. For the SPIDER tool in MEDLINE, 36.81% hits were deemed relevant at the title stage (14 articles/38 articles) and 5/14 articles (35.71%) were confirmed to meet the inclusion criteria after full text review. For the SPIDER tool in EMBASE, 16.36% were relevant at the title stage (9 articles/55 articles) and 3/9 (33.33%) were confirmed to meet the inclusion criteria after full text review.
<table>
<thead>
<tr>
<th>Articles identified</th>
<th>Title</th>
<th>Database (search tool used)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>MEDLINE (PICO)</td>
</tr>
<tr>
<td>Lohne et al. (2010)</td>
<td>The lonely battle for dignity</td>
<td>X</td>
</tr>
<tr>
<td>Mackereth et al.</td>
<td>What do people talk about during reflexology?</td>
<td>X</td>
</tr>
<tr>
<td>(2008) [17].</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Isaksson, &amp; Ahlström</td>
<td>Managing chronic sorrow</td>
<td>X</td>
</tr>
<tr>
<td>(2008) [18].</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Edwards, Barlow &amp;</td>
<td>Experiences of diagnosis and treatment among people with MS</td>
<td>X</td>
</tr>
<tr>
<td>Turner (2008) [19].</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Barker-Collo, Cartwright &amp; Read</td>
<td>Into the unknown: The</td>
<td>X</td>
</tr>
</tbody>
</table>

325
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Isaksson, &amp; Ahlström (2006)</td>
<td>Experiences of individuals</td>
<td>From symptoms to diagnosis</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Miller &amp; Jezewski (2006)</td>
<td>Relapsing MS patients' experiences with galtiramer acetate</td>
<td></td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Johnson (2003)</td>
<td>On receiving the diagnosis of MS</td>
<td></td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Miller &amp; Jezewski (2001)</td>
<td>A phenomenologic assessment of relapsing MS patients' experiences during treatment with Interferon Beta-1(+)</td>
<td></td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Miller (1997)</td>
<td>The lived experience of</td>
<td></td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Study</td>
<td>Title</td>
<td>Variables</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>----------------------------------------------------------------------</td>
<td>-----------------------------------------------------------------------</td>
<td>-----------</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Aars &amp; Bruusgaard (1989) [26].</td>
<td>Chronic disease and sexuality: An interview study</td>
<td>X X</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Rintell et al. (2012) [27].</td>
<td>Patients' perspectives on quality of mental health care</td>
<td>X X X</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Laidlaw &amp; Henwood (2003) [28].</td>
<td>Patients with multiple sclerosis: Their experiences and perceptions of MRI</td>
<td>X X X</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Koopman &amp; Schweitzer (1999) [29].</td>
<td>The journey to multiple sclerosis</td>
<td>X X X</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hansen, Krogh, Bangsgaard &amp; Aabling (2008) [30].</td>
<td>Facing the diagnosis</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ref.</td>
<td>Title</td>
<td>Column 1</td>
<td>Column 2</td>
<td>Column 3</td>
<td>Column 4</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>--------------------------</td>
<td>----------------------------------------------------------------------</td>
<td>----------</td>
<td>----------</td>
<td>----------</td>
<td>----------</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Loveland (1999) [31].</td>
<td>The experiences of African Americans and Euro-Americans with multiple sclerosis</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Moriya &amp; Suzuki (2011) [32].</td>
<td>A qualitative study relating to the experiences of people with MS</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Classen &amp; Lou (2004) [33].</td>
<td>Exploring rehabilitation and wellness needs of people with MS living in South Florida</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Sensitivity and specificity

Table 7. Sensitivity and specificity for each search tool by database

<table>
<thead>
<tr>
<th>Search tool and database</th>
<th>Sensitivity (% relevant texts identified out of all relevant hits)</th>
<th>Specificity (% relevant texts identified out of all hits)</th>
</tr>
</thead>
<tbody>
<tr>
<td>CINAHL PICO</td>
<td>14/18 = 77.78</td>
<td>14/1350 = 1.04</td>
</tr>
<tr>
<td>CINAHL PICO S</td>
<td>12/18 = 66.67</td>
<td>12/146 = 8.22</td>
</tr>
<tr>
<td>CINAHL SPIDER</td>
<td>12/18 = 66.67</td>
<td>12/146 = 8.22</td>
</tr>
<tr>
<td>MEDLINE PICO</td>
<td>12/18 66.67</td>
<td>12/8158 = 0.15</td>
</tr>
<tr>
<td>MEDLINE PICO S</td>
<td>6/18 = 33.33</td>
<td>6/113 = 5.32</td>
</tr>
<tr>
<td>MEDLINE SPIDER</td>
<td>5/18 = 27.78</td>
<td>5/14 = 35.71</td>
</tr>
<tr>
<td>EMBASE PICO</td>
<td>13/18 = 72.22</td>
<td>14/14250 = 0.1</td>
</tr>
<tr>
<td>EMBASE PICO S</td>
<td>7/18 = 38.88</td>
<td>7/189 = 3.7</td>
</tr>
<tr>
<td>EMBASE SPIDER</td>
<td>3/18 = 16.67</td>
<td>3/55 = 5.45</td>
</tr>
</tbody>
</table>

The SPIDER tool identified 13 relevant articles out of 239 articles across all three databases (5.43%) compared to PICOS which identified 13 articles out of 448 articles (2.90%) and PICO which identified 18 articles out of 23758 articles (0.076%). Of the 18 relevant articles identified by the PICO tool, 66.66% came from both MEDLINE and CINAHL Plus (12 articles each), and 72.22% came from EMBASE (13 articles). Of the 13 relevant articles identified by the PICOS tool 46.15% came from MEDLINE (6 articles), 53.84% came from EMBASE (7 articles) and 92.31% came from CINAHL Plus (12 articles). Of the 13 relevant articles identified by SPIDER, 38.46% came from MEDLINE (5 articles) and 23.07% came from EMBASE (3 articles) and 92.30% came from CINAHL Plus (12 articles).

Different articles were found across different tools and databases (as shown in Table 6). All three databases were checked for all articles. One article was available in CINAHL Plus but not identified by any of the tools [17]. Two papers were identified in all databases through all search tools. Five papers were identified in MEDLINE through all search tools, three identified in EMBASE through all search tools and 12 identified in CINAHL through all search tools. Five papers were identified solely in CINAHL Plus, with one of these papers only identified using the PICO search method. One paper was
identified by all search tools in EMBASE but not identified by any in MEDLINE. No new studies were identified using the SPIDER or PICOS tools alone in any database.

**Discussion**

In this article we addressed the aim of replicating a comparison between the SPIDER, PICOS and PICO search tools. As previously described in Cooke et al. [9], the SPIDER tool produced a greatly reduced number of initial hits to sift through, however in this study it missed five studies that were identified through the PICO method. This may be partly be explained by the nature of the research question prompting the search. As this study included subthemes of studies whose focus differed from the initial research question (i.e. only a smaller section of the paper related to health care) then it’s possible that these studies were picked up by a broader search but not the highly specific SPIDER search. Other authors researching the process of qualitative literature reviews have previously commented that there appears to be a decision to be made about the benefits of comprehensiveness of findings versus the accuracy of the studies identified [11]. Given the common nature of using sub-sections of papers for systematic reviews then our findings suggest that comprehensiveness needs to be the key for this type of search.

The PICOS tool was more specific than the PICO tool, but did not identify any additional relevant hits to the SPIDER tool, suggesting it is of equal sensitivity. PICOS identified the same number of papers as the SPIDER tool and both demonstrated a substantially lower number of hits generated than a regular PICO search. The SPIDER tool showed the greatest specificity due the small number of hits generated. This may mean that review teams with very limited resources or time, and who are not aiming for a totally comprehensive search, would benefit from using the SPIDER tool. This might be applicable particularly to studies such as qualitative syntheses, where the research aim is theoretical saturation, not a comprehensive search [34]. In addition, articles written to influence policy often require swift publication, providing another area in which either SPIDER or PICOS might improve current practice.

The issue of time was also related to the number of relevant articles identified per database. Whilst EMBASE generated nearly twice as many hits as MEDLINE, only one additional paper was found. The PICO tool identified all articles, suggesting that where time is not a factor, it might be of more benefit to use this tool, as SPIDER
demonstrated lower sensitivity, did not identify any new articles and identified fewer relevant articles than PICO.

Our findings indicate that it is worthwhile testing a chosen search tool across various databases as they produce different results; i.e. CINAHL Plus identified papers not identified in MEDLINE or EMBASE databases. It is therefore important for future research to investigate the potential of the SPIDER vs. PICOS and PICO tools as a base for the recommended comprehensive searching process, by investigating the contribution of the SPIDER and PICOS tools at every stage from the initial search hits, to the final included relevant articles.

As CINAHL is a database dedicated to nursing and allied health research, it was expected that it would produce a greater number of relevant articles than more medically focussed databases[10], as nursing and allied areas have traditionally been at the forefront of qualitative investigations into Multiple Sclerosis.

SPIDER proved to be a tool designed to formulate search terms easily, as it naturally fits the crucial elements of the search question. However, even though some qualitative keywords are necessary to identify qualitative studies, including the words qualitative research AND the name of the type of research e.g. “grounded theory” might be too restrictive, particularly given the poor use of the qualitative index term, and might partially explain the fewer studies identified by SPIDER in comparison to PICO. Studies not identified by the SPIDER model in MEDLINE and EMBASE databases did not use keywords such as “qualitative”, but some described qualitative methods, such as “phenomenological-hermeneutic” [16] or “interview(s)” [20,23].

In all PICO searches for MEDLINE and EMBASE the word “qualitative” combined with the phrase “multiple sclerosis” identified many quantitative studies reporting brain scan assessments that were wholly unrelated to the search aim. This was because the word “qualitative” in this context referred to using a qualitative method to provide information about the quality of the scan and any potential flaws [35]. This caused a problem with specificity, resulting in thousands of inappropriate hits as there was no way to exclude studies with the word “qualitative” unless all articles clearly utilised and indexed qualitative research methods in the title, abstract and keywords. Many studies were excluded at the full text stage on the basis that the samples were mixed: being comprised of either various neurological conditions or mixed groups of people i.e. patients and carers/ patients and health care professionals and so forth.
Without clearer titles and abstracts, and potentially an indexing phrase that indicates mixed samples, there is no way of avoiding this issue. Excluding the phrases “caregivers” or “health care professionals” would have excluded any studies that used these phrases (for example in the introduction or implication for future research sections) and therefore it is difficult to see how this could be prevented. A strength and limitation of our study is that whilst it details a real world example of evidence searching, it only addresses one topic. Further research should test these search tools against a wider variety of narrative review and meta-synthesis topics.

Conclusions

SPIDER greatly reduced the initial number of articles identified on a given search due to increased specificity, however because of lower sensitivity omitted many relevant papers. The PICOS tool resulted in an overall more sensitive search, but still demonstrated poor specificity on this topic. Further investigations of the specificity and sensitivity of SPIDER and PICOS on varied topics will be of benefit to research teams with limited time and resources or articles necessary to impact on policy or change current practice. However, where comprehensiveness is a key factor we suggest that the PICO tool should be used preferentially. Part of the lower identification rate for SPIDER (in comparison to PICO) was poor labelling and use of qualitative keywords in indexing studies. As both individual research submissions and journal/database indexers improve, or standardise, the indexing of qualitative studies, it is likely that the relevance of the SPIDER tool will increase. The recommendation for current practice therefore is to use the PICO tool across a variety of databases. In this article we have shown that SPIDER is relevant for those researchers completing systematic narrative reviews of qualitative literature but not as effective as PICO. Future research should investigate the use of SPIDER and PICOS across varied databases.

Competing interests

All authors declare they have no competing interests.

Author’s contributions

AM designed the study, conducted all searches, appraised all potential studies and wrote and revised the draft manuscript and subsequent manuscripts.
SC made significant contributions to the conception and design of the study, assisted with the presentation of findings and assisted with drafting and revising the manuscript.

CCG and RM made significant contributions to the conception and design of the study, assisted with the presentation of findings and assisted with drafting and revising the manuscript.

SCS conceived and designed the study, assisted with searches, appraised relevant studies and assisted with drafting and revising the manuscript.

All authors read and approved the final manuscript.

Authors’ information
1University of Manchester, Centre for Primary Care, Williamson Building, Oxford Road, Manchester, M13 9PL, United Kingdom. 2Keele University, Institute of Primary Care and Health Sciences, Keele, United Kingdom. 3Manchester Mental Health and Social Care Trust, Research and Innovation 3rd Floor, Rawnsley Building, Central Manchester Hospitals site, Hathersage Road, Manchester, M13 9WL, United Kingdom.

Acknowledgements
This study was funded by a School for Primary Care Research PhD studentship from the National Institute for Health Research. Support in selecting search terms is acknowledged from Olivia Walsby, Academic Engagement Librarian. Support in designing this study and assessing the method is acknowledged from Rosalind McNally, Information Specialist.

References


[http://www.york.ac.uk/inst/crd/pdf/Systematic_Reviews.pdf]


[34] Booth A: Cochrane or cock-eyed? How should we conduct systematic reviews of qualitative research? In *Qualitative Evidence-Based Practice Conference*: 14-16 May 2001; Coventry. [http://www.leeds.ac.uk/educol/documents/00001724.htm]

Experiences of UK health care services for people with MS: a systematic narrative review

Abigail Methley, Stephen Campbell, Carolyn Chew-Graham, Sudeh Charaqui-Sohi; Institute of Population Health – Primary Care, University of Manchester

Introduction

The NHS recently implemented a policy aiming to improve patient experiences through more flexible, patient-led health care services1. As part of a PhD investigating the experiences of UK health services by people with MS, a literature review was carried out on the topic. Systematic reviews on pharmacological treatments and rehabilitation for MS were located, however none had been completed on the health care experiences of people with MS in the UK and therefore that was the aim of this review.

Method

Inclusion criteria:
- any publication data
- qualitative studies only (defined by the Cochrane qualitative methods group) as those which both collected and analysed data using a qualitative method
- focused on patients’ experiences, views, attitudes to and perceptions of UK health services for MS.

Studies involving mixed samples of people with MS and carers or health care professionals were excluded, as were studies that used mixed patient groups e.g. MS and Huntington’s disease. Searches were conducted in four of the largest medical research databases (psychINFO, Medline, EMBASE, CINAHL), alongside the MS Society library, Multiple Sclerosis Journal and the British Journal of Neuroscience Nursing.

Data collection and analysis

Study data were independently extracted and appraised for quality by two researchers using the Critical Appraisal Skills Programme checklist for qualitative syntheses (adapted for use with qualitative syntheses11).

Findings

459 articles were initially identified. 403 were rejected upon reading their abstract or research summary as they failed to meet the inclusion criteria and 56 articles were rejected after reading the study in full, leaving six articles12 (one study reported over two articles12). These five studies were conducted between 2001 and 2008. Four of the studies were conducted in England12-14, one in Northern Ireland15. Overall, reporting of demographic information including ethnicity, participant ages, disease duration and disability was very varied. Limited reporting contributed to low scores on the quality appraisal, as did poor justification for sample selection/size, and limited reporting of analysis process.

The limited number of studies and the variety of areas covered meant that the data were too heterogeneous to use an in-depth qualitative synthesis method (for example meta-ethnography16) and a narrative summary approach was used.

Findings of the studies could be broadly divided into two areas: diagnosis and palliative care. The process of diagnosis was overall a negative and lengthy experience17, 18. Diagnosis was a very emotive experience, transcending from distress at the awareness of initial symptoms, through to fear and uncertainty during and after diagnosis, and in some cases, shock, devastation or relief when diagnosis was confirmed18, 19.

Studies reported a lack of advice and information about MS at the time of diagnosis18, 19. Lack of information and understanding could cause fear and perceptions of loss and control (e.g. when undergoing MRI scanning19). The timeliness of access to information was therefore crucial.

Studies commonly reported dissatisfaction with services where information provision was limited18, 19. Whilst occupational therapists, physiotherapists and community nurses were perceived to be knowledgeable sources of information, general practitioners were felt to be less knowledgeable on MS and not always able to provide appropriate information11.

Once a diagnosis of MS had been confirmed, studies reported difficulties accessing both treatments and services for MS care18, 19. Continuity of care was reported to be poor during both diagnosis and ongoing care, especially relational continuity of individual neurologists19. Studies reported that participants could feel “abandoned” or “isolated” by the health care system where they did not receive appropriate support. Communication with health care professionals was often experienced negatively by participants, where it was perceived as unsympathetic and insensitive18, 19.
Embrey14 was the only study to report the experiences of palliative care of people with MS. This study found that therapeutic interventions resulted in many benefits including symptom relief, a sense of achievement, and opportunities for health promotion. Additional benefits were friendship, reduced carer burden and positive experiences with staff. Perceived negatives were the infrequency of interventions and concerns over the long term continuity of the service.

**Discussion**

Included studies investigated experiences of diagnosis and palliative care, with limited information on experiences in the middle of the care pathway. Overall themes which transcended the care pathway were:

- the emotional experience of care
- perceived support from health care professionals
- the importance of continuous and accessible care services.

The issues resulting in negative experiences of services are unfortunately well established in the literature on this topic. However, this review suggests that despite increased awareness and policy, these topics still require addressing in primary, secondary and community services for people with MS across the UK, although more current evidence is needed.

**Implications for practice, research and commissioning**

As previously discussed in research on MS, communication with health care staff is key to the experiences of people with MS of health care. Findings from included studies suggest that poor interpersonal communication is still a significant issue in clinical practice, despite the introduction of the 2003 NICE guideline14. A priority should be to improve professional-patient communication, through raising awareness of the impact of negative interactions, and providing training if necessary, similar to oncology services19.

Studies reported negative experiences where lack of information caused distress and uncertainty. The NHS has previously acknowledged the need to improve the emotional experiences of patients, and this is clearly applicable to people with MS14. Providing timely and credible information may assist in this area. The included studies also suggest that experiences of both diagnosis and ongoing care could be improved by better responsiveness and increased continuity of care between primary, community and specialist care. All studies included in this review were published in the last decade, however, many participants had been diagnosed for a long period of time before the study took place. Therefore, experiences may have improved due to the increased role of MS specialist nurses and improved diagnostic technology, but it has not been possible to evaluate that in this review.

**Implications for commissioning**

Patient concerns over the continuity and quality of care services in the UK are a pertinent issue due to the closure or restriction of some NHS and charity facilities14. The inclusion of neurological conditions (including MS) in one of the four Strategic Clinical Networks is hoped to improve the continuity of care across primary and secondary care services14. However, a service audit of MS care in 2011 revealed difficulties accessing relevant services dependent on local funding priorities, referrals and availability of services, therefore further variety may be displayed due to the differing priorities of clinical commissioning groups15. It will therefore be necessary for further research to investigate these issues within the new NHS structure.

**Strengths and limitations of the study**

The conclusions presented are drawn from a limited body of research, on limited aspects of the care pathway and where the quality of reporting was mixed. There is a need to increase the quality of reporting in qualitative research to gain a more thorough understanding of the full health care experience for people with MS.

From the limited demographic data it appears that more participants under the age of 35 should be included in research to represent young adults with MS. Additionally, only one study reported ethnicity data, so despite well-established difficulties in help seeking and barriers to accessing health care reported by people from ethnic minority backgrounds15, the experiences of these people with MS are unknown.

**Summary**

This review provides an overview of qualitative literature investigating the experiences of people with MS of UK health care services. Identified studies focused on diagnosis and palliative care, suggesting the need for up to date information on the whole of the care pathway, for service delivery and commissioning. Emotional experiences of health care, access and continuity of care and support from health care professionals are key to the health care experiences of people with MS. However current literature reflects a limited sample, neglecting younger people and people from ethnic minorities, whose experiences remain unknown.

Call: 01462 476700
Secondary progressive multiple sclerosis: new book now available

Our new book on secondary progressive MS is now available to order. The book explains:

- the processes that are happening as the pattern of someone’s MS changes and why it can take time for the new diagnosis to be confirmed
- approaches to treating secondary progressive MS – both symptomatic and rehabilitation strategies
- the emotional side of the transition to secondary progressive MS and ways to manage this
- the growing level of research into progressive forms of MS.

It also looks at how to stay healthy and independent with secondary progressive MS and the health professionals who may be involved in supporting the individual.

New look Way Ahead

The first edition of Way Ahead was published in January 2007. Since then it has been a simple four-page newsletter. The aim of Way Ahead is to share articles about current research, best practice and inform health professionals about various projects the MS Trust was working on.

Although the aim of Way Ahead hasn’t changed, the design has gone through several iterations through to the current 15-page offering you are reading today which was introduced in 2008. We felt it was time for a change and will be introducing a new design in the next issue (January 2015).

Many of our contributors have mentioned that writing for Way Ahead was a good stepping stone before embarking on writing for a fully fledged journal. We hope that the more sophisticated style of the new look Way Ahead periodical will encourage even more of you to do the same!

Endnote

This paper has been written up in full and published in the journal Health Expectations as: Methley AM, Cheatham Graham C, Campbell S, Chônghah Soh S. Experiences of UK health-care services for people with multiple sclerosis: a systematic narrative review. Health Expect 2014, Jul 2 [Epub ahead of print]

Acknowledgements

This project was fully funded by a National Institute of Health Research School for Primary Care Studentship. The views expressed are those of the authors and not necessarily those of the NHS, the NIHR or the Department of Health.

www.mstrust.org.uk
### Appendix D: Systematic review search strategy

<table>
<thead>
<tr>
<th>Supplementary Information Table 1: Search terms for all databases</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>MEDLINE</strong></td>
</tr>
<tr>
<td>Health care</td>
</tr>
<tr>
<td>Perceptions</td>
</tr>
<tr>
<td>Patients</td>
</tr>
<tr>
<td>---------------------</td>
</tr>
<tr>
<td>exp Patients OR patient* tw OR service user* tw OR service-user* tw OR exp consumer participation OR consumer tw</td>
</tr>
<tr>
<td>OR understand$ tw</td>
</tr>
<tr>
<td></td>
</tr>
</tbody>
</table>

Health care terms AND Perception terms AND Patient terms AND MS terms AND Qualitative terms
## Supplementary information 2. Quality appraisal of included studies.*

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Is there a clear statement of aims?</td>
<td>Y</td>
<td>Y</td>
<td>N</td>
<td>Y</td>
<td>Y</td>
</tr>
<tr>
<td>Is a qualitative methodology appropriate?</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
</tr>
<tr>
<td>Is a theoretical perspective identified?</td>
<td>N</td>
<td>Y</td>
<td>N</td>
<td>N</td>
<td>N</td>
</tr>
<tr>
<td>Is it clear which setting the sample was selected from?</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
</tr>
<tr>
<td>Is it clear why this setting was chosen?</td>
<td>N</td>
<td>Y</td>
<td>N</td>
<td>N</td>
<td>N</td>
</tr>
<tr>
<td>Is clear and adequate information given on who was selected?</td>
<td>Y</td>
<td>N</td>
<td>Y</td>
<td>N</td>
<td>Y</td>
</tr>
<tr>
<td>Is it clear why these samples were selected?</td>
<td>N</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
</tr>
<tr>
<td>Is it clear how the sample was recruited?</td>
<td>Y</td>
<td>N</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
</tr>
<tr>
<td>Is the sample size justified by the author?</td>
<td>N</td>
<td>N</td>
<td>N</td>
<td>N</td>
<td>Y</td>
</tr>
<tr>
<td>Is it clear how many people accepted or refused to take part?</td>
<td>N</td>
<td>N</td>
<td>N</td>
<td>N</td>
<td>N</td>
</tr>
<tr>
<td>Is it clear why some participants chose not to take part?</td>
<td>N</td>
<td>N</td>
<td>N</td>
<td>N</td>
<td>N</td>
</tr>
<tr>
<td>Is it clear where the setting of the data collection was?</td>
<td>N</td>
<td>N</td>
<td>Y</td>
<td>Y</td>
<td>N</td>
</tr>
<tr>
<td>Is it clear why that setting was chosen?</td>
<td>N</td>
<td>N</td>
<td>N</td>
<td>Y</td>
<td>N</td>
</tr>
<tr>
<td>Is it clear how the purpose of the research was explained and presented to the participants?</td>
<td>Y</td>
<td>N</td>
<td>N</td>
<td>Y</td>
<td>Y</td>
</tr>
<tr>
<td>Question</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
</tr>
<tr>
<td>-------------------------------------------------------------------------</td>
<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
</tr>
<tr>
<td>Is it clear how the data were collected and why?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Is it clear how the data were recorded?</td>
<td>Y</td>
<td>N</td>
<td>N</td>
<td>Y</td>
<td>Y</td>
</tr>
<tr>
<td>Is there evidence of flexibility or an iterative process in the way the research was conducted?</td>
<td>N</td>
<td>Y</td>
<td>Y</td>
<td>N</td>
<td>N</td>
</tr>
<tr>
<td>Is it clear who collected the data?</td>
<td>N</td>
<td>N</td>
<td>N</td>
<td>N</td>
<td>Y</td>
</tr>
<tr>
<td>Is it clear how the analysis was done?</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
</tr>
<tr>
<td>Is it clear how the categories/themes were derived from the data?</td>
<td>Y</td>
<td>Y</td>
<td>N</td>
<td>N</td>
<td>Y</td>
</tr>
<tr>
<td>Is there adequate description of the analysis?</td>
<td>Y</td>
<td>Y</td>
<td>N</td>
<td>N</td>
<td>Y</td>
</tr>
<tr>
<td>Have attempts been made to feed results back to respondents?</td>
<td>N</td>
<td>N</td>
<td>Y</td>
<td>N</td>
<td>Y</td>
</tr>
<tr>
<td>Have different sources of data about the same issue been compared where appropriate (triangulation)?</td>
<td>N</td>
<td>N</td>
<td>Y</td>
<td>N</td>
<td>Y</td>
</tr>
<tr>
<td>Was the analysis repeated by more than one researcher to ensure reliability?</td>
<td>Y</td>
<td>N</td>
<td>N</td>
<td>N</td>
<td>N</td>
</tr>
<tr>
<td>Is it clear whether the researchers critically examined their own role, potential bias and influence?</td>
<td>N</td>
<td>N</td>
<td>N</td>
<td>N</td>
<td>N</td>
</tr>
<tr>
<td>Has the relationship between researchers and participants been adequately considered?</td>
<td>N</td>
<td>N</td>
<td>N</td>
<td>N</td>
<td>N</td>
</tr>
<tr>
<td>Were the findings explicit and easy to understand?</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
</tr>
<tr>
<td>Are sufficient data presented to support the descriptive findings?</td>
<td>Y</td>
<td>Y</td>
<td>N</td>
<td>N</td>
<td>Y</td>
</tr>
<tr>
<td>Question</td>
<td>Y</td>
<td>N</td>
<td>Y</td>
<td>Y</td>
<td>N</td>
</tr>
<tr>
<td>------------------------------------------------------------------------</td>
<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
</tr>
<tr>
<td>Are quotes numbered/identified?</td>
<td>Y</td>
<td>N</td>
<td>Y</td>
<td>Y</td>
<td>N</td>
</tr>
<tr>
<td>Do the researchers explain how the data presented in the paper were selected from the original sample?</td>
<td>Y</td>
<td>N</td>
<td>N</td>
<td>N</td>
<td>N</td>
</tr>
<tr>
<td>Do the researchers indicate how they developed their conceptual interpretations of what the data contained?</td>
<td>N</td>
<td>N</td>
<td>N</td>
<td>N</td>
<td>N</td>
</tr>
<tr>
<td>Are negative, unusual or contradictory cases presented?</td>
<td>Y</td>
<td>N</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
</tr>
<tr>
<td>Is there adequate discussion of the evidence both for and against the researchers’ interpretations?</td>
<td>Y</td>
<td>N</td>
<td>N</td>
<td>Y</td>
<td>N</td>
</tr>
<tr>
<td>Is there descriptive, conceptual or theoretical congruence between this and other work?</td>
<td>Y</td>
<td>N</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
</tr>
<tr>
<td>Are the findings of this study transferable to a wider population?</td>
<td>Y</td>
<td>N</td>
<td>Y</td>
<td>Y</td>
<td>N</td>
</tr>
<tr>
<td>Does this study add to knowledge or theory in the field?</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
</tr>
<tr>
<td>Are these findings important to practice?</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
</tr>
<tr>
<td>Total score out of 37 (%)</td>
<td>22 (59.46%)</td>
<td>15 (40.5%)</td>
<td>18 (48.6%)</td>
<td>19 (51.35%)</td>
<td>22 (59.46%)</td>
</tr>
</tbody>
</table>
Appendix F: NHS Research Ethics Approval

National Research Ethics Service Approval

Health Research Authority

National Research Ethics Service
NRES Committee North West - Greater Manchester Central
3rd Floor
Barlow House
4 Minshull Street
Manchester
M1 3DZ

Telephone: 0161 625 7825
Facsimile: 0161 625 7299

29 May 2012

Ms Abigail Methley
University of Manchester
6th Floor
Williamson Building
Oxford Road
Manchester
M13 9PL

Dear Ms Methley

Study title: Experiences and perceptions of health care services from people with Multiple Sclerosis and their clinicians: a qualitative study

REC reference: 12/NW/0385

Thank you for your letter of 24 May 2012, responding to the Committee’s request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised subject to the conditions specified below.

Ethical review of research sites

NHS sites
The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

**Conditions of the favourable opinion**

The favourable opinion is subject to the following conditions being met prior to the start of the study.

**Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.**

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at [http://www.rdforum.nhs.uk](http://www.rdforum.nhs.uk).

Where a NHS organisation’s role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

Sponsors are not required to notify the Committee of approvals from host organisations

**It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).**

**Approved documents**

The final list of documents reviewed and approved by the Committee is as follows:

<table>
<thead>
<tr>
<th>Document</th>
<th>Version</th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>Summary/Synopsis</td>
<td>Participant with MS</td>
<td>27 March 2012</td>
</tr>
<tr>
<td></td>
<td>- Version 1</td>
<td></td>
</tr>
<tr>
<td>Summary/Synopsis</td>
<td>Participant with MS</td>
<td>27 March 2012</td>
</tr>
<tr>
<td></td>
<td>longitudinal study -</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Version 1</td>
<td></td>
</tr>
<tr>
<td>Summary/Synopsis</td>
<td>GP - Version 1</td>
<td>27 March 2012</td>
</tr>
<tr>
<td>Summary/Synopsis</td>
<td>Practice Nurse -</td>
<td>27 March 2012</td>
</tr>
<tr>
<td></td>
<td>Version 1</td>
<td></td>
</tr>
<tr>
<td>Summary/Synopsis</td>
<td>MS Specialist Nurse -</td>
<td>27 March 2012</td>
</tr>
<tr>
<td></td>
<td>Version 1</td>
<td></td>
</tr>
<tr>
<td>Summary/Synopsis</td>
<td>IAPT Mental Health Nurse</td>
<td>27 March 2012</td>
</tr>
<tr>
<td>Response to Request for Further Information</td>
<td></td>
<td>24 May 2012</td>
</tr>
<tr>
<td>REC application</td>
<td>3.3</td>
<td>23 April 2012</td>
</tr>
<tr>
<td>Questionnaire: Demographic Questionnaire GPs</td>
<td>1</td>
<td>27 March 2012</td>
</tr>
<tr>
<td>Document Type</td>
<td>Page</td>
<td>Date</td>
</tr>
<tr>
<td>---------------------------------------------------</td>
<td>------</td>
<td>------------------</td>
</tr>
<tr>
<td>Questionnaire: Demographic Questionnaire</td>
<td>1</td>
<td>27 March 2012</td>
</tr>
<tr>
<td>Questionnaire: Demographic Questionnaire Practice Nurses</td>
<td>1</td>
<td>27 March 2012</td>
</tr>
<tr>
<td>Questionnaire: Demographic Questionnaire MS Specialist Nurses</td>
<td>1</td>
<td>27 March 2012</td>
</tr>
<tr>
<td>Questionnaire: Demographic Questionnaire IAPT Mental Health Practitioners</td>
<td>1</td>
<td>27 March 2012</td>
</tr>
<tr>
<td>Protocol</td>
<td>1</td>
<td>27 March 2012</td>
</tr>
<tr>
<td>Participant Information Sheet: For People with Multiple Sclerosis</td>
<td>1</td>
<td>27 March 2012</td>
</tr>
<tr>
<td>Participant Information Sheet: Participants with Multiple Sclerosis</td>
<td>2</td>
<td>27 March 2012</td>
</tr>
<tr>
<td>Participant Information Sheet: Practice Nurses/MS Specialist Nurses/IAPT Mental Health Practitioners</td>
<td>2</td>
<td>27 March 2012</td>
</tr>
<tr>
<td>Participant Information Sheet: General Practitioners</td>
<td>2</td>
<td>27 March 2012</td>
</tr>
<tr>
<td>Participant Consent Form: Participant with MS - Time 1</td>
<td>1</td>
<td>27 March 2012</td>
</tr>
<tr>
<td>Participant Consent Form: Participant with MS - 6 months</td>
<td>1</td>
<td>27 March 2012</td>
</tr>
<tr>
<td>Participant Consent Form: Participant with MS - 12 months</td>
<td>1</td>
<td>27 March 2012</td>
</tr>
<tr>
<td>Participant Consent Form: Participant with MS</td>
<td>2</td>
<td>27 March 2012</td>
</tr>
<tr>
<td>Participant Consent Form: Health Care Professional</td>
<td>2</td>
<td>27 March 2012</td>
</tr>
<tr>
<td>Participant Consent Form: GP</td>
<td>2</td>
<td>27 March 2012</td>
</tr>
<tr>
<td>Other: Poster</td>
<td>1</td>
<td>27 March 2012</td>
</tr>
<tr>
<td>Letter of invitation to participant</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Letter of invitation to participant</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Letter of invitation to participant</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Letter of invitation to participant</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Letter of invitation to participant</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Letter of invitation to participant</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Letter of invitation to participant</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Letter of invitation to participant</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Letter of invitation to participant</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Letter of invitation to participant</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Letter of invitation to participant</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Letter from Sponsor</td>
<td></td>
<td>23 April 2012</td>
</tr>
<tr>
<td>Investigator CV</td>
<td></td>
<td>26 March 2012</td>
</tr>
<tr>
<td>Investigator CV</td>
<td></td>
<td>21 January 2012</td>
</tr>
<tr>
<td>Investigator CV</td>
<td></td>
<td>27 March 2012</td>
</tr>
<tr>
<td>Investigator CV</td>
<td></td>
<td>26 March 2012</td>
</tr>
<tr>
<td>Interview Schedules/Topic Guides</td>
<td></td>
<td>27 March 2012</td>
</tr>
<tr>
<td>Interview Schedules/Topic Guides</td>
<td></td>
<td>27 March 2012</td>
</tr>
<tr>
<td>Interview Schedules/Topic Guides</td>
<td></td>
<td>27 March 2012</td>
</tr>
<tr>
<td>Interview Schedules/Topic Guides</td>
<td></td>
<td>27 March 2012</td>
</tr>
<tr>
<td>Interview Schedules/Topic Guides</td>
<td></td>
<td>27 March 2012</td>
</tr>
<tr>
<td>Interview Schedules/Topic Guides</td>
<td></td>
<td>27 March 2012</td>
</tr>
<tr>
<td>GP/Consultant Information Sheets</td>
<td>2</td>
<td>27 March 2012</td>
</tr>
</tbody>
</table>
Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document “After ethical review – guidance for researchers” gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

Further information is available at National Research Ethics Service website > After Review

**12/NW/0385** Please quote this number on all correspondence

With the Committee’s best wishes for the success of this project

Yours sincerely

Signed on behalf of
Professor S J Mitchell
Chair

Email: kath.osborne@northwest.nhs.uk
Appendix G: University Ethics Committee approval

Dear [Name],

I write to confirm that we have received all the necessary documentation for this study and can confirm that the University has endorsed the favourable MREC ethical opinion. There is therefore no ethical impediment to the research project proceeding. Our reference for the study is 10099.

Kind regards,

Eliza

Eliza Perrett
Research Ethics Office
Room 2.04
Crimlaw Building
University of Manchester
Oxford Road
Manchester M13 9PL

Please consider the requirements before printing this email.
Appendix H: NHS Research and Development approval
Appendix I-i: GP Practice letter of invitation

GP Practice invitation letter

Dear <Named GP>

Healthcare services for people with Multiple Sclerosis

I am writing to invite you to take part in this study, which aims to investigate healthcare services for people with MS. There is little qualitative research available on the experiences of people with MS of healthcare services, or the experience and treatment of psychological and emotional issues. It is important to study these areas from the perspectives of both healthcare professionals and people with MS. We are therefore proposing a study investigating these issues from both the service user’s perspective and the perspective of healthcare professionals.

This study is based at the National School for Primary Care Research at the University of Manchester. It has been given ethical approval and is currently recruiting.

If you would be willing to assist us, we can aid your practice to:
1) Identify a list of up to 5 patients of any age, gender and ethnicity, with a confirmed MS diagnosis.
2) Prepare information packs and invitation letters so practice staff need only add on names and addresses (so researchers do not have access to patient details).

We would ask that you screen the list of patients to remove anyone you thought it would be inappropriate for us to approach.

We would also like to invite you to participate in this study yourself. Participation involves a qualitative interview lasting 30-40 minutes at a place and time convenient to you. You will be compensated £50 for your time. This interview will let you share your perspectives on current MS services and your experiences of working with people with MS.

Further information on the study is attached and for any queries please contact:

abigail.methley@postgrad.manchester.ac.uk

01612757654

Many thanks for your time,
Yours faithfully,

Abigail Methley
Professor Carolyn Chew-Graham
Appendix I-ii: Participant Information Sheet for GPs

**Participant information sheet- General Practitioners**  
**Exploring perspectives on care for participants with Multiple Sclerosis**  
**Introduction**  
We would like to invite you to take part in this study as you are a GP working within the areas of Bury, Stockport, Trafford or Manchester PCT and we are interested in your experiences of working with people with Multiple Sclerosis. This study will take 30-40 minutes.  
Before you decide if you would like to take part it is important for you to understand why the research is being done and what it will involve. Please take time to read this information sheet carefully and feel free to discuss this with anyone should you wish. The researcher will be available to answer any questions you may have about the study.

**What is the purpose of the study**  
Currently there is little research investigating healthcare services for MS from the perspective of healthcare professionals. Findings in this area may help improve knowledge regarding the experiences of healthcare professionals, which may potentially highlight areas for support.

**Do I have to take part?**  
No. It is completely your choice whether or not to take part. You may withdraw from the study at any time by contacting the researcher on the contact details provided below.

**What will happen to me if I take part?**  
1. You will be asked to identify patients with MS at your clinic and (if you deem them eligible to take part) then to invite them to the study. Invitation letters have been prewritten for this and information packs will be provided.
2. You will be asked to discuss your experiences of working with people with MS for up to an hour with a researcher. This interview will take place at your place of work or another convenient location. Interviews may take place at a University of Manchester building however unfortunately travel expenses cannot be reimbursed.
3. In this interview you will be asked to identify if the Practice Nurse at your Practice is involved in care of people with MS. If so they will be asked to participate in the study at a later date.
4. Upon completion of the interview you will be reimbursed at the rate of £50 per 30-40 minute interview to compensate you for your time.

All interviews will be audio recorded to help with data analysis. However should you wish to participate but not have your interview recorded then handwritten notes may be taken instead. Direct quotes may be published in any publication of results, however these will be anonymous with any identifiable information e.g. names or places removed.

If you wish the researcher will send you a copy of the themes devised from your interview transcript for you to comment on and return.
What are the possible disadvantages and risks of taking part?

It is possible that this interview may be mildly tiring, however this is not expected to be a major issue as you may terminate the interview whenever you so wish.

It is also possible that it may be difficult to fit an interview into a busy schedule, so the researcher will visit you at work or another convenient location to have a minimal impact on your day.

What are the possible benefits of taking part?

Few studies offer the opportunity for healthcare professionals to have their voices heard. This study offers you the opportunity to share your experiences and views with an unbiased researcher who will then aim to present the analysed data to healthcare professionals through publications and presentations. However, there are no direct benefits of this study. No financial reimbursements will be made.

What happens when the research study stops?

You will be sent a summary of the study results in the post. No personal information specific to patients will be presented in the results.

All data has to be stored anonymously by the University for a minimum of 10 years. This data may need to be looked at by monitors and auditors during this time. After this period it will be confidentially destroyed.

What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions. If they are unable to resolve your concern or you wish to make a complaint regarding the study, you can get in touch with Professor Stephen Campbell at the University of Manchester on (0)161 2757655. Alternatively, you could contact a University Research Practice and Governance Co-ordinator on 0161 275 7583 or 0161 275 8093 or by email at research-governance@manchester.ac.uk

Will my taking part in the study be kept confidential?

All your information will be treated and stored confidentially, however if you tell us anything that raises concern about your safety or the safety of anyone else (including children and vulnerable adults), then we will have to take this information to the relevant authority. We will tell you what information we will report and who we will tell about it. None of your colleagues or patients will be informed that you are taking part in this research.

Who is organising and funding the research?

The researcher is completing this study through a studentship provided by the National Institute for Health Research. This study is organised by the University of Manchester.

Who has reviewed this study?

This study has been reviewed by National Research Ethics Committee North West-Greater Manchester Central (number 12/NW/0385) and University of Manchester Research Ethics Committee (number 12080).
Contact details

The lead researcher for this study is Abigail Methley who is based at the University of Manchester and can be contacted on

07950619368

abigail.methley@postgrad.manchester.ac.uk

Primary Care Research Team,
Williamson Building
University of Manchester
Oxford Road, Manchester
M13 9PL

Thank you for taking the time to read this information sheet. Please feel free to discuss any questions you may have with the researcher.
Appendix I-iii: Invitation letter to participants from their GP surgery

Practice headed paper

Patient Invitation Letter
Health care services for Multiple Sclerosis

Dear <Patient name>

This letter is to tell you about a research study which is looking into the views and experiences of people with Multiple Sclerosis. We are helping researchers at the University of Manchester with this study. You are being invited to take part because you are registered at this practice and have a diagnosis of MS.

If you agree to take part the study involves talking to a researcher for up to an hour about your experiences of health care services for MS and any experiences you may have of psychological or emotional issues in MS such as anxiety, depression or low mood.

Further details of the research can be found on the enclosed information sheet. If you would like to take part in this study or have any queries please contact the researcher on the details enclosed and they will be happy to give you more information or answer any questions you may have.

If you decide not to take part then you do not have to give a reason and this will not affect your future care.

Thank you for thinking about helping with this study.

GP Practice
Appendix I-iv: Participant Information Sheet for participants with MS

Exploring perspectives on care for people with Multiple Sclerosis

Version 2 24.05.12

Introduction

We would like to invite you to take part in this study. The study consists of taking part in an interview lasting roughly an hour.

Before you decide if you would like to take part it is important for you to understand why the research is being done and what it will involve. Please take time to read this information sheet carefully and feel free to discuss this with friends or family if you wish. The researcher will be on hand to answer any questions you may have about the study.

What is the purpose of the study?

Currently there is little research investigating the experiences of people with MS of healthcare services for both mental and physical healthcare. Due to the unpredictable nature of MS people may experience psychological and emotional issues such as anxiety or low mood. More information on these topics may improve the relevance and quality of healthcare provided to people with MS.

Do I have to take part?

No. It is completely your choice whether or not to take part. You may withdraw from the study at any time by contacting the researcher on the contact details provided below. If you chose not to participate or withdraw from the study later on then this will have no impact on the care or services you receive.

What will happen to me if I take part?

You will be asked to sign your consent to taking part in this research. You will then be invited to participate in an interview to tell a researcher about your experiences of living with MS, including the psychological and emotional aspects of MS and using healthcare services. This interview will take place at your home or work unless you would prefer to be interviewed at a University building. Should you wish to be interviewed at the University unfortunately we cannot reimburse your travel expenses.

All interviews will be audio recorded to help with data analysis. However should you wish to participate but not have your interview recorded then handwritten notes may be taken instead. Direct quotes may be published in any publication of results, however these will be anonymous with any identifiable information e.g. names or places removed.

You are welcome to have a family member or friend around during the interview if you feel they are needed (e.g. for health or communication reasons), however where
possible we request that the interview is conducted solely with you to allow you to
discuss your experiences.

**What are the possible disadvantages and risks of taking part?**

We are aware that people with MS often experience fatigue (both cognitive and
physical). If you feel fatigued at any point then you can take a break or postpone the
interview until another time. We are also aware that people with MS may have good
days and bad days, and even if an interview is arranged in advance it is possible that
you may not wish to take part on that day. If this is the case then simply phone the
researcher who will postpone the interview until another time. Similarly, if you
experience a relapse and do not wish to participate at this time then please contact the
researcher and the interview can again be postponed.

It is possible that you may find discussing living with MS or any psychological and
emotional issues may be distressing. Should you become distressed and wish to stop
the interview will be stopped immediately. Should you wish to skip any question this is
also not a problem.

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

Many people with MS report that they rarely get the chance to make their voices heard
and share their stories about living with MS and experiences with healthcare services.
This study offers you the opportunity to share your experiences and views with an
unbiased researcher who will then aim to present the analysed data to healthcare
professionals through publications and presentations. However, there are no direct
benefits of this study. You will not receive any financial reward for taking part.

**Will my taking part in the study be kept confidential?**

All your information will be treated and stored confidentially, however if you tell us
anything that raises concern about your safety or the safety of anyone else (including
children and vulnerable adults), then we will have to take this information to the
relevant authority. We will tell you what information we will report and who we will tell
about it.

**What happens when the research study stops?**

You will be sent a summary of the study results in the post. No personal information
specific to patients will be presented in the results. If you take part in the longer study
you will also receive a second feedback sheet after this section has finished.

All data has to be stored anonymously by the University for a minimum of 10 years.
This data may need to be looked at by monitors and auditors during this time. After this
period it will be confidentially destroyed.

**What if there is a problem?**

If you have a concern about any aspect of this study, you should ask to speak to the
researchers who will do their best to answer your questions. If they are unable to
resolve your or you wish to make a complaint regarding the study, you can get in touch
with Professor Stephen Campbell at the University of Manchester on (0)161 2757655. Alternatively, you could contact a University Research Practice and Governance Co-ordinator on 0161 275 7583 or 0161 275 8093 or by email at research-governance@manchester.ac.uk

**Who should I contact for more information about taking part in a research study?**

You can get general advice on participating in research from the Patient Advice and Liaison Service (PALS). Freephone – 0800 015 1462 Email: PALS@manchester.nhs.uk

Patient Advice and Liaison Service Room 3, 1st Floor Higher Openshaw Primary Care Centre Ashton Old Road Openshaw Manchester M11 1JG

**Who is organising and funding the research?**

The researcher is completing this study through a studentship provided by the National Institute for Health Research. This study is organised by the University of Manchester.

**Who has reviewed this study?**

This study has been reviewed by National Research Ethics Committee North West-Greater Manchester Central (number 12/NW/0385) and University of Manchester Research Ethics Committee (number 12080).

**Contact details**

The lead researcher for this study is Abigail Methley who is based at the University of Manchester and can be contacted on

07950619368

abigail.methley@postgrad.manchester.ac.uk

Primary Care Research Team,

Williamson Building

University of Manchester

Oxford Road, Manchester

M13 9PL

Thank you for taking the time to read this information sheet. Please feel free to discuss any questions you may have with the researcher.
Appendix I-v: Topic guide for GPs v1

- Could you tell me about your practice/place of work (Numbers of GPs/nurses/registered patients)
- what sorts of patients do you see on a day to day basis?
- How many patients with MS do you have registered with the practice?
- Perceptions of MS care or experiences
- Could you tell me about your experiences of working with patients with MS,
  1. Do people attend the practice (or do they mostly seek care from specialist clinics?)
  2. What sorts of problems are presented?
  3. Are there any particular challenges that patients with MS have? (particularly explore communication issues)
  4. Are there any issues for you or your practice/service in caring for people with MS?
  5. What sort of communication do you have with specialist care?
  6. Could you tell me about a particular patient/particular challenge?

- Do you come across people with MS who have mental health problems?
- How do they normally present?
- Are there any difficulties in eliciting of depression/anxiety in people with MS?
- How do you manage a patient with MS who is depressed?
- (can you think of a specific patient? That was a good or bad experience
- Do you think that there are any gaps in services for people with MS (and Mental Health problems)?
- How could services improve? What else is needed? What sort of (extra) services (if any) should be commissioned?
Appendix I-vi: Demographic questionnaire for GPs

**Demographic questionnaire for GPs**

1. What is your current age?

   - 20-30 □
   - 31-40 □
   - 41-50 □
   - 51-60 □
   - 61-70 □

2. What is your gender?

   - Male □
   - Female □

3. What is your ethnicity? Please tick below

<table>
<thead>
<tr>
<th>Ethnicity</th>
<th>Please tick</th>
</tr>
</thead>
<tbody>
<tr>
<td>White - English / Welsh / Scottish / Northern Irish / British</td>
<td></td>
</tr>
<tr>
<td>White - Irish</td>
<td></td>
</tr>
<tr>
<td>White - Gypsy or Irish Traveller</td>
<td></td>
</tr>
<tr>
<td>White - Any Other White background</td>
<td></td>
</tr>
<tr>
<td>Mixed / Multiple ethnic group - White and Black Caribbean</td>
<td></td>
</tr>
<tr>
<td>Mixed / Multiple ethnic group - White and Black African</td>
<td></td>
</tr>
<tr>
<td>Mixed / Multiple ethnic group - White and Asian</td>
<td></td>
</tr>
<tr>
<td>Mixed / Multiple ethnic group - Any Other Mixed / multiple ethnic background</td>
<td></td>
</tr>
<tr>
<td>Asian / Asian British – Indian</td>
<td></td>
</tr>
<tr>
<td>Asian / Asian British – Pakistani</td>
<td></td>
</tr>
<tr>
<td>Asian / Asian British – Bangladeshi</td>
<td></td>
</tr>
<tr>
<td>Asian / Asian British – Chinese</td>
<td></td>
</tr>
<tr>
<td>Asian / Asian British - Any other Asian background</td>
<td></td>
</tr>
<tr>
<td>Black / African / Caribbean / Black British – African</td>
<td></td>
</tr>
<tr>
<td>Black / African / Caribbean / Black British – Caribbean</td>
<td></td>
</tr>
<tr>
<td>Black / African / Caribbean / Black British – Any other Black / African / Caribbean background</td>
<td></td>
</tr>
<tr>
<td>Other ethnic group – Arab</td>
<td></td>
</tr>
</tbody>
</table>
4. How long have you been a GP? ____________________

5. Do you work in a training practice?

   Yes [ ]   No [ ]

6. Do you work in a teaching practice?

   Yes [ ]   No [ ]

7. Is your practice area rural, urban, semi-rural or semi-urban? (If unsure please just write the postcode)

   Rural [ ] Semi-rural [ ] Semi-urban [ ] Urban [ ]

8. Are you full time or part time in General Practice?

   FTE [ ] PT [ ]

9. Are you a partner or a salaried doctor?

   Partner [ ] Salaried [ ]

10. Are you a locum doctor, sessional doctor or Registrar?

     Locum [ ] Sessional [ ] Registrar [ ] None of these [ ]

11. What is your Practice Registered list size? ____________________

12. Do you have any special interests?
Appendix I-vii: Letter of invitation to Practice Nurse

Letter of invitation to Practice Nurse

Dear

Healthcare services for people with Multiple Sclerosis

I am writing to invite you to take part in a study investigating healthcare services for people with MS.

Participation involves a qualitative interview lasting 30 minutes at a place and time convenient to you (including telephone interviews). You will be compensated £30 for your time.

This interview will let you share your perspectives on current MS services and your experiences of working with people with MS. You do not need to currently have a patient with MS registered with you in order to participate.

This study is based at the National School for Primary Care Research at the University of Manchester. It has been given ethical approval (12/NW/0385) and is currently recruiting. Further information on the study is enclosed and for any queries please contact:

abigail.methley@postgrad.manchester.ac.uk

07950 619368

Many thanks for your time,
Yours sincerely,

Abigail Methley
Professor Carolyn Chew-Graham
Appendix I-viii: Participant Information Sheet for Practice Nurses

Participant information sheet- Practice Nurses
Exploring perspectives on care for people with Multiple Sclerosis

Introduction
We would like to invite you to take part in this study as you are a Practice Nurse working within the areas of Stockport, Trafford, Bury or Manchester. This study will take a maximum of 30 minutes and will involve talking to a researcher about your experiences of working with people with MS.
Before you decide if you would like to take part it is important for you to understand why the research is being done and what it will involve. Please take time to read this information sheet carefully and feel free to discuss this with anyone should you wish.
The researcher will be on hand to answer any questions you may have about the study.

What is the purpose of the study
Currently there is little research investigating healthcare services for MS from the perspective of healthcare professionals. Findings in this area may help improve knowledge regarding the experiences of healthcare professionals, which may potentially highlight areas for support.

Do I have to take part?
No. It is completely your choice whether or not to take part. You may withdraw from the study at any time by contacting the researcher on the contact details provided below.

What will happen to me if I take part?
If you decide to take part you will be asked to discuss your experiences of working with people with MS for up to 30 minutes with a researcher. This interview will take place at your place of work or another convenient location. Should you wish to be interviewed at a University of Manchester building instead of your place of work this will be possible but we will be unable to reimburse any travel expenses.
You will be compensated for your time at a rate of £30 per 30 minute interview.
All interviews will be audio recorded to help with data analysis. However should you wish to participate but not have your interview recorded then handwritten notes may be taken instead. Direct quotes may be published in any publication of results, however these will be anonymous with any identifiable information e.g. names or places removed.
If you wish the researcher will send you a copy of the themes devised from your interview transcript for you to comment on and return.

What are the possible disadvantages and risks of taking part?
It is possible that this interview may be mildly tiring, however this is not expected to be a major issue as you may terminate the interview whenever you so wish.
It is also possible that it may be difficult to fit an interview into a busy schedule, so the researcher will visit you at work if possible to have a minimal impact on your day.
Interviews can also take place via the telephone.
What are the possible benefits of taking part?

Few studies offer the opportunity for healthcare professionals to have their voices heard. This study offers you the opportunity to share your experiences and views with an unbiased researcher who will then aim to present the analysed data to healthcare professionals through publications and presentations. However, there are no direct benefits of this study.

What happens when the research study stops?

You will be sent a summary of the study results in the post. No personal information specific to patients will be presented in the results.

All data has to be stored anonymously by the University for a minimum of 10 years. This data may need to be looked at by monitors and auditors during this time. After this period it will be confidentially destroyed.

What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions. If they are unable to resolve your concern or you wish to make a complaint regarding the study, you can get in touch with Professor Stephen Campbell at the University of Manchester on (0)161 275 4700. Alternatively, you could contact a University Research Practice and Governance Co-ordinator on 0161 275 7583 or 0161 275 8093 or by email to research-governance@manchester.ac.uk

Will my taking part in the study be kept confidential?

All your information will be treated and stored confidentially. None of your patients will be informed that you are taking part in this research.

Who is organising and funding the research?

The researcher is completing this study through a studentship provided by the National Institute for Health Research. This study is organised by the University of Manchester.

Who has reviewed this study?

This study has been reviewed by National Research Ethics Committee North West-Greater Manchester Central (number 12/NW/0385) and University of Manchester Research Ethics Committee (number 12080).

Contact details

The lead researcher for this study is Abigail Methley who is based at the University of Manchester and can be contacted on

07950619368

abigail.methley@postgrad.manchester.ac.uk

Primary Care Research Team,

Williamson Building

University of Manchester, Oxford Road,

Manchester, M13 9PL

Thank you for taking the time to read this information sheet. Please feel free to discuss any questions you may have with the researcher.
Appendix I-ix: Letter of invitation to Multiple Sclerosis Specialist Nurses

Letter of invitation to Specialist MS Nurse
Exploring perspectives on care for Multiple Sclerosis
Dear Sir/Madam.
I am a PhD student at the University of Manchester currently running a study investigating people’s experiences of health care services for Multiple Sclerosis (MS). Past research suggests that health care for MS is variable across the UK and there is very little research exploring health care professionals’ experiences and views of providing services to people with MS. This study hopes to identify areas and issues that are important to health care professionals working with people with MS. I would therefore be very interested in hearing about your experiences and views of working with people with MS. This study involves taking part in an interview that would last no longer than 45 minutes to discuss your views and experiences. The interview can take place at your place of work or another convenient location, at a time convenient to you. I have enclosed some more information on the study but if you have any questions please feel free to contact me on:
07950619368 or 0161 2757654
abigail.methley@postgrad.manchester.ac.uk
Many thanks
Abigail Methley
Appendix I-x: Topic guide for Practice Nurse v2

Exploring perspectives of care for people with Multiple Sclerosis
Semi-structured interview questions for Practice Nurses

- Could you tell me about your practice/place of work,
  - What sorts of patients do you see?
  - How would you describe your role?
  - Are you aware of how many patients with MS are registered with the practice?

- Could you tell me about your experiences working with patients with MS
  - What needs do you think they have? (and prompt for physical, psychological and social)
  - Are there any particular challenges that patients with MS experience?
  - How do you think you could address these needs?
  - What are roles of the practice and specialist care?
  - Any communication problems?
  - Are there any issues for you or your practice/service in caring for people with MS?
  - Could you tell me about a particular patient/particular challenge?
  - Training needs?

- Do you play a role in managing emotional or psychological problems in people? (in chronic conditions more generally?)
  - Have you come across people with MS who have mental health problems?
  - Can you think of a specific patient?
  - How do they normally present?
  - Are there any difficulties in eliciting of depression/anxiety in people with MS?
  - How might you manage a patient with MS who is depressed or has anxiety?

- Are you aware of the services that are available for people w MH problems?
- Do you think that there are any gaps in services for people with MS (and Mental Health problems)?
- How could services for people with MS improve?
  - What else might be needed?
  - Is there anything you would like to do but don’t at present (and why)?
Appendix I-xi: Topic guide for MS Specialist Nurse v2

- Could you tell me about your job/role?
  - How big is your caseload?
- What sorts of patients do you see?
- Could you tell me about your experiences working with patients with MS
  - Are there any particular challenges that patients with MS have?
  - What needs do you think they have? (and prompt for physical, psychological and social)
- Are there any issues for you or your service in caring for people with MS?
  - Could you tell me about a particular patient/particular challenge?
- Do you come across people with MS who have mental health problems?
- Do you play a role in managing emotional or psychological problems in people? (in chronic conditions more generally?)
  - Can you think of a specific patient?
  - How do they normally present?
  - Are there any difficulties in eliciting of depression/anxiety in people with MS?
  - How might you manage a patient with MS who is depressed or has anxiety?
- Are you aware of the services that are available for people w MH problems?
- Do you think that there are any gaps in services for people with MS (and Mental Health problems)?
- How could services for people with MS improve?
  - What else might be needed?
  - Is there anything you would like to do but don’t at present (and why)?
Appendix I-xii: Demographic questionnaire for Practice Nurses

**Demographic questionnaire for Practice Nurses**

1. What is your current age?
   - 20-30
   - 31-40
   - 41-50
2. What is your gender?
   - Male
   - Female
3. What is your ethnicity? Please tick below

<table>
<thead>
<tr>
<th>Ethnicity</th>
<th>Please tick</th>
</tr>
</thead>
<tbody>
<tr>
<td>White - English / Welsh / Scottish / Northern Irish / British</td>
<td></td>
</tr>
<tr>
<td>White - Irish</td>
<td></td>
</tr>
<tr>
<td>White - Gypsy or Irish Traveller</td>
<td></td>
</tr>
<tr>
<td>White - Any Other White background</td>
<td></td>
</tr>
<tr>
<td>Mixed / Multiple ethnic group - White and Black Caribbean</td>
<td></td>
</tr>
<tr>
<td>Mixed / Multiple ethnic group - White and Black African</td>
<td></td>
</tr>
<tr>
<td>Mixed / Multiple ethnic group - White and Asian</td>
<td></td>
</tr>
<tr>
<td>Mixed / Multiple ethnic group - Any Other Mixed / multiple ethnic background</td>
<td></td>
</tr>
<tr>
<td>Asian / Asian British – Indian</td>
<td></td>
</tr>
<tr>
<td>Asian / Asian British – Pakistani</td>
<td></td>
</tr>
<tr>
<td>Asian / Asian British – Bangladeshi</td>
<td></td>
</tr>
<tr>
<td>Asian / Asian British – Chinese</td>
<td></td>
</tr>
<tr>
<td>Asian / Asian British - Any other Asian background</td>
<td></td>
</tr>
<tr>
<td>Black / African / Caribbean / Black British – African</td>
<td></td>
</tr>
<tr>
<td>Black / African / Caribbean / Black British – Caribbean</td>
<td></td>
</tr>
<tr>
<td>Black / African / Caribbean / Black British – Any other Black / African / Caribbean background</td>
<td></td>
</tr>
<tr>
<td>Other ethnic group – Arab</td>
<td></td>
</tr>
<tr>
<td>Other ethnic group – Any other ethnic group</td>
<td></td>
</tr>
<tr>
<td>Any other</td>
<td></td>
</tr>
<tr>
<td>Not known/not provided</td>
<td></td>
</tr>
</tbody>
</table>
4. How long have you been a qualified nurse?
5. What was your role before starting your current role as a Practice Nurse?
6. How long have you been working as a Practice Nurse?
7. Do you have any special areas of clinical interest or expertise?
Appendix I-xiii: Demographic questionnaire for MS Specialist Nurses

Demographic questionnaire for MS Specialist Nurses

1. What is your current age?
   - 20-30
   - 31-40
   - 41-50
   - 51-60
   - 61-70

2. What is your gender?
   - Male
   - Female

3. What is your ethnicity? Please tick below

<table>
<thead>
<tr>
<th>Ethnicity</th>
<th>Please tick</th>
</tr>
</thead>
<tbody>
<tr>
<td>White - English / Welsh / Scottish / Northern Irish / British</td>
<td></td>
</tr>
<tr>
<td>White - Irish</td>
<td></td>
</tr>
<tr>
<td>White - Gypsy or Irish Traveller</td>
<td></td>
</tr>
<tr>
<td>White - Any Other White background</td>
<td></td>
</tr>
<tr>
<td>Mixed / Multiple ethnic group - White and Black Caribbean</td>
<td></td>
</tr>
<tr>
<td>Mixed / Multiple ethnic group - White and Black African</td>
<td></td>
</tr>
<tr>
<td>Mixed / Multiple ethnic group - White and Asian</td>
<td></td>
</tr>
<tr>
<td>Mixed / Multiple ethnic group - Any Other Mixed / multiple ethnic background</td>
<td></td>
</tr>
<tr>
<td>Asian / Asian British – Indian</td>
<td></td>
</tr>
<tr>
<td>Asian / Asian British – Pakistani</td>
<td></td>
</tr>
<tr>
<td>Asian / Asian British – Bangladeshi</td>
<td></td>
</tr>
<tr>
<td>Asian / Asian British – Chinese</td>
<td></td>
</tr>
<tr>
<td>Asian / Asian British - Any other Asian background</td>
<td></td>
</tr>
<tr>
<td>Black / African / Caribbean / Black British – African</td>
<td></td>
</tr>
<tr>
<td>Black / African / Caribbean / Black British – Caribbean</td>
<td></td>
</tr>
<tr>
<td>Black / African / Caribbean / Black British – Any other Black / African / Caribbean background</td>
<td></td>
</tr>
<tr>
<td>Other ethnic group – Arab</td>
<td></td>
</tr>
<tr>
<td>Other ethnic group – Any other ethnic group</td>
<td></td>
</tr>
<tr>
<td>Any other</td>
<td></td>
</tr>
<tr>
<td>Not known/not provided</td>
<td></td>
</tr>
</tbody>
</table>

4. How long have you been a qualified nurse?
5. What was your main area of work before specialising in MS (if any)?
6. How long have you been an MS specialist nurse?
Exploring perspectives on care for people with Multiple Sclerosis

Dear Sir/ Madam,

I am contacting you regarding your MS Society branch or social group. I am a PhD student at the University of Manchester currently running a study investigating people’s experiences of healthcare services for Multiple Sclerosis. Past research suggests that people with MS can have variable experiences of healthcare services but this has not yet been investigated through talking to people with MS in depth about their experiences. I hope to talk to people with MS about this issue through an interview taking no more than an hour, which would take place at a time and location convenient to each participant. This research will allow an overview of the experiences and explore important issues from the perspective of people with MS, which is currently much needed in healthcare services.

I would be very grateful for the opportunity to discuss my study with the members of your branch/social group. This will allow me to both present my research and also answer any questions/queries that your members may have. No one will be under any pressure to participate and I hope it will be an interesting presentation and discussion for everyone (including those who do not wish to be involved in the research study). In order to have a minimal impact on your planned activities my presentation can be as detailed or brief as is convenient for you.

Please contact me on:
07950619368
abigail.methley@postgrad.manchester.ac.uk

Many thanks
Abigail Methley
Do you or does someone you know have **Multiple Sclerosis**?

We are looking for people to discuss what it is like to live with MS and their experiences of health care.

Male and female participants aged over 18 with any type of MS are invited to participate.

Please contact a researcher on:

- abigail.methley@postgrad.manchester.ac.uk
- 07950619368

for more information,

Thank you

Version 1
27.03.12
Appendix I-xvi: Recruitment advertisement for University intranet

**Volunteers with Multiple Sclerosis required for interview study**

**Description**

Volunteers with Multiple Sclerosis (MS) are required for an interview study investigating living with Multiple Sclerosis and experiences of health care services. Participants must be over 18, have a diagnosis of Multiple Sclerosis, and be fluent English speakers currently living in Manchester or the North West of England. If you agree to participate you will be asked to talk to a researcher for no longer than an hour about your experiences of living with MS, any psychological or emotional issues you may have experienced (e.g. anxiety, low mood) and your experiences/opinions of health care services for people with MS. If you would like to participate or would like further information please contact a researcher on:

abigail.methley@postgrad.manchester.ac.uk
01612757654

Thank you

Ethics committee name: NREC North West- Greater Manchester Central

University ethics committee number and and/or NHS reference number: 12/NW/0385
Appendix I-xvii: Topic guide for people with MS v1

- Please can you tell me about what it is like to live with MS? How does having MS impact on your day to day life?
- Please can you tell me about your experiences with health care services (GP, hospital, other)
- Some people with MS get upset or depressed, could you tell me if you have had any such problems?
- How did you deal with these problems? Did you seek help from your GP? Can you tell me about that?
- How do you think you might deal with these problems if they came up in the future?
Exploring perspectives of care for people with Multiple Sclerosis
Semi-structured interview questions for people with MS (1.5 hr max)

Tell me a bit about yourself (5 mins max)
- Are you currently working?
- Who are you living with at the moment?

Previous consultations
When was your last consultation about your MS?
- Why did you feel the need to attend? What made you go there?
- Who was it with?
- Can you tell me what happened?
- Did it achieve what you hoped it would?

Could you tell me about a recent consultation for your MS that went well and why?
Could you tell me about a recent consultation for your MS that went badly and why?

Who do you go and consult/see about your MS?
- Difference between relapse and remission care

Primary care
- When did you last see your GP?
- What do you think is the role of your GP in MS care/non-MS care?
- How frequently do you visit your GP? More than one GP?
- How easy is it to see your GP?
- Why did you go to see them?

Specialist/secondary care
- What do you think is the role of your MS nurse?
- How frequently do you see your MS nurse?
- How easy is it to see your MS nurse?
- What do you expect from your MS Nurse when you visit her?

- Do you see a neurologist?
- What do you think is the role of your Neurologist?
- How frequently do you see your Neurologist?
- How easy is it to see your Neurologist?
- What do you expect from your Neurologist when you visit them?

Other services
- Do you use any other services for your MS? E.g. continence nurse, OT, physio etc.
- Have you ever consulted an alternative/complementary practitioner? For what? How useful?
- Have you ever made contact w voluntary groups/charities? Explore experience if have; If you don’t use them then why not?
- For all: Frequently/easy to see/expectations

Health care
- “How do you manage your MS?”
- “Do you feel you have received enough information on your condition, treatment and available services?”
- “Do you feel that you work with your health care professionals to make treatment or care decisions?” “Do you feel your HCPs help you to care for your MS on your own (or with the support of family members if appropriate)?”
- Do you plan your care for MS?
- How do you manage your MS?

Psychological care
Some people with MS get upset or have low mood, could you tell me if you have had any such problems?
- How did you cope?
- Did you go to get help, if so from whom?
- What was your experience of getting help?
- How easy was it to get help?
- What help did you need at that time?

What do you think are the strengths and weaknesses of your current healthcare? Is there anything else missing from current services?

(If time) Do you have any other chronic conditions? Do you see a difference in your consultations for this compared to your MS?

(If time) What it is like to live with MS at the moment?
- How does having MS impact on your day to day life?
- How is life different since developing MS?
- How do you feel MS has impacted on your identity/ how you see yourself?
Appendix I-xix: Demographic questionnaire for people with MS

**Demographic questionnaire for People with MS**

1. What is your current age?
   - 18-30
   - 31-40
   - 41-50
   - 51-60
   - 61-70

2. What is your gender?
   - Male
   - Female

3. What is your ethnicity? Please tick the appropriate box below

<table>
<thead>
<tr>
<th>Ethnicity</th>
<th>Please tick</th>
</tr>
</thead>
<tbody>
<tr>
<td>White - English / Welsh / Scottish / Northern Irish / British</td>
<td></td>
</tr>
<tr>
<td>White - Irish</td>
<td></td>
</tr>
<tr>
<td>White - Gypsy or Irish Traveller</td>
<td></td>
</tr>
<tr>
<td>White - Any Other White background</td>
<td></td>
</tr>
<tr>
<td>Mixed / Multiple ethnic group - White and Black Caribbean</td>
<td></td>
</tr>
<tr>
<td>Mixed / Multiple ethnic group - White and Black African</td>
<td></td>
</tr>
<tr>
<td>Mixed / Multiple ethnic group - White and Asian</td>
<td></td>
</tr>
<tr>
<td>Mixed / Multiple ethnic group - Any Other Mixed / multiple ethnic background</td>
<td></td>
</tr>
<tr>
<td>Asian / Asian British – Indian</td>
<td></td>
</tr>
<tr>
<td>Asian / Asian British – Pakistani</td>
<td></td>
</tr>
<tr>
<td>Asian / Asian British – Bangladeshi</td>
<td></td>
</tr>
<tr>
<td>Asian / Asian British – Chinese</td>
<td></td>
</tr>
<tr>
<td>Asian / Asian British - Any other Asian background</td>
<td></td>
</tr>
<tr>
<td>Black / African / Caribbean / Black British – African</td>
<td></td>
</tr>
<tr>
<td>Black / African / Caribbean / Black British – Caribbean</td>
<td></td>
</tr>
<tr>
<td>Black / African / Caribbean / Black British – Any other Black / African / Caribbean background</td>
<td></td>
</tr>
<tr>
<td>Other ethnic group – Arab</td>
<td></td>
</tr>
<tr>
<td>Other ethnic group – Any other ethnic group</td>
<td></td>
</tr>
<tr>
<td>Any other</td>
<td></td>
</tr>
<tr>
<td>Not known/not provided</td>
<td></td>
</tr>
</tbody>
</table>
4. What is your relationship status? Please tick the appropriate box below

<table>
<thead>
<tr>
<th>Relationship status</th>
<th>Please tick</th>
</tr>
</thead>
<tbody>
<tr>
<td>Single</td>
<td></td>
</tr>
<tr>
<td>Married</td>
<td></td>
</tr>
<tr>
<td>Separated, but still legally married</td>
<td></td>
</tr>
<tr>
<td>Divorced</td>
<td></td>
</tr>
<tr>
<td>Widowed</td>
<td></td>
</tr>
<tr>
<td>In a registered same-sex civil partnership</td>
<td></td>
</tr>
<tr>
<td>Separated, but still legally in a same-sex civil partnership</td>
<td></td>
</tr>
<tr>
<td>Formerly in a same-sex civil partnership which is now legally dissolved</td>
<td></td>
</tr>
<tr>
<td>Surviving partner from a same-sex civil partnership</td>
<td></td>
</tr>
</tbody>
</table>

5. What is your highest level of education? Please tick the appropriate box below

<table>
<thead>
<tr>
<th>Highest level of education achieved</th>
<th>Please tick</th>
</tr>
</thead>
<tbody>
<tr>
<td>• 1-4 O levels / CSEs / GCSEs (any grades), Entry Level, Foundation Diploma</td>
<td></td>
</tr>
<tr>
<td>• NVQ Level 1, Foundation GNVQ, Basic Skills</td>
<td></td>
</tr>
<tr>
<td>• 5+ O levels (passes) / CSEs (grade 1) / GCSEs (grades A*-C), School Certificate, 1 A level / 2-3 AS levels / VCEs, Higher Diploma</td>
<td></td>
</tr>
<tr>
<td>• NVQ Level 2, Intermediate GNVQ, City and Guilds Craft, BTEC First / General Diploma, RSA Diploma</td>
<td></td>
</tr>
<tr>
<td>• Apprenticeship</td>
<td></td>
</tr>
<tr>
<td>• 2+ A levels / VCEs, 4+ AS levels, Higher School Certificate, Progression / Advanced Diploma</td>
<td></td>
</tr>
<tr>
<td>• NVQ Level 3, Advanced GNVQ, City and Guilds Advanced Craft, ONC, OND, BTEC National, RSA Advanced Diploma</td>
<td></td>
</tr>
<tr>
<td>• Degree (for example BA, BSc), Higher degree (for example MA, PhD, PGCE)</td>
<td></td>
</tr>
<tr>
<td>• NVQ Level 4-5, HNC, HND, RSA Higher Diploma, BTEC Higher Level</td>
<td></td>
</tr>
<tr>
<td>• Professional qualifications (for example teaching, nursing, accountancy)</td>
<td></td>
</tr>
<tr>
<td>• Other vocational / work-related qualifications</td>
<td></td>
</tr>
<tr>
<td>• Foreign qualifications</td>
<td></td>
</tr>
<tr>
<td>• No qualifications</td>
<td></td>
</tr>
</tbody>
</table>
6. What is your current employment status? Please tick the appropriate box below

<table>
<thead>
<tr>
<th>Employment</th>
<th>Please tick</th>
</tr>
</thead>
<tbody>
<tr>
<td>Employed</td>
<td></td>
</tr>
<tr>
<td>Self-employed</td>
<td></td>
</tr>
<tr>
<td>Out of work and looking for work</td>
<td></td>
</tr>
<tr>
<td>Out of work but not currently looking for work</td>
<td></td>
</tr>
<tr>
<td>A homemaker</td>
<td></td>
</tr>
<tr>
<td>A student</td>
<td></td>
</tr>
<tr>
<td>Retired</td>
<td></td>
</tr>
<tr>
<td>Unable to work</td>
<td></td>
</tr>
</tbody>
</table>
Appendix I-xx: Consent form for GPs

Exploring perspectives of care for people with Multiple Sclerosis
GP consent form Version 3 09.08.13

<table>
<thead>
<tr>
<th>1) I confirm that I have read and understood the information sheet for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.</th>
</tr>
</thead>
<tbody>
<tr>
<td>2) I understand that my participation is voluntary and that I am free to withdraw at any time, without giving a reason, without this impacting on any care I receive or affecting my legal rights.</td>
</tr>
<tr>
<td>---</td>
</tr>
<tr>
<td>3) I understand that I shall be paid at the rate of £50 per 30-40 minute interview to compensate me for my time.</td>
</tr>
<tr>
<td>---</td>
</tr>
<tr>
<td>4) I understand that I shall be interviewed.</td>
</tr>
<tr>
<td>---</td>
</tr>
<tr>
<td>5) I understand that direct quotations shall be made in any publications and that all data will be anonymised.</td>
</tr>
<tr>
<td>---</td>
</tr>
<tr>
<td>5a) I give permission for the interview to be digitally audio recorded.</td>
</tr>
<tr>
<td>---</td>
</tr>
<tr>
<td>OR</td>
</tr>
<tr>
<td>5b) I do not give permission for the interview to be digitally audio recorded, but I give permission for notes to be taken instead.</td>
</tr>
<tr>
<td>---</td>
</tr>
<tr>
<td>6) I understand that any personal information collected during the study will be anonymised and remain confidential.</td>
</tr>
<tr>
<td>---</td>
</tr>
<tr>
<td>7) I agree to anonymised information being stored at the University of Manchester for up to 10 years after the end of this study. I understand that these will be held securely and that access to these by researchers not involved in the current study will be subject to further ethical review.</td>
</tr>
<tr>
<td>---</td>
</tr>
<tr>
<td>8) I understand that data collected during the study may be looked at by individuals from the University of Manchester consortium, from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.</td>
</tr>
<tr>
<td>---</td>
</tr>
<tr>
<td>9) I agree to complete a basic demographic form.</td>
</tr>
<tr>
<td>---</td>
</tr>
<tr>
<td>10) I agree to take part in the above study.</td>
</tr>
<tr>
<td>---</td>
</tr>
<tr>
<td>11) I agree to identify a Practice Nurse in my Practice if they are relevant to the routine care of people with MS.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Name of Participant</th>
<th>Date</th>
<th>Signature</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Name of Researcher</th>
<th>Date</th>
<th>Signature</th>
</tr>
</thead>
</table>

380
Appendix I-xxi: Consent form for Practice Nurses

Exploring perspectives of care for people with Multiple Sclerosis - Practice Nurse consent form V3 01.09.13

1) I confirm that I have read and understood the information sheet for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily

2) I understand that my participation is voluntary and that I am free to withdraw at any time, without giving a reason, without this impacting on any care I receive or affecting my legal rights.

3) I understand that I will be compensated for my time at a rate of £30 per 30 minute interview.

4) I understand that I shall be interviewed

5) I understand that direct quotations shall be made in any publications and that all data will be anonymised

5a) I give permission for the interview to be digitally audio recorded.

OR

5b) I do not give permission for the interview to be digitally audio recorded, but I give permission for notes to be taken instead.

6) I understand that any personal information collected during the study will be anonymised and remain confidential.

7) I agree to anonymised information being stored at the University of Manchester for up to 10 years after the end of this study. I understand that these will be held securely and that access to these by researchers not involved in the current study will be subject to further ethical review.

8) I understand that data collected during the study may be looked at by individuals from the University of Manchester consortium, from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.

9) I agree to complete a basic demographic questionnaire

10) I agree to take part in the above study

Name of Participant Date Signature

Name of Researcher Date Signature
### Exploring perspectives of care for people with Multiple Sclerosis

**Health Care Professional consent form Version 1 27.03.12**

<table>
<thead>
<tr>
<th>Number</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>1)</td>
<td>I confirm that I have read and understood the information sheet for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.</td>
</tr>
<tr>
<td>2)</td>
<td>I understand that my participation is voluntary and that I am free to withdraw at any time, without giving a reason, without this impacting on any care I receive or affecting my legal rights.</td>
</tr>
<tr>
<td>3)</td>
<td>I understand that I shall be interviewed.</td>
</tr>
<tr>
<td>4)</td>
<td>I understand that direct quotations shall be made in any publications and that all data will be anonymised.</td>
</tr>
<tr>
<td>5a)</td>
<td>I give permission for the interview to be digitally <strong>audio</strong> recorded.</td>
</tr>
<tr>
<td>OR</td>
<td></td>
</tr>
<tr>
<td>5b)</td>
<td>I do not give permission for the interview to be digitally <strong>audio</strong> recorded, but I give permission for notes to be taken instead.</td>
</tr>
<tr>
<td>6)</td>
<td>I understand that any personal information collected during the study will be anonymised and remain confidential.</td>
</tr>
<tr>
<td>7)</td>
<td>I agree to anonymised information being stored at the University of Manchester for up to 10 years after the end of this study. I understand that these will be held securely and that access to these by researchers not involved in the current study will be subject to further ethical review.</td>
</tr>
<tr>
<td>8)</td>
<td>I understand that data collected during the study may be looked at by individuals from the University of Manchester consortium, from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.</td>
</tr>
<tr>
<td>9)</td>
<td>I agree to complete a basic demographic questionnaire.</td>
</tr>
<tr>
<td>10)</td>
<td>I agree to take part in the above study.</td>
</tr>
</tbody>
</table>

**Signature Area**

<table>
<thead>
<tr>
<th>Name of Participant</th>
<th>Date</th>
<th>Signature</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Name of Researcher</th>
<th>Date</th>
<th>Signature</th>
</tr>
</thead>
</table>

Please initial box
Exploring perspectives of care for people with Multiple Sclerosis
Participant with MS consent form- Version 2 24.05.12

Please initial box

1) I confirm that I have read and understood the information sheet for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily

2) I understand that my participation is voluntary and that I am free to withdraw at any time, without giving a reason, without this impacting on any care I receive or affecting my legal rights.

3) I understand that I shall be interviewed

4) I understand that direct quotations shall be made in any publications and that all data will be anonymised

5a) I give permission for the interview to be digitally audio recorded.

OR

5b) I do not give permission for the interview to be digitally audio recorded, but I give permission for notes to be taken instead.

6) I understand that any personal information collected during the study will be anonymised and remain confidential. However, if I reveal some information that suggests I pose a threat to myself or others, my GP will be informed.

7) I agree to anonymised information being stored at the University of Manchester for up to 10 years after the end of this study. I understand that these will be held securely and that access to these by researchers not involved in the current study will be subject to further ethical review.

8) I understand that data collected during the study may be looked at by individuals from the University of Manchester consortium, from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.

9) I agree to complete a basic demographic form

10) I agree to take part in the above study

11) I agree to take part in a longitudinal follow up

Name of Participant Date Signature

Name of Researcher Date Signature
### Appendix J: Coding framework for interviews with people with MS ($n = 260$)

<table>
<thead>
<tr>
<th>Theme</th>
<th>Category</th>
<th>Code</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Experience of MS</td>
<td>1a. Impact of symptoms</td>
<td>Intense pain</td>
<td>Experience of pain; could be unexplained or identified as MS</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Numbness</td>
<td>Experience of numbness; could be unexplained or identified as MS</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Spasms</td>
<td>Spasms attributed to MS</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Fatigue</td>
<td>Fatigue attributed to MS</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Vision loss</td>
<td>Vision loss attributed to MS</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Mobility</td>
<td>Mobility impairment due to MS</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Incontinence</td>
<td>Incontinence due to MS</td>
</tr>
<tr>
<td></td>
<td>Impact on family</td>
<td></td>
<td>The physical and psychological impact of MS symptoms on the participant's family</td>
</tr>
<tr>
<td></td>
<td>Impact on career</td>
<td></td>
<td>The physical and psychological impact of MS symptoms on the participant's career</td>
</tr>
<tr>
<td></td>
<td>Impact on social life</td>
<td></td>
<td>The physical and psychological impact of MS symptoms on the participant's social life</td>
</tr>
<tr>
<td></td>
<td>Impact on independence</td>
<td></td>
<td>The physical and psychological impact of MS symptoms on the participant's independence</td>
</tr>
<tr>
<td></td>
<td>Serious condition/state of health</td>
<td></td>
<td>The severity of the participants' condition- often described at initial relapse</td>
</tr>
<tr>
<td></td>
<td>Disclosure- to family/employer/neighbors</td>
<td></td>
<td>Disclosure of MS diagnosis and impact of symptoms to important people</td>
</tr>
<tr>
<td></td>
<td>Lack of knowledge about symptoms</td>
<td></td>
<td>Participant's lack of knowledge about MS symptoms e.g. how MS presents, length of duration</td>
</tr>
<tr>
<td></td>
<td>Burden- one thing after another</td>
<td></td>
<td>Participants' feeling that there was no chance to recover before another physical or psychological stressor occurred</td>
</tr>
<tr>
<td></td>
<td>Frustration</td>
<td></td>
<td>Frustration at the physical and psychological impact of MS symptoms</td>
</tr>
<tr>
<td>Impact on sleep</td>
<td>The impact of physical MS symptoms on participants' ability to sleep</td>
<td></td>
<td></td>
</tr>
<tr>
<td>----------------</td>
<td>--------------------------------------------------------------------</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Limitations of symptoms</td>
<td>How participants described MS as limiting their daily activities</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Downward progression/deterioration</td>
<td>Participants' awareness of their previous deterioration and likely future deterioration of health</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Depression &amp; low mood</td>
<td>Depression and low mood in relation to MS</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Anxiety</td>
<td>Anxiety in relation to MS</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lost important things in life</td>
<td>The sense of loss related to losing important things e.g. relationships, career due to the impact of MS</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Overwhelmed by MS</td>
<td>Feeling psychologically and physically overwhelmed by the lived experience of MS</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Getting your head around it</td>
<td>The initial difficulties and process of learning to understand and accept the reality and future of MS</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Unfair</td>
<td>The sense of unfairness related to the onset of MS</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Confidence</td>
<td>Loss of confidence due to the physical and psychological impact of MS</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Isolation</td>
<td>Isolation due to the physical and psychological impact of MS</td>
<td></td>
<td></td>
</tr>
<tr>
<td>&quot;horror stories&quot;</td>
<td>Participants' experiences of others stories of MS progression, deterioration and poor care experiences which were commonly termed &quot;horror stories&quot;</td>
<td></td>
<td></td>
</tr>
<tr>
<td>social comparison</td>
<td>Comparing oneself to others, either with MS or without MS and the differences perceived</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fear</td>
<td>Fear of future MS relapses and/or deterioration</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Devastating</td>
<td>The feeling of devastation experienced upon diagnosis of MS or appreciation of disability/limitations</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Normalising symptoms</td>
<td>Where participants attributed MS symptoms to more commonly occurring experiences e.g. business, old age: either intentionally or unintentionally (lack of knowledge)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Impact dependent on age</td>
<td>The view of older participants that MS has more of an impact on the young, as it is more unusual to experience ill health at a younger age.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>------------------------</td>
<td>---------------------------------------------------------------------------------------------------------------------------------</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Psychological acceptance</td>
<td>The lengthy process of psychologically accepting the reality and lifelong nature of MS.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Effort</td>
<td>The perception of all activity as effortful.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>It’s not so bad</td>
<td>The perception that MS progression and limitations on life were not as severe as expected.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No cure</td>
<td>The awareness that there is currently no cure of MS.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Living in fear</td>
<td>Living in fear of future MS relapses and/or deterioration of physical health.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Falls</td>
<td>The experience of, or fear of, falls due to impaired balance and mobility.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Comorbidity</td>
<td>The experience of physical health problems in addition to MS: these could be totally discrete or interrelated.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Infection</td>
<td>The experience of frequent infections and subsequent deterioration in health: these could be related to MS (e.g. due to catheterising) or separate.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cognitive symptoms</td>
<td>The experience of cognitive symptoms such as forgetting, word finding difficulties, appraised as being due to MS.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1b. Uncertainty of symptoms and progression</td>
<td>Not being able to plan ahead due to the unpredictability of MS symptoms and impact.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Can’t plan</td>
<td>Not being able to predict the future or future activities due to the unpredictability of MS symptoms and impact.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Can’t predict</td>
<td>Lack of knowledge regarding the cause of depression in MS.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Unsure whether MS is biological cause of depression</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Category</td>
<td>Description</td>
<td></td>
<td></td>
</tr>
<tr>
<td>--------------------------------</td>
<td>-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Understanding/Awareness of symptoms and relapses</td>
<td>Participants' perceived level of understanding and awareness regarding their MS symptoms and relapses. This was described as minimal during the first relapse and increasing over time.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Adjustment takes time</td>
<td>Participants' experiences of psychologically and physically adjusting to life with MS. This was described as requiring a long period of time.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Triggers</td>
<td>Triggers attributed to the onset of MS symptoms and relapses. These could be psychological e.g. bereavement or physical e.g. infection.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Stress</td>
<td>The attribution of stress as the cause of symptoms or relapses. The appraisal of MS as unpredictable, with relapses often occurring unexpectedly after a period of stability.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hits when you don't expect it</td>
<td>Experiences of recovering from MS symptoms spontaneously without medical intervention.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Recovery without intervention</td>
<td>The difference between the symptoms experienced during relapse and participants' residual daily symptoms.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Difference between relapse symptoms and daily symptoms</td>
<td>The experience of MS progression and deterioration in health over time.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Progression over time</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1c. Identity and labels</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Change in how people see you</td>
<td>Participants' awareness that other peoples' perceptions of them altered once they knew they had MS.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Label</td>
<td>Feeling labelled by their MS: this could be negative e.g. stigmatising, or positive e.g. eligible for support, part of a peer group with MS.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Assumptions</td>
<td>Perceived assumptions made by other people once they knew of the participants' MS.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Attitudes</td>
<td>Attitudes that other people held towards someone with MS. Perceived judgement by others about someone with MS. This often differed between people who knew the person with MS previously and those who knew them after, but could sometimes include judgements</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Judgement from others</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Complainer</td>
<td>Perceptions of being viewed as a &quot;complainer&quot;</td>
<td></td>
<td></td>
</tr>
<tr>
<td>------------</td>
<td>---------------------------------------------</td>
<td></td>
<td></td>
</tr>
<tr>
<td>&quot;Most people my age are ill&quot;</td>
<td>The perception by older people with MS that ill health was less unusual in later life than for young people diagnosed with MS</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Diagnosed at &quot;peak of life&quot;</td>
<td>The perception that the onset of MS occurred at the height of personal and professional success</td>
<td></td>
<td></td>
</tr>
<tr>
<td>&quot;I'm not ill&quot;</td>
<td>The perception that MS does not have a daily debilitating impact, and therefore the participant is not an &quot;ill&quot; person</td>
<td></td>
<td></td>
</tr>
<tr>
<td>New identity- not the person I was/self-perceptions</td>
<td>Participants' sense of a change in their identity, often due to the loss of important roles</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Don't want sympathy</td>
<td>Participants' experiences of wanting support but not sympathy or pity</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

| Invisible symptoms | Participants' experiences of wanting support but not sympathy or pity |

| 2. Self-management of symptoms | The perception that professionals cannot understand the experience of symptoms as well as the individual with MS |
| 2a. Expert patients | The perception that participants were better educated and more aware of MS than many health care professionals |
| "I know my body better than professionals" | Participants' self-directed research on MS cause, symptoms, prognosis and treatments |
| "I know MS better than professionals" | Participants' use of online information for their research |
| "Do my own research" | Participants' appraisal of the credibility of (often online) evidence or... |
Tell professional what’s needed
Informed and rational health care user
Strong justification for using services
Expect information from HCP
Prepared for medical decision making in advance
Awareness of options
Proactive
Preferred level of HCP involvement/support
"Trust your own judgement"
Prior knowledge/experience of MS
Person with MS has a professional level of knowledge
Bypass GP e.g. UTI

peer reported experiences
Participants' perceptions that as they were more knowledgeable on MS they directed their health care professionals' actions
Participants' perceptions of themselves as informed and rational users of services
The perception that participants had a strong justification for their use of services e.g. pain, severity of disability
Participants' expectations that health care professionals would provide relevant and understandable information to support their decision making
Participants' expressed the preference to be informed in advance of medical decision making in consultations, so they had time to evaluate and appraise the relevant information
Participants' perceived awareness of potential options and their appraisal of their level of awareness and understanding of these
Participants' reported preference to be proactive in their health care use and decision making
Participants' preference for the level of health care professional involvement: this varied from minimal involvement to proactive outreach involvement
Participants' view that it was important to trust your personal judgement when in conflict with health care professionals
Participants prior knowledge or experience of MS in family, friends, professional role or the media
Participants whose employment as a health care professional resulted in a professional level of MS knowledge
Participants' preference to bypass health care consultations in favour of
<table>
<thead>
<tr>
<th>Management strategies</th>
<th>Collaborative management with GP/HCP</th>
<th>2b. Waiting with symptoms before seeking help</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Participants' experiences of working collaboratively with health care professionals to make decisions and manage their care: these experiences could be positive or negative</td>
<td></td>
</tr>
<tr>
<td>Self-managed medication</td>
<td>Participants' experiences of altering or ceasing medication without professional involved</td>
<td></td>
</tr>
<tr>
<td>Take life as it comes</td>
<td>The need to experience and manage situations as they arise</td>
<td></td>
</tr>
<tr>
<td>Manage symptoms as and when needed</td>
<td>The preference or need to manage symptoms as they arose (pharmacological, psychological or behavioural)</td>
<td></td>
</tr>
<tr>
<td>Increased health activities/decreased unhealthy activities</td>
<td>Participants' experiences of proactively increasing their wellbeing to improve their overall health</td>
<td></td>
</tr>
<tr>
<td>Awareness of body and symptoms as monitoring</td>
<td>Monitoring symptoms by being aware of normal symptoms and sensations within the body, and how and when these changed</td>
<td></td>
</tr>
<tr>
<td>Better to be aware of body than medicated</td>
<td>Participants' preferences to be able to monitor their symptoms rather than remove them, as a method of being aware of their MS through awareness of their body</td>
<td></td>
</tr>
<tr>
<td>Awareness of difference in body-justification for help seeking</td>
<td>Participants' experiences that awareness of big differences in bodily symptoms e.g. pain/numbness were a justification for help seeking</td>
<td></td>
</tr>
<tr>
<td>Unmanageable symptoms e.g. spasms, fatigue</td>
<td>Participants' experiences that some symptoms cannot, or are not, effectively managed</td>
<td></td>
</tr>
<tr>
<td>Get used to symptoms</td>
<td>Participants' experiences that over time you can become &quot;used&quot; to living with some milder MS symptoms</td>
<td></td>
</tr>
<tr>
<td>Variable symptoms</td>
<td>Participants' experiences of the fluctuation in their MS symptoms</td>
<td></td>
</tr>
</tbody>
</table>
Motivation

Participants' belief that motivation was essential to achieve daily and long term goals with MS

Mental attitude (positive)

Participants' belief that positive mental attitude was needed to minimise the impact of MS on life

Don't let MS limit life

Making the proactive design to not let MS limit life

Just keep going/just get on with it/just deal with it

The need to not give up and just keep coping with life with MS

Flexible adaptive strategies

Participants' experience that only flexible and adaptive strategies could manage the unpredictable MS symptoms

Conserve energy

Participants' need to conserve energy to manage fatigue

Know your limits

Participants' need to be aware of the limits of their activity to prevent detrimental impact on health

Family/friends monitoring symptoms and help seeking

The role of family and friends in monitoring symptoms and facilitating help seeking

Normal coping skills don't work

Onset of MS symptoms challenges previously learnt psychological and physical strategies for managing ill health

Not viewing self as a medication user

Participants' perceptions of themselves as not medication users, even where they took pharmacological symptomatic relief

Refusing medication/treatment

Participants' choice and rationale in refusing medication for symptomatic relief or disease modifying treatments

Psychological services

Experience of psychological services including counselling, clinical psychology

Hospital ward

Experiences of inpatient stay

Physiotherapy

Experiences of physiotherapy

Continence team

Experiences of using a continence team

MS diets

Experiences of using diets reported to improve MS

Vitamin B

Experiences of vitamin B reported to improve MS (provided through ...
<table>
<thead>
<tr>
<th>Support from friends &amp; family</th>
<th>The crucial role of family and friends in providing emotional and physical support for MS symptoms</th>
</tr>
</thead>
<tbody>
<tr>
<td>Complementary medicines</td>
<td>Including acupuncture, reiki (not NHS)</td>
</tr>
<tr>
<td>Optician</td>
<td>Experiences of opticians for visual loss</td>
</tr>
<tr>
<td>Steroids</td>
<td>Participants experiences of steroids prescribed for MS relapses: positive and negative</td>
</tr>
<tr>
<td>Prefer commentary to hospital medicine</td>
<td>Preference for complementary medicine over traditional medicine, perception of it being less harmful</td>
</tr>
<tr>
<td>Individual differences</td>
<td>Participants' perceptions of the variety of needs and treatment outcomes for people with MS</td>
</tr>
<tr>
<td>trial &amp; error</td>
<td>Participants' experiences of trialling management strategies to find the most effective approach</td>
</tr>
<tr>
<td>MS Society/MS charities</td>
<td>Participants' experiences of MS charities: positive and negative</td>
</tr>
<tr>
<td>Changing support needs over time</td>
<td>Participants' experiences of changing symptoms and therefore changing support needs over time</td>
</tr>
<tr>
<td>Peers with MS</td>
<td>Participants' experiences of peers with MS: positive and negative</td>
</tr>
<tr>
<td>Proactively preventing low mood thing</td>
<td>Participants' perception that low mood could be prevented with proactive self-management</td>
</tr>
<tr>
<td>HCP dependency as a negative thing</td>
<td>Participants' views that dependency on health care professionals was negative and should be minimised</td>
</tr>
<tr>
<td>Exercise</td>
<td>Participants' use of exercise to maintain wellbeing</td>
</tr>
<tr>
<td>Recovery time from overdoing it</td>
<td>Participants' reported the need for recovery time after over-exertion</td>
</tr>
<tr>
<td>Fine balance between pushing self and pacing</td>
<td>Participants' experiences of finding the balance between not limiting activities and not over-exerting with negative consequences</td>
</tr>
<tr>
<td>Avoid stress</td>
<td>As stress was viewed as a trigger, participants prevented stress where possible to maximise wellbeing</td>
</tr>
<tr>
<td>Topic</td>
<td>Description</td>
</tr>
<tr>
<td>-------------------------------------------</td>
<td>-----------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Catheterising</td>
<td>Catheterising was viewed as a management strategy to increase independence and wellbeing</td>
</tr>
<tr>
<td>Effective s-m = control</td>
<td>Effective self-management was viewed as providing control over MS</td>
</tr>
<tr>
<td>Physical rehabilitation aids</td>
<td>Participants' experiences of physical rehabilitation aids</td>
</tr>
<tr>
<td>Social services</td>
<td>Experiences of social services</td>
</tr>
<tr>
<td>DLA/disability benefit</td>
<td>Experiences of receiving DLA or disability support</td>
</tr>
<tr>
<td>Housekeeping support needed</td>
<td>Participants' need for increased support with housekeeping tasks</td>
</tr>
<tr>
<td>Strategies not always feasible</td>
<td>Participants' frustration with unfeasible recommended strategies</td>
</tr>
<tr>
<td>&quot;Not giving in to MS&quot;</td>
<td>Participants' experience of making the proactive decision to not give in to MS</td>
</tr>
<tr>
<td>Keep busy</td>
<td>Participants' experience of keeping busy and active to maintain their psychological and physical wellbeing</td>
</tr>
<tr>
<td>Eligibility for services/support</td>
<td>Participants' perceptions and experiences of eligibility for support and services to assist with MS</td>
</tr>
</tbody>
</table>

3. Access

3a. Staying in the loop/system

<table>
<thead>
<tr>
<th>Topic</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Attend annual appointments to stay in system</td>
<td>Participants' experiences of attending annual reviews to remain under the care of specialist MS services</td>
</tr>
<tr>
<td>Informed decision to stay in the loop</td>
<td>Participants' informed decision to stay in the loop (engagement with services) or disengage</td>
</tr>
<tr>
<td>Knowledge from being in the loop</td>
<td>Participants' perceptions that being under the care of specialist MS services meant they would be made aware of new treatment developments</td>
</tr>
<tr>
<td>Time taken up by appointments/treatment</td>
<td>The time burden of medical appointments/treatment</td>
</tr>
<tr>
<td>Post code lottery/inequity</td>
<td>Geographical inequity in access to services and treatment</td>
</tr>
</tbody>
</table>
3b. Timeliness and availability

- Emergency access- A & E
- Participants' experiences of emergency service access e.g. A & E
- Private health care
- Participants' experiences of private health care
- Telephoning service & answer machine
- Participants' experiences of contacting professionals via telephone and answer machine: positive and negative
- Speed of access
- Participants' experiences of speed of access to NHS and private hospital services
- Speed of results
- Participants' experiences of speed of results of MS testing
- Local versus distance treatment centres
- Participants' experiences of attending local or distance treatment centres
- Accessibility of different staff
- Participants' experiences of accessing various professionals e.g. GP/ms nurse/consultant neurologist
- Services available/not available through NHS
- Participants' awareness of which services were available through the NHS
- Financial/budget cuts/money saving/politics
- Participants' awareness and experiences of the impact of political, financial and structural changes to NHS and council services on their experiences of care
- Rapid access services
- Participants' experiences of MS rapid access services
- Home visits
- Participants' experiences of home visits when experiencing severe disability
- Employer flexibility
- Impact of employer flexibility on participants' use of services and experiences of living with MS

3c. Navigation

- Accessing neurology department- physical distance
- The physical distance between hospital entrances and neurology departments which is problematic for people with mobility impairment
- Severity of symptoms justifies level of staff
- Participants' perception of the severity of symptoms corresponds to perceived appropriate professional
- Judgement of symptoms as MS or
- Participants' experiences of difficulty and proficiency in correctly
<table>
<thead>
<tr>
<th>not-MS</th>
<th>appraising symptoms as caused by MS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Severity of symptoms justifies help seeking</td>
<td>Participants' appraisal of the severity of symptoms as a justification for help-seeking e.g. pain</td>
</tr>
<tr>
<td>MS nurse as go to person</td>
<td>Perceptions of the MS nurse as the immediate contact for MS symptoms</td>
</tr>
<tr>
<td>GP as go to person</td>
<td>Perceptions of the GP as the immediate contact for MS symptoms</td>
</tr>
<tr>
<td>Recommendations from friends</td>
<td>Participants' experiences of using friends (with MS or not) as a source of information/recommendations for navigating services and health needs</td>
</tr>
<tr>
<td>Consultant as last port of call</td>
<td>Perceptions' of the MS consultant neurologist as the last contact for MS symptoms</td>
</tr>
<tr>
<td>Confusing vs straightforward pathway</td>
<td>Experiences of navigating services for MS: positive and negative</td>
</tr>
<tr>
<td>Choice of HCP depends on major problem</td>
<td>Participants' experiences of selecting appropriate services based on the most important symptom at that point in time</td>
</tr>
<tr>
<td>Difficulty accessing MS nurse</td>
<td>Participants' experiences of difficulty getting through to the MS nurse on the telephone</td>
</tr>
<tr>
<td>Not MS nurse if not active MS</td>
<td>Participants' experience of not viewing the MS nurse as central to their care if they did not perceive their MS as currently active</td>
</tr>
<tr>
<td>Insider HCP knowledge</td>
<td>Participants who were also professionals perceived an &quot;insider&quot; level of knowledge about services</td>
</tr>
<tr>
<td>Knowledge and contacts to navigate system</td>
<td>Participants awareness of their knowledge and contacts to navigate the health care system</td>
</tr>
<tr>
<td>&quot;Play the system&quot;</td>
<td>Participants' experience of having to &quot;play the system&quot; to get the necessary response</td>
</tr>
<tr>
<td>GP doesn't get involved with MS</td>
<td>Participants' experience of the GP not addressing MS symptoms or management</td>
</tr>
<tr>
<td>Self-referral/direct</td>
<td>Participants' experience of self-referral and direct contact with services</td>
</tr>
<tr>
<td>Generic services e.g. continence</td>
<td>Participants' experiences of generic services</td>
</tr>
<tr>
<td>4. Interactions with health care professionals</td>
<td></td>
</tr>
<tr>
<td>-----------------------------------------------</td>
<td></td>
</tr>
<tr>
<td><strong>Justifying use of services</strong></td>
<td>Participants' perceptions of justifying their use of services e.g. severity</td>
</tr>
<tr>
<td>Professional advising on available services</td>
<td>Participants' experiences of professionals advising relevant services and signposting</td>
</tr>
<tr>
<td><strong>Bad experience</strong></td>
<td>Participants' negative experiences of services: commonly at the onset of MS</td>
</tr>
<tr>
<td><strong>Good experience</strong></td>
<td>Participants' positive experiences of services</td>
</tr>
<tr>
<td><strong>Diagnosis</strong></td>
<td>Participants' experiences of diagnosis</td>
</tr>
<tr>
<td><strong>Don't make a big deal out of things-stoic</strong></td>
<td>Participants' perceptions of themselves as stoic, not making a &quot;big deal&quot; of symptoms</td>
</tr>
<tr>
<td><strong>Only go to health care when essential</strong></td>
<td>Participants' perceptions of themselves as only using health care services when essential</td>
</tr>
<tr>
<td><strong>Put you off going back</strong></td>
<td>Negative experiences of health care recursively affecting future service use</td>
</tr>
<tr>
<td><strong>Fluctuating experiences</strong></td>
<td>Experiences of health care that incorporated inconsistently positive and negative experiences of health care</td>
</tr>
<tr>
<td><strong>Time professionals spend with you = value</strong></td>
<td>Participants perceived that time with professionals asked as an indicator of value: positive and negative</td>
</tr>
<tr>
<td><strong>Staff interaction style</strong></td>
<td>Participants' appraisal of professionals' interaction style: positive and negative</td>
</tr>
<tr>
<td>&quot;liking&quot;/disliking staff member professional to professional interaction</td>
<td>Participants' personal responses to individual staff members</td>
</tr>
<tr>
<td><strong>Emotional support</strong></td>
<td>Participants who were health care professionals interacting with other health care professionals</td>
</tr>
<tr>
<td></td>
<td>Participants' experiences of emotional support from health care professional: positive and negative</td>
</tr>
<tr>
<td>4a. Loss of personhood</td>
<td>&quot;You're a number&quot;</td>
</tr>
<tr>
<td>------------------------</td>
<td>------------------</td>
</tr>
<tr>
<td>Discrediting patient lived experience/opinions</td>
<td>Participants' experiences of professionals who discredited their lived experience and opinions</td>
</tr>
<tr>
<td>Superior professional attitude problem</td>
<td>Participants' experiences of professionals who they perceived as having a &quot;superior&quot; attitude</td>
</tr>
<tr>
<td>&quot;All in your head&quot;/&quot;Hypochondriac&quot;</td>
<td>Participants' experiences of stigmatising judgement from professionals and others about the credibility of their symptoms (with implications about their identity)</td>
</tr>
<tr>
<td>&quot;Mad&quot;</td>
<td>Participants' experiences of stigmatising judgement from professionals and others about their psychological wellbeing</td>
</tr>
<tr>
<td>Not/valued as a person</td>
<td>Participants' experiences of not being valued as an individual person</td>
</tr>
<tr>
<td>Bed blocker/outstaying your welcome</td>
<td>Participants' experiences of professionals' judgement of the severity of their symptoms and eligibility for care</td>
</tr>
<tr>
<td>Inensitive interaction</td>
<td>Participants' experiences of intensive interactions with professionals</td>
</tr>
<tr>
<td>Incorrect diagnosis</td>
<td>Participants' experiences of incorrect diagnoses by professionals</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>4b. Professional judgements</th>
<th>Professional missed signs</th>
<th>Participants' experiences of professionals missing signs of MS relapse/progression</th>
</tr>
</thead>
<tbody>
<tr>
<td>Professional knowledge</td>
<td>Participants' experiences of professionals lacking medical knowledge of MS</td>
<td></td>
</tr>
<tr>
<td>Medical advice not fitting with person</td>
<td>Participants' experiences of being given medical advice which did not match their priorities, preferences and interests</td>
<td></td>
</tr>
<tr>
<td>Trust</td>
<td>Participants' experiences of developing trust with professionals: positive and negative</td>
<td></td>
</tr>
<tr>
<td>Alternative explanations</td>
<td>Participants' experiences of professionals investigating alternative causes or explanations: positive and negative</td>
<td></td>
</tr>
<tr>
<td>Topic</td>
<td>Description</td>
<td></td>
</tr>
<tr>
<td>------------------------------------------------------------</td>
<td>---------------------------------------------------------------------------------------------------------------------------------------------</td>
<td></td>
</tr>
<tr>
<td>Identifying cause of symptoms</td>
<td>Participants' experiences of professionals failing to identify the cause of symptoms</td>
<td></td>
</tr>
<tr>
<td>Professional awareness</td>
<td>Participants' experiences and perceptions of professionals' awareness of MS</td>
<td></td>
</tr>
<tr>
<td>Risk taking</td>
<td>Participants' experiences and perceptions of risk taking in medical decision making: positive and negative</td>
<td></td>
</tr>
<tr>
<td>need to &quot;convince&quot; professionals- credibility</td>
<td>Participants' experiences of needing to &quot;convince&quot; professionals of the credibility of their experience and opinion</td>
<td></td>
</tr>
<tr>
<td>&quot;your&quot; normal- not medical normal</td>
<td>Participants' experiences of professionals understanding that their personal norm may not be the same as the norm for people with MS as a group</td>
<td></td>
</tr>
<tr>
<td>Don't listen to you</td>
<td>Participants' experiences of health care professionals not listening to their needs or concerns</td>
<td></td>
</tr>
<tr>
<td>Discharged without proper care</td>
<td>Participants' experiences of being discharged from hospitals or services without perceiving their needs as being met</td>
<td></td>
</tr>
<tr>
<td>Scans/tests</td>
<td>Participants' experiences of the scanning/testing procedures for MS</td>
<td></td>
</tr>
<tr>
<td>Disappointed in system</td>
<td>Participants' experiences of feeling disappointed in health care systems</td>
<td></td>
</tr>
<tr>
<td>Questions unanswered</td>
<td>Participants' experiences of feeling health care professionals did not answer their questions</td>
<td></td>
</tr>
<tr>
<td>Coherence and explanations</td>
<td>Participants' experience of searching for a sense of coherence and a suitable explanation for their symptoms and MS onset</td>
<td></td>
</tr>
<tr>
<td>Hospital incompetence</td>
<td>Participants' negative experiences of hospital inpatient stay</td>
<td></td>
</tr>
<tr>
<td>If you know what it is you can treat it</td>
<td>Participants' perceptions that naming and explaining symptoms was necessary for treatment</td>
<td></td>
</tr>
<tr>
<td>Medication ineffective</td>
<td>Participants' experiences of ineffective medication</td>
<td></td>
</tr>
<tr>
<td>Side effects of medication</td>
<td>Participants' experiences of medication side-effects</td>
<td></td>
</tr>
<tr>
<td>Supportive</td>
<td>Participants' experiences of supportive health care professionals</td>
<td></td>
</tr>
<tr>
<td>Category</td>
<td>Description</td>
<td></td>
</tr>
<tr>
<td>-------------------------------------------</td>
<td>-----------------------------------------------------------------------------</td>
<td></td>
</tr>
<tr>
<td>Helpful</td>
<td>Participants' experiences of helpful health care professionals</td>
<td></td>
</tr>
<tr>
<td>Provision of information &amp; suggestions</td>
<td>Participants' experiences of information and suggestions provided by health care professionals</td>
<td></td>
</tr>
<tr>
<td>Communication style</td>
<td>Participants' experiences of health care professionals' communication style: positive and negative</td>
<td></td>
</tr>
<tr>
<td>Understanding</td>
<td>Participants experiences of feeling understood by their health care professionals: positive and negative</td>
<td></td>
</tr>
<tr>
<td>Professionals don't provide anything useful</td>
<td>Participants' experiences of health care professionals not providing anything useful within consultations</td>
<td></td>
</tr>
<tr>
<td>Compassion/sympathetic/empathic</td>
<td>Participants' experiences of professionals acting in a compassionate, sympathetic or empathic manner: positive and negative</td>
<td></td>
</tr>
<tr>
<td>Social care refusing to do tasks</td>
<td>Participants' experiences of social care not assisting with household tasks</td>
<td></td>
</tr>
<tr>
<td>Need for greater support/care</td>
<td>Participants' experiences of needing greater support and care from health care services</td>
<td></td>
</tr>
<tr>
<td>Time constraints of professional</td>
<td>Participants' experiences and awareness of the time constraints experienced by professionals</td>
<td></td>
</tr>
<tr>
<td>&quot;nothing we can do&quot; response from</td>
<td>Participants' experiences of a &quot;nothing we can do response&quot; from professionals</td>
<td></td>
</tr>
<tr>
<td>professionals</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Disengage with services</td>
<td>Participants' experiences of disengaging with services due to unresponsive care</td>
<td></td>
</tr>
<tr>
<td>Reactive not proactive</td>
<td>Participants' experiences of health care as reactive not proactive, managing symptoms post relapse but not preventing relapses</td>
<td></td>
</tr>
<tr>
<td>5. Continuity of care</td>
<td></td>
<td></td>
</tr>
<tr>
<td>5a. Coordination</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Level of follow up based on need and</td>
<td>Participants' experiences that level of follow up</td>
<td></td>
</tr>
<tr>
<td>symptoms</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Participants' experiences of a professional (commonly a GP or MS nurse) coordinating all other services

Participants' experiences of communication between professionals: positive and negative

Participants' experiences of coordination of services: positive and negative

Participants' perceptions that care should be holistic

Participants' experiences of appointments that were often cancelled with little explanation

Participants' experiences of multiple hospitals with no continuous care

Participants' experiences of in continuous care, with many unconnected service providers

Participants' experiences of neurologists after diagnosis

Participants' experiences of continuous health care professionals after diagnosis: positive and negative

Participants' experiences of annual review: positive and negative

Participants feelings of abandonment when no follow up received from professionals

Participants' perceptions and experiences of continuity allowing professionals to develop an awareness of their personal situation

Participants' perceptions and experiences of continuity allowing professionals to develop an awareness of their past clinical and social history
<table>
<thead>
<tr>
<th>Topic</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Familiarity</td>
<td>Participants' experiences of familiar health care professionals</td>
</tr>
<tr>
<td>Consistency of advice</td>
<td>Participants' experiences of continuity of care affecting consistency of advice: positive and negative</td>
</tr>
<tr>
<td>Lack of continuity disrupts care</td>
<td>Participants' experiences of lack of continuity disrupting care</td>
</tr>
<tr>
<td>Continuity ensures high quality</td>
<td>Participants' experiences of continuity enabling high quality care</td>
</tr>
<tr>
<td>Vulnerability</td>
<td>Participants' experiences of vulnerability where care was not continuous</td>
</tr>
<tr>
<td>Continuity increases sense of control</td>
<td>Participants' experiences of feeling more in control of their MS where care was continuous</td>
</tr>
<tr>
<td>Trust</td>
<td>Participants' experiences of trust in relation to continuity of care</td>
</tr>
<tr>
<td>Difficulties communicating with MS</td>
<td>Participants' experiences of preferring continuity of care due to MS symptoms causing difficulties in communicating</td>
</tr>
<tr>
<td>Continuity allows assessment of severity for individuals</td>
<td>Participants' perception that continuity of care allows professionals to assess individual severity of symptoms and change</td>
</tr>
<tr>
<td>&quot;Keep tabs&quot;- personal responsibility for patient</td>
<td>Participants' perception that relational continuity allowed professionals to have personal responsibility and &quot;keep tabs&quot; on an individual</td>
</tr>
<tr>
<td>Lack of social care continuity</td>
<td>Participants' experiences of poor continuity within social care teams e.g. support workers, health care assistants</td>
</tr>
<tr>
<td>Lack of GP continuity</td>
<td>Participants' experiences of multiple GPs with no continuous care</td>
</tr>
</tbody>
</table>
### Appendix K: Conferences at which I have presented/been accepted to present

<table>
<thead>
<tr>
<th>Conference</th>
<th>Location</th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>NIHR SPCR Trainees event</td>
<td>Oxford</td>
<td>September 2012</td>
</tr>
<tr>
<td>European Committee for Treatment and Research into Multiple Sclerosis</td>
<td>Lyon</td>
<td>October 2012</td>
</tr>
<tr>
<td>SAPC North</td>
<td>Kendal</td>
<td>November 2012</td>
</tr>
<tr>
<td>Primary Care Mental Health</td>
<td>Manchester</td>
<td>March 2013</td>
</tr>
<tr>
<td>SAPC</td>
<td>Nottingham</td>
<td>July 2013</td>
</tr>
<tr>
<td>SAPC North</td>
<td>Kendal</td>
<td>November 2013</td>
</tr>
<tr>
<td>NIHR SPCR Trainees event</td>
<td>Oxford</td>
<td>September 2013</td>
</tr>
<tr>
<td>Keele University qualitative methodology conference</td>
<td>Keele</td>
<td>March 2014</td>
</tr>
<tr>
<td>Primary Care Mental Health</td>
<td>Exeter</td>
<td>March 2014</td>
</tr>
<tr>
<td>Rehabilitation in MS</td>
<td>Brighton</td>
<td>June 2014</td>
</tr>
<tr>
<td>SAPC</td>
<td>Edinburgh</td>
<td>July 2014</td>
</tr>
<tr>
<td>Health Services Research Network</td>
<td>Nottingham</td>
<td>July 2014</td>
</tr>
<tr>
<td>BPS Division of Health Psychology conference</td>
<td>York</td>
<td>September 2014</td>
</tr>
<tr>
<td>NIHR SPCR Trainees event</td>
<td>Oxford</td>
<td>September 2014</td>
</tr>
<tr>
<td>NIHR SPCR Showcase</td>
<td>Oxford</td>
<td>September 2014</td>
</tr>
<tr>
<td>NAPCRG</td>
<td>New York</td>
<td>November 2014</td>
</tr>
<tr>
<td>BPS Division of Clinical Psychology conference</td>
<td>Glasgow</td>
<td>December 2014</td>
</tr>
</tbody>
</table>
### Appendix L: Dissemination plan and future outputs

<table>
<thead>
<tr>
<th>Output</th>
<th>Target audience</th>
<th>Predicted date</th>
</tr>
</thead>
<tbody>
<tr>
<td>Department seminars.</td>
<td>Centre for primary care- Health services researchers and health care professionals</td>
<td>Annually 2011-2014.</td>
</tr>
<tr>
<td>Systematic review publication in the journal Health Expectations.</td>
<td>Health care professionals and health services researchers.</td>
<td>Published in July 2014.</td>
</tr>
<tr>
<td>Lay language presentation of findings and research methods.</td>
<td>Secondary school and college students, as part of my role as a STEM ambassador for the Museum of Science and Industry.</td>
<td>Quarterly 2011 to 2014.</td>
</tr>
<tr>
<td>Invited lay summary of systematic review findings to be published in Way Ahead, an MS Trust publication.</td>
<td>People with MS, carers and health care professionals working with people with MS.</td>
<td>Autumn 2014.</td>
</tr>
<tr>
<td>A presentation of findings was offered to the three MS Society groups who aided in recruitment. I am presenting my findings at one branch’s information day in March 2015. The two other branches reported that a newsletter would be preferable.</td>
<td>People with MS &amp; MS Society.</td>
<td>N/A</td>
</tr>
<tr>
<td>Presentation of findings.</td>
<td>PRIMER, the Centre for Primary Care PPI group who have provided feedback on study design and dissemination of findings.</td>
<td></td>
</tr>
<tr>
<td>Publication of comparisons of search models for qualitative literature.</td>
<td>Health care professionals and health services researchers.</td>
<td>Under review in September 2014.</td>
</tr>
<tr>
<td>Newsletter of study results in lay language.</td>
<td>Study participants, people with MS, MS charities and carer support groups.</td>
<td>Currently I am devising this newsletter in collaboration with my service user representative, to be sent as soon as possible.</td>
</tr>
<tr>
<td>Newsletter of study for health care professionals.</td>
<td>Professionals in primary and secondary care in the North West. This information will also be sent to national charities and organisations to</td>
<td>Before December 2014.</td>
</tr>
<tr>
<td>Activity</td>
<td>Event Description</td>
<td>Date</td>
</tr>
<tr>
<td>-------------------------------------------------------------------------</td>
<td>------------------------------------------------------------------------------------</td>
<td>---------------</td>
</tr>
<tr>
<td>Invited presentation to present study findings.</td>
<td>Annual national MS Nurses meeting in Crewe.</td>
<td>March 2015</td>
</tr>
<tr>
<td>Empirical findings publication 1</td>
<td>Health care professionals and health service researchers.</td>
<td>Before summer 2015</td>
</tr>
<tr>
<td>Empirical findings publication 2.</td>
<td>Health care professionals and health service researchers.</td>
<td>Before summer 2015</td>
</tr>
<tr>
<td>Invited lay summary of empirical findings to be published in Way Ahead,</td>
<td>People with MS, carers and health care professionals working with people with MS.</td>
<td>Summer 2015</td>
</tr>
</tbody>
</table>