Identifying the Unmet Needs in patients with Multiple Sclerosis: developing the LUN-MS questionnaire

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Abstract:

Multiple sclerosis causes gradually worsening physical and cognitive disability. Due to the complex manifestations of this disorder, patients often have a spectrum of needs. There are currently gaps in provisional services to meet physical, psychological and social needs. The LUNS is a 21-item questionnaire which is valid and reliable in assessing the unmet needs in stroke. The present study aimed to develop a modified version (the LUN-MS) and test its reliability and acceptability in MS and identify the most unmet needs. Phase 1 involved triangulation of data from three sources; the literature, a clinician’s survey, and patient-public involvement. A list of 43 MS related needs was constructed and a 46-item LUN-MS questionnaire developed. In Phase 2, 20 MS patients were given the 46-item LUN-MS, and asked to identify 10 needs that were important, and 10 needs that were unmet. This allowed the LUN-MS to be revised to a 29-item questionnaire. In Phase 3, 43 participants were recruited to complete the LUN-MS, MSIS-29 and a satisfaction questionnaire at two time points, two to four weeks apart. The intra-rater reliability of each LUN-MS item was tested (n=25), with all items having a percentage agreement above chance (>50%). 19 items also had a statistically significant kappa agreement (k>0.5, p<0.05). The satisfaction questionnaire confirmed the acceptability of the LUN-MS. Information about treatment and trials and fatigue were identified as the most unmet needs. Qualitative feedback suggested that the LUN-MS needs further adaptations before it can be routinely used. In a future study, the LUN-MS should be modified and re-tested on a larger sample. This tool could then be used to monitor needs in MS, and identify gaps in provisional services. This is the first step to improving the MS service in the UK, leading to an increased quality of life for patients with MS.
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List of abbreviations:

**MS** - Multiple Sclerosis
**CNS** – Central Nervous System
**AI** – Auto-immune
**RRMS** – Relapse-Remitting Multiple Sclerosis
**SPMS**- Secondary Progressive Multiple Sclerosis
**PPMS**- Primary Progressive Multiple Sclerosis
**pwMS** – Patients with Multiple Sclerosis
**DMT** – Disease-Modifying Therapy
**LUNS** – Long-term Unmet Needs in Stroke
**LUN-MS** – Long-term Unmet Needs in Multiple Sclerosis
**HCP** – Health Care Professional
**EDSS** – Expanded Disability Status Scale
**TI** – Timepoint 1
**T2** – Timepoint 2
**NIHR** – National Institute for Health research
**RHH** – Royal Hallamshire Hospital
Multiple sclerosis (MS) is an inflammatory disorder of the central nervous system (CNS) leading to demyelination and variable degrees of axonal degeneration (Gillham 2008). Its aetiology remains elusive, but likely involves the interaction between genetic, environmental and other factors leading to an aberrant autoimmune (AI) attack against the myelin sheath that surrounds central nerve cells. MS is twice as likely to affect females than males and is most commonly diagnosed between the age of 20 and 40 (Rolak & Clinic 2003). The course of MS is variable, with the patchy distribution of demyelination effecting sensory, motor, visual and brainstem pathways to varying degrees in each patient. This results in a broad spectrum of symptoms making MS a highly heterogeneous disorder.

1.1 Classification of MS

When initially diagnosed with MS, approximately 85% of patients experience a biphasic disease course with alternating episodes of neurological disability and recovery. These episodes differ in clinical phenotype, severity and length (Dutta & Trapp 2015). This is called relapse-remitting MS (RRMS). Within 20-25 years of initial diagnosis, 60-70% of patients with RRMS will advance to secondary progressive MS (SPMS). This is associated with progressive neurological decline due to significant axonal loss. Furthermore, 10% of patients are initially diagnosed with primary progressive MS (PPMS) associated with a steady neurological decline from disease onset, without phases of recovery. Despite patients with MS (pwMS) being grouped into these disease subtypes, every patient will experience different disease course, progression, severity and symptoms and as such have a spectrum of different needs at different times.
1.2 Management of MS

Since the immunomodulatory drugs the interferons were used as the first disease modifying therapy (DMT) in MS, focus has been on developing pharmacological interventions to alter the disease course. However, despite research efforts, DMTs are still only proven to be effective in RRMS, and are associated with a number of significant risks, the severity of which directly correlates with the rate of relapse reduction. Because of this, many symptomatic treatments have been developed, targeting common problems such as spasticity and pain. Although these pharmacological advances are unarguably important, the needs of patients must be considered. This is particularly important to ensure the highest possible quality of life, whilst developing effective drug therapies remains problematic.

1.3 Unmet needs in MS

The UK department of health has defined “need” as ‘the requirement of individuals to enable them to achieve, maintain or restore an acceptable level of social independence or quality of life, as defined by the particular care agency or authority’ (The health of the nation: a strategy for health in England 1992). This definition refers to six categories of needs: health care; personal and social care; accommodation and finance; education and employment; leisure; and transport and access. As discussed, pwMS have a broad spectrum of needs, that may change as disease state progresses. Unmet needs in MS are those needs that are not currently being met by the MS service in the UK. It is important to identify unmet needs at an individual, service and population level, in order to appropriately adjust services to improve quality of life.

A previous questionnaire has been designed to assess unmet needs in MS. The Services and needs assessment instrument (SUN) questionnaire, adapted from a previously validated disability needs questionnaire, was developed and tested on patients and carers across five
European countries (Kersten et al. 2000). The needs were categorized into seven broad domains; basic needs, equipment needs, service needs, information needs, financial needs, self-actualization needs and other needs. The author’s concluded that the SUN needs assessment is a valuable tool to identify unmet needs for pwMS and their careers across different countries.

Although both the UK department of health definition and the SUN questionnaire provide a holistic measure of needs, there is currently no suitable tool for pwMS to assign priorities to certain needs at different times. As MS is a highly heterogeneous disorder, associated with a variety of fluctuating symptoms at different disease stages (Disanto et al. 2011), there is the need for a short, easy to complete questionnaire that can be given routinely at appointments. This would allow a quick but accurate assessment of patients’ current needs. The SUN questionnaire is not suitable for this, as it consists of 89 questions in a variety of formats, making it time-consuming and potentially complicated to complete (Kersten et al. 2000).

The present study aims to develop an unmet needs questionnaire suitable for pwMS to routinely complete. This was done by adapting the LUNS (Long-Term Unmet Needs in Stroke) questionnaire, a 22-item tool consisting of questions with yes/no responses (Forster 2013). This has been found to be valid, reliable and acceptable in identifying unmet needs in stroke patients.
1.4 Study Aims:

In order to effectively modify the LUNS stroke questionnaire for pwMS, the study was divided into 3 phases;

**Phase 1:** Develop the Long-Term Unmet needs in MS (LUN-MS) long-list questionnaire; stakeholder consultation and engagement with the literature to develop a list of unmet need in MS.

**Phase 2:** Test the acceptability and content validity of the LUN-MS long-list questionnaire using pwMS and create the shortened LUN-MS questionnaire.

**Phase 3:** Test the reliability and acceptability of the shortened LUN-MS using pwMS and identify the most unmet needs.

Each chapter will;

a) Discuss the methodology from each phase,

b) Present the results,

c) Discuss the impact of the results

1.5 Role of the investigator (CK):

- Analysed data collected from the PPI Lego Serious Play Session (data collection by EH and other researchers)

- Collected and analysed data at the Chair Aerobics focus group

- Developed and analysed the clinician’s survey (this was circulated by EH)

- Developed the long-list of unmet needs and subsequently the LUN-MS longlist questionnaire

- Consented patients and administered all questionnaires in phases 2 & 3

- Conducted think-aloud interviews in Phase 2
- Adapted the LUN-MS long-list questionnaire to produce the shortened LUN-MS
- Analysed all results from phases 1, 2 & 3
2 Chapter 2: Phase 1

2.1 Aims

- To develop a long-list of unmet needs in Multiple Sclerosis
- To use this list to design the LUN-MS long-list questionnaire

In order to establish a long-list of unmet needs, data was triangulated from 3 sources; reviewing the literature, an online clinicians survey, and patient-public involvement (PPI) sessions. This juxtaposition of insider and outsider opinions ensured all potential unmet needs were included in the list. This chapter will present the methods and results from each consultation and discuss their impact on the present study.

2.1.1 Ethics and confidentiality:

Phase 1 was a service evaluation that has received ethical approval from the University of Sheffield due to it being a student project. During the sessions described below, no participant specific information was collected, and no statements were associated with any individuals. This part of the study therefore did not require external ethical approval.
2.2 Reviewing the literature

2.2.1 Methods:

A literature search was performed to identify the unmet needs reported by pwMS in previous studies. The terms ‘unmet needs’ and ‘multiple sclerosis’ were searched in the Pub Med database, and papers ordered by best match. Duplicates were removed, and the remaining titles were screened for eligibility. Those considered irrelevant to the present study were removed, leaving a final list of full text papers to be reviewed.

2.2.2 Results:

The original search found 101 papers relating to the term ‘unmet needs in Multiple Sclerosis’, 37 of which had full paper accessibility. No duplicates were found, but 24 papers were excluded due to title ineligibility. The remaining 13 papers were reviewed. From these a total of 3070 pwMS were surveyed using a variety of techniques including interviews, focus groups and questionnaires. 216 healthcare professionals and 220 significant others/close relatives were also surveyed.

2.2.2.1 Unmet needs in Multiple sclerosis:

In a study in Canada, 22,513 people with confirmed health related impairment completed the participation and activity limitation survey (PALS) (Patten et al. 2012). Health related impairments included both neurological and systemic activity limiting conditions. Of those surveyed, 245 patients had MS. PwMS more frequently reported unmet needs than those with other disability.

An Italian study found that 79% of 1205 pwMS reported at least 1 unmet need (Ponzio et al. 2015). The needs identified were categorised into healthcare needs and social care needs.
Healthcare needs are those that require medical management or a healthcare intervention, and include physical, emotional and behavioural impairments. Social care needs include the support services that individuals with specific limiting impairments may require in order to live as independently as possible with the highest potential quality of life. Ponzio et al. found that 75% of patients reported at least one social care need, compared to 39% who reported at least one healthcare need. Psychological support was the most prevalent healthcare need identified by 27% patients, whilst access to transport was the most important social care need with 41%.

2.2.2.2 Relapsing-Remitting vs. Progressive disease:

A 12 category unmet needs questionnaire completed by 325 pwMS in Ireland found that 52% reported at least 1 unmet need (Lonergan et al. 2015). Of those, 32% mentioned social needs, 30% mentioned physiotherapy, 18% financial support, and 15% employment. On further analysis of needs of patients with different MS subtypes, Lonergan et al. (2015) found that the majority of participants that mentioned physiotherapy were progressive MS patients.

(Heesen et al. 2008) surveyed 166 recently and long-term diagnosed pwMS to address the needs that are considered important in different disease states. Patient recently diagnosed with MS valued gait, vision and speech the most, followed closely by pain. Patients with longer-term disease gave vision followed by gait and speech the highest priority, followed by thinking and memory.

In 2014, a qualitative cross-sectional needs assessment was carried out on 15 patients severely affected by MS (Galushko et al. 2014). Almost all patients reported a reduced network of friends since their diagnosis, with some reporting a painful breakdown of
relationships. Healthcare services contained the greatest portion of unmet needs, with access to services, treatment options (including psychological support), and financial support all reported.

2.2.2.3 Patient vs. healthcare professional opinion:

Rieckmann et al. (2018) used workshops to investigate the prioritisation of unmet needs between pwMS (n=11) and Healthcare professionals (HCPs), (n=10). Both pwMS and HCPs regarded the need for a cure, lack of DMTs for progressive patients, access to appropriate treatment and care, research into quality of life, longer HCP-patient consultations, public awareness and better quality information as important. PwMS regarded management of hidden symptoms and mental health as a priority, whereas HCPs considered symptomatic treatment to be more important. PwMS also reported the need for more personalised information for different disease stages.
2.2.3 Discussion:

The literature suggests that pwMS have more unmet needs that those with other conditions. This highlights the importance of developing a tool specifically for pwMS to identify unmet needs. Both Ponzio et al. (2015) and Lonergan et al. (2015) highlighted that social care needs tend to be more unmet than healthcare needs, whilst Heesen et al. (2008) emphasized the difference in prioritisation of needs in different disease subtypes. As the LUN-MS questionnaire aims to target the full spectrum of needs in MS across all disease states, careful consideration will be taken when choosing the final questions, to ensure there is no bias towards a certain MS subtype. There was also a difference between pwMS and HCP recognition and prioritisation of needs, highlighting the importance of consulting both groups in the following sections (2.3; 2.4).

The literature search contributed to the formation of the long-list of unmet needs. The main important needs identified by patients across the papers reviewed were:

- Psychological support
- Mental health support
- Access to transport
- Physiotherapy
- Financial support
- Employment
- Gait
- Vision
- Speech
- Pain
- Thinking and memory
- Relationships with friends/partners

These were all included in the list of needs constructed.
2.3 Clinician’s survey

2.3.1 Methods:

An online survey was designed and circulated around HCPs at the Royal Hallamshire Hospital (RHH). Participants were asked to identify five important MS related needs that should be met by the MS service, and five needs that they feel are currently unmet by the service (*Appendix A*).

2.3.2 Results:

A total of five HCPs, three neurologists and two MS therapists responded to the survey. 17 important needs (*Figure 1*) and 15 unmet needs (*Figure 2*) were identified. These were grouped into healthcare needs (blue), symptomatic management (pink) and clinical care (green).
Figure 1: Important needs identified by five HCPs, grouped into healthcare needs (blue), symptomatic management (pink) and clinical care (green). The number of participants that mentioned a particular need is shown in brackets.
Figure 2: The unmet needs identified by five clinicians, categorised into healthcare needs (blue), symptomatic management (pink) and clinical care (green). The number of participants who reported a particular need are shown in brackets.
2.3.3 Discussion:

The participants in the clinician’s survey identified healthcare (e.g. DMTs) and symptomatic (e.g. bladder/bowel care) needs as most unmet. This is in contrast to the patient opinion gathered from the literature (2.2) and PPI sessions (2.4). However, because of the small sample size that responded to this survey this needs exploring further before clear conclusions can be made.
2.4 Patient-Public involvement

2.4.1 Introduction:

In order to use patient perspective of MS related needs to guide the questions included in the LUN-MS long-list questionnaire, two different modes of PPI were used; Lego Serious Play and a focus group. The National Institute for Health Research (NIHR) defines public involvement in research as “research being carried out ‘with’ or ‘by’ members of the public rather than ‘to’, ‘about’, or ‘for’ them (NIHR, 2015). In this context the term public includes patients, potential patients, careers and people from involved organisations. The PPI sessions in the present study were part of a broader service evaluation of MS services to explore the need for further research in this area.

PPI in healthcare research has benefits to both the consumer and the researcher (Bagley et al. 2016). Whilst the consumer benefits from the research being conducted, PPI is also in the interest of the research group by ensuring the research is relevant, follows ethical guidelines and meets its overall aim to benefit those effected.

Patient reported outcome measure (PROM) development was traditionally guided by clinical experts within the field of investigation (Staniszewska et al. 2012). However, evidence of discrepancies between the views of patients and HCPs (see 2.2) has shifted the focus towards the use of PPI. Involving patients throughout the present study increased the likelihood of the LUN-MS being found acceptable for unmet need assessment in pwMS.
2.4.2 Lego Serious Play:

2.4.2.1 Methods:

Lego serious play is a method of group communication and problem solving to explore a particular topic, in the case of this study barriers faced in MS. Participants were invited to attend workshop on 27/02/2018 at the Sheffield Institute of Translational Neuroscience (as the investigator (CK) was not present at this session for full description see Appendix B). The workshop aimed to discuss two themes; a nightmare experience with MS and the ideal MS service. Having both patients and relatives/partners present at this session allowed both the patient and career perspective to be explored. (Potemkowski et al. 2017) investigated the difference between prioritisation of needs of pwMS and carers/close relatives and suggested that prioritisation of needs is similar across these groups. This indicates that exploring the carer perspective may also be useful when conducting needs assessment research.

2.4.2.2 Results:

A total of five participants attended the workshop; three pwMS, one partner and one relative. Two people with MS used a wheelchair and one used two crutches. Photographs were taken of each of the models built and matched with the descriptions recorded (Figures 3-8).

Theme 1: ‘Nightmare MS Experience’

One woman described the hurdles she has faced since being diagnosed with MS. She explained how it feels like she is constantly having to jump over hurdles to get the things she needs and is often faced with a ‘brick wall’ (Figure 3). Similarly, another patient used a brick wall to describe the barriers between her and the help that she needs (Figure 4). The final participant described the experience of ‘losing her legs’, and people looking away when she
needed help. Again she built a wall to demonstrate the barriers between patients and the MS service (Figure 5).

Theme 2: ‘Ideal MS service’

One participant described how the information was there, just not all in one place that is easy to access (Figure 6). She suggested that the ideal MS service would have all the information together and provide the means for everyone to understand that information. The other participants also focused on the idea of one point of information. One participant described this by building a MS ‘information hub’ (Figure 7). The final participant highlighted the need for connectivity of all the different MS services, so that different departments are integrated ensuring information, expertise and knowledge is shared between them (Figure 8).
When participants were asked ‘can you make a model that represents a bad experience you have faced within the current MS service?’

**Figure 3:** This model represents the experience of having to overcome hurdles since being diagnosed with MS.

**Figure 4:** This model was used to describe the feeling of a barrier between the patient and the help that they need.

**Figure 5:** This participant built a model to represent a brick wall and people looking away when the patient needed help.
When participants were asked ‘can you make a model that represents what you think would make the ideal MS service?’

**Figure 6:**

![Image](image1.png)

*Figure 6: This figure represents a good MS service, with a bridge giving access to information.*

**Figure 7:**

![Image](image2.png)

*Figure 7: This tower represents an MS hub, where you can access information and MS services all in one place.*

**Figure 8:**

![Image](image3.png)

*Figure 8: This model shows an ideal MS service; a connected service with information being passed between different specialist areas.*
2.4.3 Chair Aerobics:

2.4.3.1 Methods:

Participants were recruited from the MS society Chair Aerobics group on the 27th April 2018 at Burton Street Foundation in Sheffield, and invited to attend a 1.5-hour focus group. Three facilitators attended the session and were introduced by the lead facilitator who had been to a session previously. Attendees were provided with refreshments and split into smaller groups (2-8 per group). Each group was given a poster (Appendix C) explaining the aims of the consultation and presenting the results from the Lego Serious Play session. This PPI session was also split into two main themes; an MS ‘nightmare’ and the ideal MS service. The attendees discussed each theme whilst the researchers made notes. At the end of the session participants were given the researchers contact details so they could be involved in later stages of the study. The notes from all researchers were combined by CK (Appendix D) and grouped in subthemes each representing a specific need. When analysed, these subthemes were grouped into three categories; information, healthcare, and social care, reflecting approaches to needs assessment in the literature (2.2).

2.4.3.2 Results

A total of 27 participants attended the focus group, including pwMS, their partners and/or careers, and two members of the MS society. Most of the patients had advanced MS and used walkers or wheelchairs. The post-analysis subthemes are shown below (Figure 9;10)
Figure 9: The subthemes identified when participants were asked to describe a nightmare MS experience. These subthemes were categorised into information; healthcare or social care needs.
Figure 10: The subthemes highlighted when participants were asked to describe the ideal MS service. These subthemes were categorised into information, healthcare and social care.
2.4.4 Discussion:

The main problem highlighted in Theme 1 in the Lego Serious Play session was the idea of a ‘brick wall’ between pwMS and the MS service. Participants used this metaphor to describe the barriers they’ve faced since being diagnosed. Participants wanted a more connected service, with all needs (healthcare, social care, information) being met in one place. This highlights the importance of developing an unmet needs questionnaire to identify in which areas these barriers are faced.

The results from second PPI session (chair aerobics) had a greater focus on individual needs. The main subthemes identified included access to information, the needs of partners/carers, and the need for extra support services in the psychological and emotional aspects of MS. The needs identified from the patient consultations described were included in the list of needs created.
2.5 Summary

The results from Phase 1 demonstrated a difference in opinions of HCPs and patients. Clinician’s focused on healthcare needs such as access to DMTs and symptomatic management whilst patients focused on psychosocial needs such as information and psychological support. This mirrors the work by Rieckmann et al. (2018) comparing patient and HCP opinions and emphasizes the importance of PPI in clinical research (2.4). This highlights the need for a questionnaire to help pwMS address the needs that are important to them. The list constructed took account of the range of needs identified from all consultations, their importance to pwMS, and the variation in these needs according to the type of MS. This was also influence by supervisors (EH and SN) who have experience caring for people with MS and other progressive debilitating neurological disorders. The final list consisted of 43 needs reflecting the difference areas of biopsychosocial needs in MS (Appendix E).
2.6 Questionnaire design

The long-list of unmet needs was used to develop the LUN-MS long-list questionnaire (Appendix F). (Gillham 2008) outlines that questionnaire design can be divided into two important stages; drafting questions and designing layout. Creating and testing the LUN-MS long-list questionnaire allowed questions to be piloted before the final LUN-MS was developed. Questions were divided into 5 categories; information, clinical care, self-management, physical needs, psychosocial needs and relationships. These categories were chosen after combining the key themes from the literature search, clinician’s survey and PPI sessions. This clustering of similarly themed questions created a logical development order, supporting the focus on each question making the questionnaire easier to complete.

2.6.1 Drafting questions:

An important factor to consider when drafting questions is the language used. Some of the needs included in the LUN-MS long-list were addressed in more than one statement. An example of this is when addressing cognitive decline. Both ‘I feel my cognitive abilities have declined since my diagnosis and would like help with this’ and ‘I would like more support/advice on the cognitive aspects of MS’ were included and compared. Similarly, question format varied between different needs, for example ‘I have problems with x and would like help with this’ and ‘I would like help managing x’, where x represents a specific need. This prevented the questionnaire from becoming monotonous.

2.6.2 Designing layout:

When designing the layout of questionnaires, it is important to consider two factors: how things look and how things work (Gillham 2008). The visual layout of the LUN-MS longlist questionnaire reflected the layout used in the LUNS (Appendix G), which is acceptable in
stroke patients (Forster 2013). An appropriately sized font was used, and some questions had key words bolded in order to focus the question on the need being identified.

The LUN-MS longlist followed a selected responses approach. Next to each statement were two possible responses; ‘important’ and ‘currently a problem’. Participants were asked to select approximately 10 questions that were important, and 10 that were currently a problem. This ensured that both unmet needs, and needs that patients considered important (even if it didn’t currently affect them) were identified. Instructions on completing the questionnaire were written at the top of the page. According to (Gillham 2008) ensuring respondents are clear about the aim of a questionnaire and what is expected of them makes them much more likely to respond appropriately and helpfully. Clarity was particularly important for our cohort of patients, as MS is often associated with cognitive dysfunction (Rao et al., 1991).
3 Chapter 3: Phase 2

3.1 Aims

- To test the acceptability and content validity of the questions included in LUN-MS long-list questionnaire
- To use the think-aloud interview technique to test the acceptability of the language and layout in the LUN-MS long-list questionnaire
- To narrow down the questions in the LUN-MS long-list questionnaire to create a shortened version of the LUN-MS
3.2 Methods

3.2.1 Participants:

The LUN-MS long-list questionnaire developed in Phase 1 was tested on patients with Multiple Sclerosis attending the Neuro Day Care unit or MS clinic at the RHH in Sheffield.

*Inclusion criteria:*

- pwMS diagnosed by a consultant neurologist
- Ability to provide informed written or witnessed consent and completed the questionnaire (as judged by the patients’ nurse, physician or investigator)

*Exclusion criteria:*

- Associated neurological, cardiac, musculoskeletal and pulmonary diseases which could affect unmet needs (as judged by the patients’ nurse, physician or investigator)

To prevent bias and ensure a range of participants took part we allowed witnesses consent, offered help completing the questionnaire and provided the option to complete the questionnaire at home.

3.2.2 Ethics and confidentiality:

Phase 2 and 3 have ethical approval from the HRA, REC and STH research and development department (*Appendix H*). All quotes and data were anonymised. Participants were able to withdraw from the study at any time. If this was within two weeks of data collection they were given the option to have their data removed from study.
3.2.3 Data storage:

Data was stored on UoS encrypted computers and the UoS intranet. Patient identifiable data was stored on paper in a locked filing cabinet in the Sheffield Institute for Translational Neuroscience. This will be destroyed within 12 months of study completion, or earlier if it is no longer required. Other paper data will be stored for a minimum of 5 years. Where patient interviews were conducted (Phase 2) recordings were stored on a password protected encrypted Dictaphone, and all patient identifiable information was removed. These will be destroyed within 12 months of study completion or earlier if it is no longer required.

3.2.4 Recruitment:

Clinicians working within the Neuro Day Care unit and MS clinics were informed of the study protocol and inclusion/exclusion criteria. The clinicians identified potential participants and informed the investigator about any patient expressing an interest to take part in the study. The investigator then approached the patient, further explained the details of the study and provided an information sheet (PIS) and consent form (Appendix I; J). The participant was given time to read the PIS thoroughly and ask the investigator any questions. The investigator (CK) then took consent. Copies of the PIS and consent form were given to the patient and filed in their notes.

3.2.5 Materials:

Participants were provided with a questionnaire pack to be completed (Appendix K). This contained the following:

- Participant information page (to be filled in by the investigator; age, gender, type of MS, EDSS (Expanded Disability Status Scale) and DMT use)
- The LUN-MS long-list questionnaire
- A satisfaction questionnaire

Those wanting to complete the LUN-MS long-list questionnaire at home were given a freepost envelope so they could return it to the investigator. Parking expenses were offered.

3.2.6 Procedure:

The participant was asked to read to and complete the LUN-MS long-list questionnaire. A satisfaction questionnaire was included to assess the overall acceptability of the LUN-MS long-list. Participants were given two optional free text questions to answer:

- Are there any other problems that we have missed?
- Do you have any other comments?

This allowed for any needs that were not identified in Phase 1 to be included in the final version of the LUN-MS. Furthermore, this gave participants the opportunity to comment on the format, style and language of the questions and questionnaire as a whole. The investigator (CK) was available throughout, so any verbal feedback could be given.

3.2.7 Think-aloud Interviews:

As highlighted by Drennan (2003), developing wording that is clear and unambiguous is vital in questionnaire design, as it ensures respondents can successfully answer the question in a way that is meaningful for the research being conducted. The think-aloud technique (also referred to as cognitive interviewing) is often used in healthcare research to test the content validity of questionnaires. It has been shown to reduce non-completion of single questions within a questionnaire by identifying language and styles that may be particularly problematic in the sample population. Five respondents were invited to participate in a think-
aloud interview. While completing the questionnaire these participants were recorded on a password protected encrypted Dictaphone. At the end of the questionnaire, the investigator asked a few questions about its acceptability. The recordings were transcribed and analysed by the investigator (Appendix L).

3.2.8 Data analysis:

The questions in the LUN-MS long-list questionnaire were ordered from the most to least popular, taking into consideration both those marked as important and as unmet. For the needs addressed using two different styles of questions, it was noted which style was preferred by most respondents. The qualitative data from the satisfaction questionnaire was grouped into the two questions asked. Comments from the think-aloud transcriptions were grouped into themes. Specific quotations from the most common/important themes were extracted for further descriptive analysis.
3.3 Results

3.3.1 Participant demographics:

20 pwMS were recruited to complete the LUN-MS long-list questionnaire; 18 with RRMS, one with PPMS and one with SPMS (Table 1). Six of the 20 participants also consented to take part in a think-aloud interview.
# Table 1: Patient demographics for those that completed the LUN-MS long-list questionnaire.

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Participants (n=20)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age</strong></td>
<td></td>
</tr>
<tr>
<td>Mean (SD)</td>
<td>44 (12.3)</td>
</tr>
<tr>
<td>Range</td>
<td>22-68</td>
</tr>
<tr>
<td><strong>Gender</strong></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>14 (70%)</td>
</tr>
<tr>
<td>Male</td>
<td>6 (30%)</td>
</tr>
<tr>
<td><strong>Type of MS</strong></td>
<td></td>
</tr>
<tr>
<td>RRMS</td>
<td>18 (90%)</td>
</tr>
<tr>
<td>PPMS</td>
<td>1 (5%)</td>
</tr>
<tr>
<td>SPMS</td>
<td>1 (5%)</td>
</tr>
<tr>
<td><strong>EDSS</strong></td>
<td></td>
</tr>
<tr>
<td>≤4</td>
<td>13 (65%)</td>
</tr>
<tr>
<td>4&lt; ≤6</td>
<td>2 (10%)</td>
</tr>
<tr>
<td>&gt;6</td>
<td>5 (25%)</td>
</tr>
<tr>
<td><strong>DMT</strong></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>18 (90%)</td>
</tr>
<tr>
<td>No</td>
<td>2 (10%)</td>
</tr>
</tbody>
</table>

SD (Standard Deviation), RRMS (Relapse-Remitting MS), PPMS (Primary Progressive MS), SPMS (Secondary Progressive MS), EDSS (Expanded Disability Status Scale), DMT (Disease Modifying Therapy).
3.3.2 LUN-MS Long-list:

The needs identified as most important and unmet when 20 pwMS completed the LUN-MS long-list are shown (Figure 11;12;13). The number of participants that answered ‘important’ (blue) or ‘currently a problem’ (orange) for each LUN-MS item was calculated, and the questions listed from highest to lowest.
Figure 11: The top 15 LUN-MS items when listed from highest to lowest score. The blue bars represent the number of participants that identified the need as important to them, whilst the orange bar shows the number of participants that identified a need as currently a problem.
Figure 12: The middle 15 LUN-MS items when listed from highest to lowest score. The blue bars represent the number of participants that identified the need as important to them, whilst the orange bar shows the number of participants that identified a need as currently a problem.
Figure 13: The bottom 16 LUN-MS items when listed from highest to lowest score. The blue bars represent the number of participants that identified the need as important to them, whilst the orange bar shows the number of participants that identified a need as currently a problem.
3.3.3 Satisfaction questionnaire:

When asked if there were any needs that had been missed, four participants responded. Four participants also gave additional comments about the questionnaire. The qualitative data is shown in quotations below:

Are there any other problems that we have missed?

‘Other people understanding MS is the most important issue (for me) – e.g. GPs, courts, benefits etc.’

‘I would like to have an explanation of how long a patient is likely to be in hospital for treatment, so I can bring the appropriate drinks/food’

One participant also described the length of time for a definite diagnosis of MS. He described the stress of not knowing what the problem was until his official diagnosis. Another participant highlighted sleep disturbance, which may exacerbate the fatigue she experiences.

Any other comments?

‘A lot of the issues I have experienced have already been resolved’

‘This is not particularly relevant to my current situation as treatment has controlled nearly all my symptoms of MS’

‘It is important to consider different patient types – everyone’s MS is different!’

As there were no significant criticisms or issues raised, the content validity of the LUN-MS long list questionnaire was confirmed.
3.3.4 Think-aloud interviews:

3.3.4.1 Question design:

Six participants, four with RRMS, one with PPMS and one with SPMS completed the LUN-MS long-list while being recorded and asked questions by the investigator (CK). After analysing the transcriptions, the needs that were commonly addressed were grouped into themes. The main themes highlighted were information, cognition and memory, fatigue and sleep, public understanding of MS, and planning for the future. The themes are listed below with comments extracted from the transcribed data (Table 2).
<table>
<thead>
<tr>
<th>Theme</th>
<th>Question</th>
<th>Interview ID</th>
<th>Quotation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Information</td>
<td>I would like more information about exercise, lifestyle or diet</td>
<td>017</td>
<td>“It would be handy having more access to ‘this is a diet that would help you’…..it would be nice if it was more available and clear from the off……. this information is already out there but it would help if it was more easily accessible”</td>
</tr>
<tr>
<td></td>
<td></td>
<td>019</td>
<td>“It is (important)…but only because I’ve taken the initiative myself…I’ve got a dietician….just to alert people that it can make a difference would be a valuable thing for others”</td>
</tr>
<tr>
<td>Cognition and memory</td>
<td>I feel my memory has worsened since being diagnosed with MS</td>
<td>019</td>
<td>“Oh, no doubt…. my memory is shot, my immediate memory is shot………. I think it’s important that I keep my brain going…….”</td>
</tr>
<tr>
<td></td>
<td>I would like more support/advice on the cognitive aspects of MS</td>
<td>020</td>
<td>“obviously the physical is the stuff that you see first and feel first but the cognitive…that’s just in your head you know…so no one else really knows what’s happening…or they hear what you say and just think oh they’ve lost it now”</td>
</tr>
<tr>
<td>Fatigue and sleep</td>
<td>I would like advice on managing fatigue</td>
<td>017</td>
<td>“Managing fatigue would be awesome!”</td>
</tr>
<tr>
<td></td>
<td>When asked: ‘can you think of anything else we might have missed?’</td>
<td>018</td>
<td>“Yeah yeah…just constantly knackered…I don’t think I’ve had energy in the last 5 or 6 years…but I think a lot of that is down to sleep…. sleep is another thing that gets to me but I’m not sure if that’s down to MS or not”</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>“I think that is definitely a huge one the sleep and the fatigue and cognitive problems that develop from that… so maybe they’re all interlinked… so if I looked at dealing with one that may have a positive impact on others… so it’s just finding out which one can be looked at”</td>
</tr>
<tr>
<td>Public understanding of MS</td>
<td>I need some help/advice organising my finances (work/benefits)</td>
<td>017</td>
<td>“It’s not just the benefit system, I think a lot of systems could do with understanding more about MS…. certain places they don’t seem to understand from the point of view that MS is a neurological disease, but it doesn’t mean you’re mental…. but yeah it would be nice if more people understood information especially people like law courts” *</td>
</tr>
<tr>
<td>Planning for the future</td>
<td>I would like advice on planning for the future to ensure my wishes are met</td>
<td>020</td>
<td>“That’s really important I think…. that doesn’t come in to it does it…the assessment is not about that sort of thing at all …social services, health services…yeah that’s a big one isn’t it”</td>
</tr>
</tbody>
</table>

Table 2: The main themes established from the think aloud interviews conducted.

*This particular participant had problems with the court misunderstanding the impact of MS
3.3.4.2 Language and layout:

Participants agreed that the questions were easy to understand and complete. All of the participants agreed that the bolding of key words helped to focus attention on the topic of the question. The main criticism of the LUN-MS long-list questionnaire was the style of answers. Participant 016 said:

“…the questions were all easy to understand but I’m not sure about the most important and currently a problem, I would say that it would be better doing something like a scale you know what I mean?”

All participants agreed that yes/no answers in the final LUN-MS would be much easier to understand and complete.
3.4 Discussion

Phase 2 highlighted the range and importance of MS related needs. This guided the questions to be included in the final LUN-MS. However, the majority of participants (n=18) had RRMS and were on a DMT. These participants therefore had a lower level of disability that those with progressive disease (n=2). This was reflected in the EDSS scores collected with 13 (65%) of participants scoring ≤4 and only 5 (25%) of participants having a score > 6. As highlighted by Disanto et al. (2011) needs in MS vary in different disease states. The needs found to be the least important/unmet were relationships with partners, mobility and skin problems. These are associated with a greater level of disability, and therefore their position as least favourable most likely reflected the disease state of participants. Before discarding the questions, the results from the PPI session and literature review in Phase 1 were consulted. This ensured the LUN-MS questions were not bias towards the needs of patients with milder forms of MS. Again this highlights the importance of triangulating data from multiple sources, to ensure the LUN-MS is suitable for the entire MS population. The results from the think-aloud transcriptions helped confirm the acceptability and content validity of the LUN-MS long list questions. The final LUN-MS questionnaire was designed with 29 questions.
4 Chapter 4: Phase 3

4.1 Aims & Predictions

4.1.1 Aims:

- To assess the reliability and acceptability of the shortened LUN-MS questionnaire
- To identify the most unmet needs in MS patients attending the Royal Hallamshire Hospital in Sheffield
- To identify the differences in unmet needs between patients with different severity of disease

4.1.2 Predictions:

- The LUN-MS will be a reliable tool for identifying unmet needs in pwMS
- The LUN-MS will be acceptable for regular needs assessment in pwMS
- The most common unmet needs will vary depending on disease severity
4.2 Methods

4.2.1 Participants:

In order to test the reliability and acceptability of the 29-item LUN-MS questionnaire, the same recruitment process and inclusion/exclusion criteria as Phase 2 was applied (3.2). Participants that had already taken part in Phase 1 or 2 were not excluded from Phase 3.

4.2.2 Procedure:

Phase 3 of the study was divided into 2 time points, two to four weeks apart, in order to test the reliability of the LUN-MS questionnaire.

**Timepoint 1 (T1)**

The questionnaire booklet provided at T1 *(Appendix M)* contained the following:

- Participant information page (to be filled in by the investigator; age, gender, type of MS, EDSS and DMT use)
- The LUN-MS questionnaire
- Satisfaction questionnaire
- The MSIS-29 (quality of life questionnaire)
- The EQ5D-5L

A random sample of participants were timed whilst completing the LUN-MS. Participants who did not want to complete the LUN-MS questionnaire on the day of recruitment were given the questionnaire and a freepost envelope to complete at home and return to the investigator. Participants were also asked to give details of their home address, and a method of contact (telephone/email), so they could be sent T2 in the post.
Timepoint 2 (T2)

A second questionnaire booklet was posted to the participants 2-4 weeks after completion of T1. This contained a freepost envelope for participants to return the questionnaire to the investigator and a letter reminding participants of the aims of the study (Appendix N). This booklet (Appendix O) contained the following:

- Date to complete questionnaire
- The LUN-MS questionnaire
- The MSIS-29 questionnaire
- Satisfaction questionnaire

Participants were also asked the following questions about their recent physical and emotional health:

*Have you had a relapse or other major problem with your physical or emotional health since the last time you completed this questionnaire?*

*Since you completed this questionnaire in hospital 4 weeks ago do you feel your MS is....?*

*Much worse*

*A little worse*

*About the same*

*A little better*

*Much better*

This ensured that a relapse or other emotional or physical change in the participants’ disease state did not result in a change in needs between the two time points. Those that had relapsed or considered their MS to have changed were excluded from reliability analysis.
4.2.3 Data analysis:

The reliability and acceptability of the LUN-MS was assessed. Two different types of reliability were tested; intra-rater reliability, and internal reliability. Intra-rater reliability measures the homogeneity in ratings given by the same person at the two different time points, and therefore was used to measure test-retest reliability. This was measured by cross tabulation and calculating the percentage agreement for each LUN-MS item (i.e. percentage of participants that answered yes-yes or no-no). This was then statistically analysed by Cohen’s kappa, which is thought to be a more robust measure than percentage agreement as it considers the likelihood of agreement occurring by chance (Cohen 1960). The internal reliability of the LUN-MS and the MSIS-29 at each time point was measured using Cronbach’s alpha. This allowed comparison between the two to see if the LUN-MS was any more or less reliable than the MSIS-29. The acceptability of the LUN-MS was analysed using qualitative feedback from the satisfaction questionnaire at both time points.

In order to assess which needs were considered most unmet by patients at RHH, the LUN-MS items were ordered from highest to lowest by the number of participants that gave a ‘yes’ response. Subsequently, responses were grouped dependent on EDSS score (≤4, 4<≤6, >6) and the questions re-ordered in each group. This allowed the impact of disability status on unmet needs to be assessed.
4.3 Results

4.3.1 Participant demographics:

43 pwMS were recruited; 41 completed T1; 37 with RRMS, three with SPMS and one with PPMS. This included 28 females and 13 males (Table 3). All participants with RRMS were on a DMT. 16 participants were also timed whilst completing the LUN-MS, 13 with RRMS, two with SPMS and one with PPMS. The average time to complete the LUN-MS was 2.47 minutes.
<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Participants (n=41)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td></td>
</tr>
<tr>
<td>Mean (SD)</td>
<td>44 (10.0)</td>
</tr>
<tr>
<td>Range</td>
<td>26-27</td>
</tr>
<tr>
<td>Gender</td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>28 (68%)</td>
</tr>
<tr>
<td>Male</td>
<td>13 (32%)</td>
</tr>
<tr>
<td>Type of MS</td>
<td></td>
</tr>
<tr>
<td>RRMS</td>
<td>37 (90%)</td>
</tr>
<tr>
<td>PPMS</td>
<td>1 (3%)</td>
</tr>
<tr>
<td>SPMS</td>
<td>3 (7%)</td>
</tr>
<tr>
<td>EDSS</td>
<td></td>
</tr>
<tr>
<td>≤&lt;4</td>
<td>18 (44%)</td>
</tr>
<tr>
<td>4&lt; &lt;6</td>
<td>15 (37%)</td>
</tr>
<tr>
<td>&gt;6</td>
<td>8 (19%)</td>
</tr>
<tr>
<td>DMT</td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>37 (90%)</td>
</tr>
<tr>
<td>No</td>
<td>4 (10%)</td>
</tr>
</tbody>
</table>

Table 3: The patient demographics of those that completed the LUN-MS at the first time point (n=41). The EDSS (Expanded Disability Status Scale) scores were split into three groups; ≤<4, 4< ≥6, >6. These scores were chosen as they separate participants into having mild, moderate and severe (the latter of which identified by needed assistance walking) disability. See (Kurtzke 1983) for EDSS. SD (Standard deviation), RRMS (Relapse-Remitting MS), PPMS (Primary Progressive MS), SPMS (Secondary Progressive MS), DMT (Disease Modifying Therapy).
4.3.2 Reliability:

4.3.2.1 Intra-rater reliability

T2 was completed by 26 participants. For test-retest reliability analysis, only participants that completed both time points ($n=25$) were included. One participant who completed T2 did not complete T1 and therefore was excluded. Three participants reported a relapse or change to their physical or mental health since completing T1. Because of this, they were excluded from intra-rater reliability analysis as this may have led to a significant change in their unmet needs since completing T1.

In order to assess the test-retest (intra-rater) reliability of each item in the LUN-MS, data from participants that completed both time points and were not excluded due to relapse ($n=22$) was analysed using cross tabulation (Appendix P). This included 18 patients with RRMS, three with SPMS and one with PPMS. The percentage agreement was then calculated for each item (Figure 14). The baseline was set at 50% agreement as this is the likelihood that the agreement occurred by chance.
Figure 14: The calculated percentage agreement for each question in the LUN-MS questionnaire after cross tabulation analysis was performed (Appendix P). The bars represent the percentage of participants (n=22) that gave the same answer at both time point (i.e. yes-no or no-no). The yellow line shows the baseline 50% agreement, which would occur by chance.
Cohen’s Kappa:

Following this, Cohen’s Kappa was run to statistically demonstrate the reliability of each item in the LUN-MS (Table 4). The confidence interval was set at 95%. Because, in this instance, Cohen’s Kappa was used to assess the reliability of individual LUN-MS items, no Bonferroni correction was necessary. This set the critical p value at 0.05, with items p<0.05 considered statistically significant.
<table>
<thead>
<tr>
<th>Item in LUN-MS</th>
<th>Kappa (k)</th>
<th>p value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Q1</td>
<td>0.23</td>
<td>0.259</td>
</tr>
<tr>
<td>Q2</td>
<td>0.42</td>
<td>0.047 *</td>
</tr>
<tr>
<td>Q3</td>
<td>0.38</td>
<td>0.045 *</td>
</tr>
<tr>
<td>Q4</td>
<td>1.00</td>
<td>0.000 *</td>
</tr>
<tr>
<td>Q5</td>
<td>0.52</td>
<td>0.014 *</td>
</tr>
<tr>
<td>Q6</td>
<td>0.17</td>
<td>0.416</td>
</tr>
<tr>
<td>Q7</td>
<td>0.25</td>
<td>0.905</td>
</tr>
<tr>
<td>Q8</td>
<td>-0.048 **</td>
<td>0.825</td>
</tr>
<tr>
<td>Q9</td>
<td>0.45</td>
<td>0.035 *</td>
</tr>
<tr>
<td>Q10</td>
<td>0.78</td>
<td>0.000 *</td>
</tr>
<tr>
<td>Q11</td>
<td>0.54</td>
<td>0.011 *</td>
</tr>
<tr>
<td>Q12</td>
<td>0.64</td>
<td>0.002 *</td>
</tr>
<tr>
<td>Q13</td>
<td>0.54</td>
<td>0.011 *</td>
</tr>
<tr>
<td>Q14</td>
<td>0.61</td>
<td>0.004 *</td>
</tr>
<tr>
<td>Q15</td>
<td>0.46</td>
<td>0.032 *</td>
</tr>
<tr>
<td>Q16</td>
<td>0.36</td>
<td>0.076</td>
</tr>
<tr>
<td>Q17</td>
<td>0.64</td>
<td>0.003 *</td>
</tr>
<tr>
<td>Q18</td>
<td>0.70</td>
<td>0.001 *</td>
</tr>
<tr>
<td>Q19</td>
<td>0.22</td>
<td>0.294</td>
</tr>
<tr>
<td>Q20</td>
<td>0.80</td>
<td>0.000 *</td>
</tr>
<tr>
<td>Q21</td>
<td>0.14</td>
<td>0.512</td>
</tr>
<tr>
<td>Q22</td>
<td>0.40</td>
<td>0.062</td>
</tr>
<tr>
<td>Q23</td>
<td>0.67</td>
<td>0.001 *</td>
</tr>
<tr>
<td>Q24</td>
<td>0.55</td>
<td>0.010 *</td>
</tr>
<tr>
<td>Q25</td>
<td>0.52</td>
<td>0.014 *</td>
</tr>
<tr>
<td>Q26</td>
<td>0.49</td>
<td>0.018 *</td>
</tr>
<tr>
<td>Q27</td>
<td>0.23</td>
<td>0.285</td>
</tr>
<tr>
<td>Q28</td>
<td>0.22</td>
<td>0.294</td>
</tr>
<tr>
<td>Q29</td>
<td>0.49</td>
<td>0.018 *</td>
</tr>
</tbody>
</table>

Table 4: The kappa (k) and significance values (P) for each question at the two time points after Cohen’s Kappa was performed (n=22). A 95% confidence interval was set, making the critical P value 0.05 and therefore values <0.05 were considered statistically significant.

*statistical significant values (p<0.05); **The reasons for the negative kappa value found in this question will be discussed in section 4.4.1

Values of Cohen’s kappa range from -1 to +1 with +1 being a perfect agreement (e.g. Q4). Cohen suggested that value ≤0 demonstrate a less than chance agreement (no agreement), 0.010-0.20 slight, 0.21-0.40 fair, 0.41- 0.60 moderate, 0.60-0.80 substantial and 0.80 -1.0 as almost perfect (Hallgren 2012), (Cohen 1960).
4.3.2.2 Internal reliability:

Cronbach’s alpha was performed on both the LUN-MS and the MSIS-29 at both time points (Table 5). This allowed comparisons between the internal reliability of the MSIS-29 and the LUN-MS.
<table>
<thead>
<tr>
<th>Questionnaire</th>
<th>$\alpha$ - T1 (n=41)</th>
<th>$\alpha$ - T2 (n=26)</th>
</tr>
</thead>
<tbody>
<tr>
<td>LUN-MS</td>
<td>0.86</td>
<td>0.90</td>
</tr>
<tr>
<td>MSIS-29</td>
<td>0.95</td>
<td>0.94</td>
</tr>
</tbody>
</table>

*Table 5: Comparison of the Cronbach’s alpha values for the MSIS-29 and the LUN-MS at the test (n=41) and retest (n=26) times.*
An α value of ≥ 0.90 is considered excellent, and a value of 0.90 > α ≥ 0.80 is considered good (Cronbach 1951). The MSIS-29 had excellent internal reliability at both time points. The LUN-MS had good reliability at T1, and excellent reliability at T2.

4.3.3 Acceptability:

The results from the satisfaction questionnaire from all participants that completed at least one time point; T1 (n=41), T2 (n=26) were included in the acceptability analysis. This avoided the bias that would have been associated with only including individuals who chose to complete the second questionnaire, as they are most likely to have had a more positive response.

The acceptability of the LUN-MS was measured using a 5-point Likert scale; from Strongly Agree (1) to Strongly Disagree (5). The number of participants that gave each response is shown below (Figures 15-18).
Figure 15: The results from the satisfaction questionnaire at T1 (n=41). Responses to each question were given on a 5-point Likert scale, ranging from strongly disagree (light blue) to strongly agree (dark blue). As demonstrated, the majority of participants answered agree (yellow) or strongly agree (light blue) across all questions.

Figure 16: The results from the final question in the satisfaction questionnaire at T1 (n=41), assessing the acceptability of the length of the LUN-MS. As demonstrated, 100% of participants said the questionnaire length was 'about right'.

Figure 16: The results from the final question in the satisfaction questionnaire at T1 (n=41), assessing the acceptability of the length of the LUN-MS. As demonstrated, 100% of participants said the questionnaire length was 'about right'.
Figure 17: The results from the satisfaction questionnaire at T2 (n=26). Responses to each question were given on a 5-point Likert scale, ranging from strongly disagree (light blue) to strongly agree (dark blue). As demonstrated, the majority of participants answered agree (yellow) or strongly agree (blue) across all questions. No participants answered 'strongly disagree' to any of the questions at this time point.

Figure 18: The results from the final question in the satisfaction questionnaire at T2 (n=26), assessing the acceptability of the length of the LUN-MS. As demonstrated, 24 participants (92%) said the questionnaire was 'about right', while 2 participants (8%) said it was too long.
Participants were also asked to identify if there were any problems that had been missed, and for any other comments. The qualitative data from both time points was grouped together for analysis and replicates excluded (i.e. same participant making same comment). Two needs were identified as having been missed; concentration and sensory symptoms. The main comment highlighted was the limitations of having a yes/no selected response.

*Are there any other problems that we have missed?*

‘*Concentration levels being affected*’

‘*Questions about sensory symptoms, including numbness, loss of sensation, heightened sensation e.g. burning/neuropathic pain*’

*Any other comments?*

‘*Although I’ve ticket no to some questions I do have these problems but feel I have enough information or that they are already appropriately managed*’

‘*The questions are more suited to those newly diagnosed*’

‘*Some of the questions related to me but I am already receiving support so the ‘and I need some help with this’ was not relevant to me*’

‘*Most issues are not simply covered by yes/no answers, but I appreciate that this is the only way this kind of research is possible*’

‘*I suffer a lot of the symptoms in this questionnaire, but I ticket no because I already have help with them*’
4.3.4 Unmet needs:

In order to identify the most unmet needs identified in the patient cohort recruited (n=41), the number of participants that answered ‘yes’ to each item was calculated and questions were ordered from highest to lowest (Figures 19; 20). 34 (83%) of the participants identified information about treatment and trials as an unmet need. This was followed closely by information about extra support services, and management of fatigue, both of which 31 (76%) of the participants identified as unmet (Figure 19). Problems with eating and drinking was identified as the least unmet need, with only 2 (5%) of participants giving a ‘yes’ response followed closely by problems with speech which 4 (10%) of the participants identified as unmet (Figure 20).
Figure 19: The LUN-MS items that 15 or more participants (n=41) identified as unmet (i.e. gave a 'yes' response). As demonstrated, information about treatment or trials was considered unmet by the largest number of participants (n=34 (83%)) followed by fatigue and extra support services (n=31 (76%).)
Figure 20: The LUN-MS items that 15 or less participants (n=41) identified as unmet (i.e. gave a 'yes' response). As demonstrated, problems eating and drinking was considered unmet by the least number of participants (n=2 (5%)) followed by speaking (n=4 (10%)).
Unmet needs and EDSS:

Participants were further grouped dependant on their EDSS score; \( \leq 4 \) (n=18), \( 4 < \leq 6 \) (n=15), >6 (n=8) in order to establish any differences in unmet needs in different disease severities. Again, the sum of the score for each item was calculated, and questions were ordered from highest to lowest. Participants with an EDSS of \( \leq 4 \) (‘mild’ MS) considered information about treatment and trials as most unmet, followed by information about extra support services and fatigue. Similarly, participants with an EDSS of \( 4 < \leq 6 \) (‘moderate’ MS) rated information about treatment and trials, followed by fatigue and what to do if they experience a new symptom or problem, as the most unmet. Seven out of the eight participants with an EDSS >6 considered information about extra support services to be unmet, following by pain (six participants) and fatigue \( \text{(Appendix Q)} \).
4.4 Discussion

4.4.1 Reliability:

The results from the percentage agreement analysis of each item found that all questions had an agreement above that of chance (50%). Furthermore, 19 out of the 29 questions (66%) had a statistically significant kappa value (p<0.05). Figure 7 demonstrates that Q4 (100%) and Q10 (95%) had the highest percentage agreement. Cohen’s kappa statistically confirmed this with values of 1.0 (p<0.001) and 0.78 (p<0.001) respectively, demonstrating a strong significance (Table 4). This suggests that these two questions were the most reliable in the LUN-MS. Question 4 addresses the need for information about MS and pregnancy/family planning, and therefore this highly significant result is likely as this question addresses a need that generally remains static over a short time period. Question 10 addresses problems speaking, again addressing a very clear need that would be interpreted similarly between participants.

In contrast, Q21 and Q6 were found to have the lowest percentage agreement, with 59% and 65% respectively (kappa values found 0.14 and 0.17, p>0.05). Question 21 addresses low mood. Mood can fluctuate significantly day-to-day due to a variety of individual circumstances, some of which may not be MS related. The definition of ‘low mood’ may also differ between individuals, making this question potentially hard for participants to interpret. Conversely, the low reliability of Question 6, which addresses difficulty walking, is more surprising as participants that reported a relapse since T1 were excluded from reliability analysis. However, difficulty walking can be affected by a lot of other MS related symptoms such as pain and fatigue. Furthermore, temperature fluctuations can influence the severity of MS symptoms, with fatigue and walking being identified as the most effected (Petrilli et al. 2004). The latter may have particularly influenced this study as the UK temperatures have risen this summer, especially between the months of April and July when data collection took
place. This may demonstrate that even environmental factors can influence needs, further emphasising the importance of regular needs assessment. These factors may therefore have changed participants’ perception of this need when answering the questions at each time point, leading to the lower reliability found. However, caution is needed when interpreting the results from the present study due to the small sample size. A larger sample size would be needed before definitive conclusions about the reliability of these questions can be drawn.

An interesting finding from the reliability analysis was comparison of the percentage agreement and kappa value for Q8 (*I have problems eating and drinking and need some help with this*). Whilst the percentage agreement for this question was high (91%), the kappa value was -0.048 (P=0.825). A negative kappa value implies that the data from the two time points for this question agree less than would be expected by chance (Cohen 1960). This is in direct contrast to the high percentage agreement demonstrated. However, as none of the 22 participants answered yes-yes (*Table 6*), this highlights a limitation of using and interpreting the kappa statistic. Kappa depends on the true proportion of subjects in each category, and therefore is greatest when the proportion is 0.5 (Cohen 1960). This means that unless the agreement is perfect, then one category being much larger than the other (in this case no-no >> yes-yes) will result in a very small kappa value irrespective of the degree of agreement.

Analysis of the internal reliability (Cronbach’s alpha) of the LUN-MS and MSIS-29 at both time points demonstrated that both questionnaires have good to excellent internal reliability. This is used to measure of the overall reliability of the LUN-MS in addressing its aims; to identify unmet needs in MS. This demonstrates that the LUN-MS is just as reliable as the MSIS-29, which a well-recognised tool in MS research.
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<tr>
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Table 6: The number of participants (n=22) that gave each combination of responses across the two time points to question 8 in the LUN-MS questionnaire. The rows represent Timepoint 1 and the columns represent Timepoint 2. 20 participants answered no at both time points, whilst zero participants answered yes at both time points.
4.4.2 Acceptability and Functionality:

The acceptability of the questions included in the final LUN-MS and the use of the questionnaire in clinical practice was assessed using a 5-point Likert Scale. When asked if they would be happy to complete this questionnaire again as part of a research study, 33 (81%) and 18 (72%) participants at the two time points respectively answered agree or strongly agree. When asked if they would be happy to use this questionnaire as part of a routine MS clinic appointment, 31 (76%) and 16 (61%) participants respectively agreed or strongly agreed. Furthermore, the majority of participants (100% at T1 and 92% at T2) considering the length of the questionnaire ‘about right’, taking roughly 2-3 minutes. This suggests that the LUN-MS questionnaire would be suitable for regular assessment of unmet needs in MS. In contrast, the previously designed SUN questionnaire was too time consuming to be used to continuously monitor needs (Kersten et al. 2000).

4.4.3 Additional Needs:

Participants were also asked if the survey covered all their MS related needs. At T1 69% agreed or strongly agreed that the LUN-MS covered all their needs, and at T2 this dropped slightly to 64%. When participants were given the option to expand on this, two extra needs were reported; difficulty concentrating and sensory symptoms such as tingling and numbness. These are both often reported in pwMS (Markowitz C.E. 2013), and therefore should be included in the LUN-MS questionnaire.

4.4.4 Most unmet needs:

The present study identified information (specifically about treatment and trials or extra support services) and ‘invisible’ symptoms such as fatigue and memory as the most unmet needs. This suggests that the MS service in Sheffield may focus on visible symptomatic management, as these were considered unmet by less participants. However, whilst
information services may be easier to improve, controlling symptoms such as fatigue has proved difficult. Fatigue is a very common symptom of MS, which may affect up to 80% of patients (Tur 2016). Whilst the underlying neurological dysfunction that leads to fatigue is not understood, it can be triggered by other MS related symptoms such as low mood, sleep disturbances and pain. Tur (2016) suggests that there are three different approaches to fatigue management; pharmacological treatment, non-pharmacological treatment and mixed-method approaches. The only pharmacological treatment that is currently recommended by NICE for fatigue management in MS is amantadine, an anti-parkinsonism drug with influences on the dopaminergic system. However, as a main side effect of this drug is insomnia, it does not seem like a viable long-term solution for fatigue management. Cognitive behavioural therapy (CBT) has also been tested for fatigue in MS, resulting in significant improvements in fatigue scale score (Van Kessel et al. 2008). The main mixed method technique has been established in the FACETS (Fatigue: Applying Cognitive, Behavioural and Energy Effectiveness Techniques to Lifestyle) study (Thomas et al. 2013). This technique was found to reduce fatigue severity and increase fatigue self-efficacy. Whilst potential novel strategies for fatigue management in MS are being developed there is no gold standard technique. It is therefore not surprising that this was considered unmet by the majority of participants in the present study.

The needs least commonly reported as unmet in the present study were symptoms more frequently associated with progressive disease, such as eating and drinking, speaking and secondary problems due to lack of mobility. This most likely reflects the demographics of the participants recruited, with the majority being RRMS patients. It is therefore necessary to recruit a larger more representative cohort of patients before a conclusive needs assessment of pwMS in Sheffield can be performed.
Assessing the unmet needs across different EDSS scores demonstrated a slight difference in prioritisation of needs between patients with different disease severities. Whilst information about treatment and trials was identified as the most unmet need by patients with a low EDSS, 75% of patients with an EDSS >6 identified pain management as unmet. This difference in needs is in concordance with previous studies (Disanto et al. 2011). However, interestingly (Heesen et al. 2008) found that early MS patients (who tend to have a lower EDSS) valued pain higher than late MS patients, a direct contrast to the results in the present study. This discrepancy may highlight potential difficulties in using questionnaires to identify needs or problems with the pain management facility within the Sheffield MS service.
5 Chapter 5: Strengths & Limitations

5.1 Participant demographic:

Only five healthcare professionals completed the clinicians survey, three of whom were neurologists. It would have been useful to gain the perspective of more people in different MS related healthcare roles. Consultation of MS nurses may have been particularly informative for the present study, as well as future studies. The rising demands on the healthcare system means that MS specialist nurses have become increasingly important (Burke et al. 2011). Whilst there are lots of different specialities involved in MS, the MS nurse now often takes on the role of coordinator to bring services together. Moreover, during the PPI sessions in Phase 1 of the present study, it was noted that patients often spoke very highly of their MS nurse. MS nurses therefore have a holistic viewpoint on the needs of pwMS, and as such their opinions would be valuable in identifying unmet needs.

Patients participating in Phase 2 & 3 were all recruited from the RHH in Sheffield. The lack of involvement of other centres contributed to a number of issues. Firstly, there were not many progressive patients recruited (n=4). These patients do not attend the Neuro Day care unit for DMT infusions as there are currently no DMTs that have been shown to be effective in progressive disease (D’Amico et al. 2016). This also led to exclusion of patients on DMTs with other modes of administration, such as the interferons and dimethyl fumarate. These tend to be prescribed 1st line in patients with mild symptoms due to their lower risk profile (Rae-Grant et al. 2018). This lead to the study sample being unrepresentative of the entire MS population. Although the sample recruited was not as representative as we had hoped, adopting a patient centred approach throughout is likely to have increased the acceptability of the 29 item LUN-MS and is a major strength of this study.
Different centres also have different funding allocations for different services, resulting in
discrepancies between them. This means that certain needs will be met by certain services,
but not by others. Because of this, it is not possible to extrapolate the needs most commonly
being considered unmet in Sheffield to the whole MS population. In the future, the LUN-MS
will be made accessible to the whole UK MS population through the MS register, in order to
define geographical differences between unmet needs and evaluate the strengths and
weaknesses of different MS centres.

5.2 Sample size:

Recruiting from only one centre also meant the sample size was not large enough. This
limited the statistical power of Cohen’s kappa, as only 25 participants were included in intra-
rater reliability analysis. The sample size needed to achieve a good statistical power (80%)
for Cohen’s kappa was calculated for each LUN-MS item (Appendix R). For the majority of
questions this was between 50 and 60, but for questions 4 and 8 this was calculated at 92.
Interestingly, these were the questions that not many people responded ‘yes’ to. If the study
was to be repeated, it would be sufficient to aim to collect T1 and T2 responses from 60
participants. This would ensure the majority of the questions had a high enough statistical
power to reject the null hypothesis. Assuming a similar dropout rate to the present study
(42%), approximately 100 participants should be initially recruited. Recruitment could be
increase by approaching other MS centres, or extra support services (such as the MS society
chair aerobics group that took part in Phase 1).
5.3 Study design:

The test-retest reliability of the LUN-MS was established using cross tabulation. This relies on two assumptions being made; that the true score does not change between administrations of the questionnaire, and that the time period is long enough to prevent learning, carry-over effects or recall (Vaz et al. 2013). The first of these was controlled by asking participants to state if they had any significant health changes since first completing the questionnaire. As described in the study procedure, participants were asked to complete the LUN-MS at two time points, 2-4 weeks apart in order to test the questionnaires reliability. This may have increased the chance of type 1 error, leading to false positive results. Furthermore, this may oppose one of the assumptions for use of the kappa statistic; that the two responses are independent of each other (Cohen 1960). However, lengthening this time period would risk capturing disease fluctuation, or result in a greater exclusion rate due to relapse. If the study were to be repeated, we propose a 4-5-week time period as an intermediate between these two potential confounding factors.

5.4 Questionnaire design:

The main limitation of the questionnaire was the yes/no response to the questions asked, as highlighted in 4.3.3. Each question addressed a particular need, and asked patients to report whether this need was met (by answering no) or unmet (by answering yes). However, if a patient did not experience a particular need, they also had to answer ‘no’. This therefore means that, when a participant answered ‘no’ there is no way to distinguish between:

*No; I have this problem, but I don’t need help with it (i.e. met need)*

*No; I don’t currently have this problem*
Patients reported that they found this confusing and felt they would like to be able to distinguish between not having the problem and having the problem but not needing help with it.

Whilst in the LUNS study this was considered acceptable, we feel it needs further adaptation for use in pwMS. In stroke, patients experience their most severe state right after the ischemic event and tend to get better over time (Forster 2013). In comparison, pwMS are initially in their least serve disease state, and either have fluctuating (RRMS) or progressively worsening (PPMS/SPMS) symptoms. It could also be argued that the MS needs also fluctuate more frequently with other factors such as temperature or fatigue. If the LUN-MS is to be effectively used to not only report needs on a single basis, but monitor changes in needs in pwMS we recommend the LUN-MS be modified to report one of three options:

- Having the need but it being met
- Having the need but it being unmet
- Not currently having the need

A future study would then be needed in order to test the reliability, validity and acceptability of the three option LUN-MS questionnaire.

5.5 Future research:

The present study has opened up a variety of potential future research avenues. Further exploration of the different needs in different disease subtypes is needed, as well as the patterns and potential factors influencing changing needs. The LUN-MS questionnaire may also be used to explore the impact of unmet needs on self-perception of health status and quality of life. The differences in perception of needs between HCPs and pwMS should also be further explored, however was beyond the scope of this study. Furthermore, other potential demographic variables, such as ethnicity and socioeconomic background should be explored to identify any differences in needs between groups.
The next stage of the current project is to collect UK-wide responses to the LUN-MS questionnaire through the MS register. This will allow the identification of geographical differences in unmet needs, and subsequently assessment of provisional services at different MS centres across the UK. If successful, the strengths of certain centres can be built upon by others, creating a more standardized, and hopefully improved, MS needs service in this country.

5.6 Conclusion:

The present study found the LUN-MS questionnaire to have good reliability and acceptability in assessing the individual unmet needs of pwMS. This is the first study to design a questionnaire suitable for longitudinal monitoring of needs in MS. However, further analysis on a larger sample size is needed to confirm this. The LUN-MS questionnaire should be adapted according to the patient feedback described and re-assessed for reliability and acceptability. This will ensure it is the best possible tool before becoming available for use. Once further analysis is completed, the LUN-MS may be used to effectively monitor individual needs across all MS subtypes, and to look at geographical differences in provisional MS services across the UK. In the future, we hope both of these will help improve quality of life in pwMS.
6  Chapter 6: Bibliography


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NIRH - INVOLVE. 2015. What is public involvement in research? – INVOLVE


Appendix A: Identifying the long-term unmet needs of patients with Multiple Sclerosis: a survey of clinicians

We are aiming to identify the long-term unmet needs of patients with MS, in order to develop a questionnaire which could be used to record patients’ unmet needs.

At this stage we aim to create a very long list of all potential unmet needs before prioritising them and narrowing them down into a short list. Your answers will be combined with data from PPI sessions and reviewing the literature to compose a list of unmet needs.

We would be very grateful if you could help us complete a short questionnaire taking 3-5 minutes. We’d like you to identify some of the most important and most unmet needs of patients with MS, from a clinicians perspective. Unmet needs are the MS-related needs that are not currently met by MS services in the UK. These may be related to healthcare (psychological support, access to aids/DMTs etc.), or social care (financial support, career guidance, transportation assistance etc.).

This research has ethical approval from the University of Sheffield. Your contribution to this study will help shape the questionnaire we will develop, which in the future will be used to identify gaps in provision services in the UK for patients with MS. This service evaluation is anonymous.

This study is being run in the Sheffield Institute of Translational Neuroscience by Dr. Esther Hobson & Dr. Siva Nair, assisted by MSc Clinical Neurology student Charlotte Kirkland. If you have any further questions please do not hesitate to contact us using the details below:

Dr. Hobson: e.hobson@sheffield.ac.uk
Dr. Nair: k.nair@sheffield.ac.uk
Charlotte Kirkland: c.kirkland@sheffield.ac.uk
SITran no: 0114 22 22230

We thank you in advance for participating in this survey.

☐ I'm happy to take part in this survey

Next

Never submit passwords through Google Forms.
## Profession

What is your profession? *

- Neurologist
- Rehabilitation physician
- GP (with a special interest in MS)
- MS nurse
- MS therapist (OT, physiotherapist, psychologist)
- Other

## Long-term needs

Can you list 5 or more of the most important needs that could, or should, be addressed by a MS service? *

Your answer

## Unmet needs

Unmet needs are the MS-related needs that are not currently met by MS services in the UK.

Can you list 5 or more needs that, in your opinion, are currently unmet by MS services? *

Your answer

Thank you! Please press submit.

Thank you for taking part in this survey. If you have any further questions please don't hesitate to contact us:

Dr. Hobson: e.hobson@sheffield.ac.uk
Dr. Nee: l.kees@sheffield.ac.uk
Charlotte Keichland: c.kiechland@sheffield.ac.uk
SFTM: 0114 29 33930

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Appendix B:

Phase 1 – Lego Serious Play

Lego serious play is a method of group communication and problem solving to explore a particular topic, in the case of this study barriers faced in MS. Participants were invited to attend workshop on 27/02/2018 at the Sheffield Institute of Translational Neuroscience. They were recruited through local disability groups; the local MS society branch, Experience Community (a social enterprise providing outdoor experiences for people with disabilities) and the MS society centre. A poster invitation was created and circulated to members, and the lead investigator visited each group to introduce the research idea. The session was attended by one lead facilitator and three researchers and lasted approximately 1 hour 30 minutes. The workshop aimed to discuss two themes; a nightmare experience with MS and the ideal MS service. Participants were given a selection of Lego and asked to build models that best represent the two themes. A warm up exercise involved building and describing a part of their local area. The facilitator then guided a discussion about the different models that were built, whilst the researchers made notes.
Appendix C:

**Identifying the unmet needs in Multiple Sclerosis**

**THE PROJECT:**
We are aiming to identify the most unmet needs in Multiple Sclerosis to develop a questionnaire that can be used to record patients’ unmet needs. In the future this may also be used to identify and manage gaps in provisional services across the UK.
At this stage we are aiming to collect a long list of all potential unmet needs, before prioritising and narrowing them down into a short list.

**PREVIOUS RESEARCH:**
Below are some images taken at a Lego-serious play session, which we ran last month at the University of Sheffield. Participants were asked to construct models that represented their experiences with MS and MS services. Each image has a description below, as described to us by the participants themselves.

**Image 1:** The participant described the hurdles they have had to overcome since being diagnosed with MS. The black square at the end represents a brick wall between them and the help they need.

**Image 2:** This figure represented the participants experience ‘losing their legs’ and the struggle they experience getting doctors to listen to them. They described a brick wall and people looking away when they asked for help.

**Image 3:** This model was made by a carer of someone with MS who describes the dramatic change in lifestyle they experienced after the patient was given an electric wheelchair.

**Image 4:** In the second part of the session participants were asked to build a representation of the ideal MS service. The front model shows a connected service, with information being passed between different specialist areas (i.e. physio and OT).

**Image 5:** This tower represented an MS hub, where you can access information and MS services all in one place. Lack of coordination of MS services was another problem identified by our participants.

**Image 6:** This represents a good MS service. The elephant for looking for knowledge and the bridge as a helping hand to the measure which represents information and help.
Appendix D:

Phase 1: Chair Aerobics session - 27th April 2018

Themes: Nightmare MS and Ideal MS service

Subthemes: Information, Healthcare, Social care

Theme 1: MS nightmare

Information:

- Lack of information on diagnosis
- Lack of public understanding of MS
- Information about DMTs
- Information about trials
- Information about grants
- Adapted information for different stages of disease
- Information about extra support services (physio, SLT, rehab etc.)
- Information about lifestyle (e.g. exercise and diet)
- Information given in lay terms
- Publicise extra support groups

Healthcare:

- Access to DMTs
- Bladder control
- ‘Brain Fog’ (cognitive aspects of MS)
- Help with grip
- Referral to physiotherapy
- Emotional support for patient
- Emotional support for carers/partners
- More frequent neurologist appointments
- Bedside manner of HCPs
- Secondary issues due to lack of activity
- Fatigue
- Stress
- Symptomatic treatment
- Disorganisation of services
- Lack of communication between departments
Social care:

- Individuality of patient
- Pressure on relationships (friends, partner, colleagues)
- Strain on partner when in carer role
- Support for partner/carer
- Patient frustration
- Partner frustration
- Social stigma around MS
- Adaptations to home
- Adaptations to workplace
- Education in workplace
- Loss of independence
- Can’t do things that used to have to do (e.g. driving)
- Can’t do things that used to be enjoyable (e.g. cooking)
- Patients get ‘lost in the system’

Theme 2: Ideal MS service

Information:

- Leaflet on diagnosis
- Give everyone access to same information
- Referral to MS nurse after diagnosis
- One place where all information can be found
- Learning one’s own abilities and boundaries with MS

Healthcare:

- Brain training
- Coordination between hospital based and community-based activities
- Publicise other support groups
- Publicise other MS centres
- Connectivity of services

Social care:

- Community open day/ support groups
- Support groups for newly diagnosed patients
- More education in workplace
- Financial support
- Employment support
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Appendix E:

Unmet needs in Multiple Sclerosis:

The following list is composed of unmet needs identified from 3 sources; the literature, patients and carers/partners, and healthcare professionals with an experience in MS.

1. Lack of info on diagnosis
2. Information about grants
3. Information about clinical trials
4. Physical support outside of hospital
5. Social support outside of hospital
6. Financial support
7. Information about exercise/lifestyle
8. Information about diet
9. Information on benefits
10. Work advice
11. Information on leisure activities
12. DMTs for progressive disease
13. Not seeing neurologist enough (yearly appointments)
14. Bedside manner of healthcare professionals
15. Single point of access
16. Bladder and bowel care (catheterisation)
17. OT advice for hand function (grip)
18. Access to physio
19. Access to SALT
20. Plans for future (advance care)
21. Palliative care
22. Fatigue management
23. Pain management
24. Spasms/stiffness
25. Mobility
26. Secondary problems due to not walking (i.e. swollen feet)
27. Pressure sore management
28. Cognitive support
29. Psychological support
30. Emotional support
31. Stress/anxiety
32. Mobility access
33. Mobility around home
34. Individuality of patient
35. Maintaining independence
36. Carer stress
37. Strain on sexual relationships
38. Strain on other relationships (work/friends)
39. Emotional strain on partner
40. Emotional strain on other family members
41. Lack of public understanding
42. Family planning
43. Information about MS and pregnancy
Appendix F:

LUN-MS Longlist Version 1

The following is a list of questions/statements that were developed from the list of unmet needs identified from PPI sessions, a clinician’s survey, and reviewing the literature. Questions were grouped under subheadings to ensure that questions were appropriately ordered in the final CRF. Some needs were addressed in two or more different ways, so that participants could give their opinion on the wording of the questions.

Information:

1. I would like more information about my MS
2. I would like more information about the different treatments available for MS
3. I would like more information on additional support services in my area
4. I was given enough information about MS when I was first diagnosed
5. I feel the public do not understand my MS
6. When I am unsteady on my feet, I feel like people around me are looking at me
7. I would like to know about new trials for MS and how I can get involved
8. I would like there to be one place where I can find out all the information I need to

Clinical care:

1. Once yearly appointments with the neurologist is sufficient
2. I sometimes don’t feel that healthcare professionals listen to me
3. I know who to call if I have a relapse
4. The MS nurse phone in system has worked well for me when having a relapse
5. I would prefer if there was a single point of access to all help and services for MS

Self-management:

1. I would like advice on managing fatigue
2. I would like advice on bowel/bladder management and care
3. I would like advice on pain management
4. I would like advice on how to manage secondary problems due to not being able to walk (e.g. swollen feet)
5. I would like advice on how I can make my memory better
6. I would like advice on how I can improve my cognition

Physical needs:

1. I often feel unsteady on my feet
2. I have problems with my grip
3. I know where to access extra physiotherapy/exercise classes outside of the hospital
4. I have problems with my bowel/bladder care
5. I know who to call for help if I have a fall

Psychosocial needs:

1. I would like more psychological support
2. I would have liked more psychological support when I was first diagnosed with MS
3. My brain sometimes works slower than usual
4. I often find my mind wandering and would like advice on how to deal with this
5. I find my memory has worsened since being diagnosed with MS and would like some help with this
6. I feel that my cognitive abilities have decline since my diagnosis
7. I would like more support/advice on the cognitive aspects of MS
8. I need some help/advice on organising my finances (work/benefits)
9. I would like advice on how to do the things I used to enjoy but now find difficult (e.g. cooking)
10. I need extra aids/adaptations to my home
11. I would like advice on planning for the future to ensure my wishes are met
12. I often have a low mood and would like to know what help is available

Relationships:

1. I find my partner/carer gets frustrated with me
2. I don’t feel like my partner understands my MS
3. I think my partner would benefit from extra support while caring for me
4. I think my partner would benefit from psychological support
5. Dealing with MS has put a strain on my relationship
6. I am concerned about my physical relationship with my partner and would like some advice on this
Appendix G:

Longer-term Unmet Needs after Stroke

Please read each statement and answer it as follows:

Tick 'YES' if you agree with the statement
Tick 'NO' if you do not agree with the statement or it doesn’t apply to you

<table>
<thead>
<tr>
<th>Statement</th>
<th>YES</th>
<th>NO</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. I would like more information about my stroke (e.g. what is a stroke, why it has happened to me and how to avoid having another one)</td>
<td></td>
<td></td>
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<tr>
<td>2. I haven’t had my medication/blood pressure checked for some time and would like a check up</td>
<td></td>
<td></td>
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<tr>
<td>3. I regularly get pain and nothing seems to ease it</td>
<td></td>
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<tr>
<td>4. My walking and general moving seems to be getting worse and I’m not getting any help with this</td>
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<tr>
<td>5. I am worried that I might fall (again) and this is stopping me from doing my usual things</td>
<td></td>
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<tr>
<td>6. I need additional aids (e.g. kitchen equipment) or adaptations (e.g. stair lift, grab rails) inside the home</td>
<td></td>
<td></td>
</tr>
<tr>
<td>7. I need adaptations outside the home (e.g. ramp, rail) but they haven’t been ordered yet or I’ve been waiting too long</td>
<td></td>
<td></td>
</tr>
<tr>
<td>8. I need some help / advice about getting back to driving and / or getting a blue badge</td>
<td></td>
<td></td>
</tr>
<tr>
<td>9. I would like to find out about travelling on buses, taxis and / or trains</td>
<td></td>
<td></td>
</tr>
<tr>
<td>10. I would like outside help to get jobs done in my home (e.g. cleaning, cooking, ironing, fixing things)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Please Turn Over
Appendix H:

North of Scotland Research Ethics Committee (1)
Sutherland House
3 Elgin Road
Aberdeen
NHS Grampian
Telephone: 01224 596688
Fax: 01224 596990
Email: recsec@nhs.net

Please note: This is the favourable opinion of the REC only and does not allow you to start your study at NHS sites in England until you receive HRA Approval.

20 March 2018

Miss Clare Kirkland
S/Tech, 38th Floor Glassop Road
SHEFFIELD
S10 2HQ

Dear Miss Kirkland:

Study Title: Developing the LUNS-MS, a questionnaire to identify the unmet needs of people with N3

REC reference: 18/NS/0003
Protocol number: 1.0
IRAS project ID: 241772

The Proportional Review Sub-committee of the North of Scotland Research Ethics Committee (1) reviewed the above application by correspondence.

We plan to publish your research summary meeting for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this favourable opinion letter. The expectation is that this information will be published for all studies that receive an ethical opinion but should you wish to provide a substitute contact point, wish to make a request to delete, or require further information, please contact irasregistra@hr.org.uk outlining the reasons for your request. Under very limited circumstances (e.g. for student research which has received an unfavourable opinion), it may be possible to grant an exemption to the publication of the study.

Ethical opinion

On behalf of the Committee, the PR Sub-Committee gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below.

Conditions of the favourable opinion

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.

1. Please either detail in the Participant Information Sheet that the LUNS-stroke questionnaire is the basis for the modified form you are trying to come up with, or omit the title details on the form.

You should notify the REC once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with updated version numbers. Revised documents should be submitted to the REC electronically from IRAS. The REC will acknowledge receipt and provide a final list of the approved documentation for the study, which you can make available to host organisations to facilitate their permission for the study. Failure to provide the final versions to the REC may cause delay in obtaining permissions.

Management permission must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).


Where a NHS organisation’s role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R & D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of management permissions from host organisations.

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publicly accessible database. This should be before the first participant is recruited but no later than 6 weeks after recruitment of the first participant.

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.
Letter of HRA Approval

Dear Dr Nair,

Study title: Developing the LUNS-MS: a questionnaire to identify the unmet needs of people with MS
IRAS project ID: 241772
REC reference: 16/NS/0034
Sponsor: Sheffield Teaching Hospitals NHS FT

I am pleased to confirm that HRA Approval has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further from the HRA.

How should I continue to work with participating NHS organisations in England?
You should now provide a copy of this letter to all participating NHS organisations in England, as well as any documentation that has been updated as a result of the assessment.

This is a single site study sponsored by the site. The sponsor R&D office will confirm to you when the study can start following issue of HRA Approval.

It is important that you involve both the research management function (e.g. R&D office) supporting each organisation and the local research team (where there is one) in setting up your study. Contact details of the research management function for each organisation can be accessed here.

How should I work with participating NHS/NSHSC organisations in Northern Ireland, Scotland and Wales?
HRA Approval does not apply to NHS/NSHSC organisations within the devolved administrations of Northern Ireland, Scotland and Wales.

If you indicated in your IRAS form that you do have participating organisations in one or more devolved administration, the HRA has sent the final document set and the study wide governance report (including this letter) to the coordinating centre of each participating nation. You should work with the relevant national coordinating functions to ensure any national specific checks are complete, and with each site so that they are able to give management permission for the study to begin.

Please see IRAS Help for information on working with Northern Ireland, Scotland and Wales.
Appendix I:

Developing the LENS-Ms: a questionnaire to identify the unmet needs of people with MS

What is the study about?
We would like to develop a questionnaire to identify the problems of people with Multiple Sclerosis (MS) that are not currently being solved by their medical teams. We hope that the information gathered in these questionnaires can be used to improve future services. We will use a questionnaire designed for people who have had a stroke and change it to make it suitable for people with MS. We have spoken to people with MS, their carers and doctors and drafted a version of this questionnaire. This study is to find out what people with MS think about our draft questionnaire and whether it is giving us correct information. We would like to get your feedback to improve our questionnaire.

Why have I been chosen?
You have been chosen to take part because you are diagnosed with MS and receive treatment for MS at the Royal Hallamshire Hospital in Sheffield.

Do I have to take part?
No. It is up to you whether or not to take part. Taking part is entirely voluntary and will not affect your medical care. If at any point you want to stop taking part in the study you can do this at any time. If you have finished the study in the last two weeks you can ask to have any information you have given removed from the study completely.

What happens to me if I take part?
If you are interested in taking part in the study, let your doctor or nurse know and a member of the study team will meet you at the Royal Hallamshire Hospital. This is where you can hear about the study and decide whether you wish to take part.

There are three parts to the study. You may be invited to take part in one, two or all three parts if you are interested.

Part 1:
The study team member will ask you to complete a short questionnaire and give us some basic information about yourself (such as age, gender). We’d like you to choose the most important problems caused by MS that you face from a list. This will take about 10 minutes. We also look at your notes to record some information about your condition.

A small number of patients will also be invited to be recorded using a digital voice recorder, whilst they complete one questionnaire. We are doing this in order to find out what you think of the questionnaire and how we might improve it.

Part 2:
The study team member will ask you to complete four short questionnaires and give us some basic information about you (such as age, gender). The questionnaires will be about things such as your MS and quality of life and what you think of the questionnaire. This will take up to 40 minutes. We’ll also look at your notes to record some information about your condition (the type of MS you have, your examination findings and whether you take any disease modifying treatments).

Part 3:
If you have completed part 2 we’ll also ask whether you’d like to complete a further three questionnaires in three to five weeks time. This will take about 30 minutes. The study team will give you a stamped addressed envelope or you can bring them to your next appointment if you are coming back to the hospital at that time. With your permission, the study team will contact you when the time comes to complete these to remind you.

You can get help from a friend, family member or other team member to complete the questionnaire if you wish, but the answers must be yours. You may wish to have a friend or family member accompany you during the appointment. If you are being recorded completing the questionnaire we will ask that they don’t say anything during this part of the study.

Are there any expenses or payment involved?
There are no payments involved in taking part in this study. However, we will cover your car parking costs. We will provide you with a voucher to present to the parking attendant on your way out.

How do I give my permission to take part in this study?
We will ask you to read this information leaflet, ask any questions you may have and talk to your family and friends before deciding whether to take part. If you wish to take part, we’ll ask you to read and sign a short consent form. If you have difficulty reading the form then a friend or family member can sign the form to witness that you have given written consent.

What are the possible risks and benefits of taking part?
We do not expect any risks from taking part in this study. The questionnaire does not pose basic questions about topics that are quite personal to you but all your answers will be kept confidential to the research team and your medical team. You are welcome to look at the questionnaires before you decide to take part. If you wish to talk to your medical team at any point we can arrange this. We can also talk to any concerns you raise to your medical team.

While we believe there are no immediate benefits for people participating in the study, it is hoped that this work will help inform us about the unmet needs of those living with MS. We hope to develop a questionnaire tailored to MS as a result of this study so that information collected by this questionnaire can be used to improve MS services in the future.

What will happen to the results of the research project?
A study summary will be published on the website www.mstrust.org. The findings will also be published in an academic paper.

Who is doing the study?
The study is being conducted by researches from Sheffield Teaching Hospital NHS Foundation Trust and the Sheffield Institute for Translational Neuroscience (SITNe; University of Sheffield).

Researchers include trained students and doctors. It is supported by the Telegraph Trust Fund of the Collaboration for Leadership in Applied Health Research and Care Yorkshire and Humberside (CLAHRC YH).

What if there is a problem?
If you have any concerns or questions you can contact us via the contact details below. We are happy to discuss any issues you may have, or any general questions you want to ask. If you want to make a complaint you can contact us and discuss this with us directly or you can contact Sheffield Teaching Hospitals NHS Foundation Trust Patient partnership team at: Patient partnership department, S10, Royal Hallamshire Hospital, Glossop Road, Sheffield S10 2JF.

Email: info@sheffield-tea.nhs.uk or Tel: 1014 7274569.

What if something goes wrong?
As the study involves just completing some questionnaires and questionnaires there is very little chance of something going wrong. If it did happen then the study team or your clinicians will try to resolve the problem. The University of Sheffield and Sheffield Teaching Hospitals NHS Trust hold insurance the very unlikely event of there being any harm caused by the study to you or someone else.

Will any taking part in this project be kept confidential?
Yes. All the information that we collect about you during the course of the research will be kept strictly confidential. You will not be identified in any reports or publications. Sometimes we use quotes that people have given during the study when we talk about the results of the study. We might use them on posters or in written reports. All your information will be anonymised but it is possible that someone who knows you might recognise that quote as yours.

All information we collect from you will be stored in a secure way so that is only accessible to members of the research team. When you consent to take part in the study, you will be given a unique study identification number. This number will be all of your questionnaires to identify you instead of identifiable personal information. We do write in your notes and tell the hospital authorities that you have taken part. They may look at your notes or our records to make sure the research is being conducted properly and that your rights and well being are protected. Any personal data that could identify you including any records will be destroyed safely as soon as it is no longer needed (in less than one year after the study has finished). Anonymisation data will be stored safely for at least five years to make sure the study has been carried out correctly.

Who has ethically reviewed the project?
This study has been approved by the North of Scotland Research Ethics Committee whose remit it to protect your safety, right, well being and dignity.

Context for further information: You can contact the research team using any of the following methods:

Dr Sira Nair, consultant neurologist
Sheffield Teaching Hospital NHS Foundation Trust
Sheffield Institute of Translational Neuroscience
Tel: 0114 22 20250
Email: S.Nair@sitet.org

Dr Esther Robinson, research registrar
Sheffield University Hospitals NHS Foundation Trust
University of Sheffield
Email: Esther.robinson@sheffield.ac.uk

University of Sheffield
252 Glossop Road, Sheffield
S10 2JF

Research includes a questionnaire to identify the unmet needs of people with MS. S97 14/04/2014 4:55:19
**Appendix J:**

Developing the LUNIS-MS: a questionnaire to identify the unmet needs of people with MS

1. I confirm that I have read and understood the information sheet dated 01/04/2018 version 1.2 for the above study. I have had the opportunity to consider the information, the opportunity to ask questions about the study and I am happy with these answers.

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving a reason, without my medical care or legal rights being affected. In addition, should I not wish to answer any particular questions, I am free to decline.

3. I understand that relevant sections of data collected during the study may be looked at by individuals from the University of Sheffield, regulatory authorities or from the Sheffield Teaching Hospitals NHS Trust 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.

4. I understand that, if I agree, I might be invited to be interviewed and any interviews I give will be audio-recorded, and transcribed. I understand that some of my quotes may be used in publication. I understand that these quotes will be anonymised, but it is possible that someone who knows me well may be able to identify the quote as mine. I understand that I can inform the research team after the interview should I wish for any of my comments to not be used in analysis or publication.

5. I agree to take part in the above study.

Participant Signature: 

Print Name: ___________________________ Date: ________________

Witness Signature: ___________________________

Print Name: ___________________________ Date: ________________

Relationship to participant: ___________________________

Investigator: I have explained the above study to the participant and obtained consent

Signature: ___________________________

Print Name: ___________________________ Date: ________________
Appendix K:

**Part 1**

To be filled in by the investigator:

Date ..............
Study ID ......

Age .........
EDSS ...........
Gender .............
Type of MS....................
DMT Y/N

Think aloud interview? Y/N

<table>
<thead>
<tr>
<th></th>
<th>Most important</th>
<th>Currently a problem</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. I would like more information about my MS</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. I would like more information about the different treatments available for MS</td>
<td></td>
<td></td>
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<tr>
<td>3. I would like more information about extra health and social support services in my area</td>
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<tr>
<td>4. I would like more information about support from charities or other people with MS</td>
<td></td>
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<tr>
<td>5. I would like more information about how I can look after myself</td>
<td></td>
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<tr>
<td>6. I would like more information about exercise, lifestyle or diet</td>
<td></td>
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<tr>
<td>7. I would like to know about new trials for MS and how I can get involved</td>
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<tr>
<td>8.</td>
<td>I would like there to be one place where I can find out all the information I need</td>
<td></td>
</tr>
<tr>
<td>9.</td>
<td>I have lots of problems and would like to have more opportunity to talk to a specialist about them</td>
<td></td>
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<tr>
<td>10.</td>
<td>I would like to know more about what to do if I have a new symptom or problem</td>
<td></td>
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<tr>
<td>11.</td>
<td>I would like to know more about how to solve problems quickly</td>
<td></td>
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<tr>
<td>12.</td>
<td>I have lots of different problems and they don’t get solved quickly enough</td>
<td></td>
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<tr>
<td>13.</td>
<td>I have problems with my vision and need some help with this</td>
<td></td>
</tr>
<tr>
<td>14.</td>
<td>I have problems eating and drinking and need some help with this</td>
<td></td>
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<tr>
<td>15.</td>
<td>I have problems speaking or making my voice heard and need some help with this</td>
<td></td>
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<tr>
<td>16.</td>
<td>I have problems with my grip or using my hands and would like help with this</td>
<td></td>
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<tr>
<td>17.</td>
<td>I have difficulty walking, and would like help with this</td>
<td></td>
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<tr>
<td>18.</td>
<td>I would like help on managing spasms or stiffness</td>
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<tr>
<td>19.</td>
<td>I would like advice on managing fatigue</td>
<td></td>
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<tr>
<td>20.</td>
<td>I would like help on bowel/bladder management and care</td>
<td></td>
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<tr>
<td>21.</td>
<td>I would like help for managing my pain</td>
<td></td>
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<tr>
<td>22.</td>
<td>I have problems because I’m not very mobile (like swollen feet or skin problems) and would like help with this</td>
<td></td>
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<tr>
<td>23.</td>
<td>I have problems with skin sores or pressure sores and need help with this</td>
<td></td>
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<tr>
<td>24.</td>
<td>My brain sometimes works slower than usual, and I would like help with this</td>
<td></td>
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<tr>
<td>25.</td>
<td>I often find my mind wandering and would like advice on how to deal with this</td>
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<tr>
<td>26.</td>
<td>I find my memory has worsened since being diagnosed with MS and I would like help with this</td>
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<tr>
<td>27.</td>
<td>I feel that my cognitive abilities have declined since my diagnosis and would like help with this</td>
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<tr>
<td>28.</td>
<td>I would like more support/advice on the cognitive aspects of MS</td>
<td></td>
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<td>29.</td>
<td>I would like more emotional support</td>
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<tr>
<td>30.</td>
<td>I sometimes have low mood and would like help with this</td>
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<td>31.</td>
<td>I sometimes feel worried or anxious and would like help with this</td>
<td></td>
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<tr>
<td>32.</td>
<td>I sometimes feel my emotions are out of control and would like help with this</td>
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<td>33.</td>
<td>I need some help/advice on organising my finances (work/benefits)</td>
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<td>34.</td>
<td>I need help making adaptations to my home</td>
<td></td>
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<tr>
<td>35.</td>
<td>I would like advice on how to do the things I used to enjoy but now find difficult (e.g. leisure activities)</td>
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<tr>
<td>36.</td>
<td>I would like advice on how to do the things I need to do but now find difficult (e.g. driving, work, caring duties)</td>
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<tr>
<td>37.</td>
<td>I would like advice on planning for the future to ensure my wishes are met</td>
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<td>38.</td>
<td>I find my partner/carer gets frustrated with me and I'd like advice about how to cope with this</td>
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<tr>
<td>39.</td>
<td>I don't feel like my partner understands my MS and I'd like advice about how to cope with this</td>
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<tr>
<td>40.</td>
<td>I feel other people like my boss or friends don't understand MS and I'd like advice about how to cope with this</td>
<td></td>
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<tr>
<td>41.</td>
<td>I think my partner would benefit from extra support while caring for me</td>
<td></td>
</tr>
<tr>
<td>42.</td>
<td>I think my partner would benefit from emotional support while caring for me</td>
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<tr>
<td>43.</td>
<td>Having MS has put a strain on my relationship and I would like advice on this</td>
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<tr>
<td>44.</td>
<td>I am worried about my physical and/or sexual relationship with my partner and would like some advice on this</td>
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<tr>
<td>45.</td>
<td>I am worried about how other family members are affected by MS and would like some advice on this</td>
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<tr>
<td>46.</td>
<td>I would like to find out about hobbies or holidays that I might be able to take part in</td>
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</table>

**Satisfaction Questionnaire**

Are there any other problems that we have missed?

[Box for comments]

Any other comments?

Thank you for completing this questionnaire!
Appendix L:

Think-aloudtranscription_STH20247_StudyID011
08/05/2018

Interviewer: so just to confirm you’re happy for me to record and ask you some questions whilst you are completing this questionnaire
011: yep yeah
Interviewer: Fabulous, ok so I just need to take some information from you to start off with for the front, so how old are you?
011: 53
Interviewer: 53, okay and female, you have relapse-remitting MS yeah?
011: Yes
Interviewer: And you’re on disease modifying therapy and are completing a think aloud interview
Ok so basically what I’m going to ask you to do is just look through some of these statements and identifying the ones that are important to you and the one that you think are currently a problem. So, if you want to go through the first time and just talk me through the ones you think are important and then we can go through again
011: I don’t need any more information
Interviewer: You don’t need information? Okay
011: That would be nice
Interviewer: About the different treatments yeah?
011: Yeah
011: I don’t need that
011: Don’t need that
011: Don’t need that
011: Number 7, I’ve been on a trial but came because it wasn’t working so I don’t want to do new trials
Interviewer: I’ll just turn over
011: That would be good
Interviewer: Yeah
011: I’m not bothered about that
011: Don’t need that
011: Don’t need that
011: I do have some problems with my vision, but I don’t need help with that, I’ve been to the opticians for that
011: Don’t need that
011: I have problems with that, but I don’t need help, I’ve had MS for over 20 years, so I don’t need help with that (grip)
011: No, I don’t need that because I’ve been to the physio and everything
011: Don’t have that
011: Don’t have that
011: I see Liam for that normally
011: No
011: No
011: No
011: No
011: No, I still work full time
011: I just think it’s got worse with age (memory)
011: No
011: No
011: No
011: No
011: No
011: I’ve already had counselling about that, so that’s not a problem (Q31: worried/anxious)
011: I’ve already had that done (adaptation to home)
011: No
011: I don’t need that
011: Don’t need that
011: He comes to all my meetings with me and asks lots of questions, so he probably knows more about my MS than I do. He asks questions a lot of the time (Q39 – partner understanding MS) There a lot better than they used to be because Liam my MS nurse went to a work meeting to talk to people (Q40 – boss/friends understanding MS)

Interviewer: That sounds good, so do you think that helped people understand more
011: Yeah a lot more, because people look at you and think oh gosh you don’t look ill, so that helped a lot
011: No
011: No
011: No, he knew about it when I first met him anyway (Q43 – strain on relationships)

Interviewer: ok, do you mind if I just ask you a few questions about the questionnaire? How did you find doing it? Was it easy to understand the questions?
011: Yes
Interviewer: Are there any questions you didn’t understand or anything like that?
011: No
Interviewer: Obviously, a lot of these weren’t problems for you, is that because a lot of the problems that you have had have already been addressed?
011: Yes
Interviewer: Has that been more recently that those things have improved compared to when you were first diagnosed?
011: Yes, when I was first diagnosed my relapses were few and far between but over the years they’ve got more and more

Interviewer: So you’ve needed more help?
011: Yes
011: And this (point at infusion) has been really really good
Interviewer: Is there anything you think should be included, any problems you’ve found even if they have been resolved now
011: People you can talk to about getting grants and things when you’re first diagnosed would be good. I don’t think people always realise they are there

Think-aloudtranscription_STH20247_StudyID016
11/05/2018

Interviewer: Ok just to confirm that you are happy for me to record you whilst you are going through this questionnaire today
016: Yeah
Interviewer: Ok so do you want to start from the beginning then
016: I think I’ve got enough information. I wouldn’t say I’d like more information. I’m happy to have more information if there is information available but I wouldn’t say that I need it
016: I don’t think I need this one either because I’ve already been told about all the different treatments and now I’m on one
016: I would say that’s most important, number 3.
016: I’d say number 4 is also important
016: Yeah number 5 you can tick that one saying most important
016: And definitely number 6
016: Yeah I suppose that’s important, the one about trials, even though I think this is the one for me you never know what’s going to come in the future
016: I would put most important for number 8, even though I do use MS register a lot to get my information from
Interviewer: do you, is that pretty good then?
016: Yeah its very good
016: Well I do have lots of problems but I do talk to the consultant about it
016: And same with number 10, I already know what I would do if I had a new symptoms or something so I’d tell people when I came here (neuro day care) or my consultant and I’ve got MS nurses as well
016: Number 11, I would say that’s important
016: It’s not a problem, I wouldn’t say its currently a problem
Interviewer: number 12?
016: Yeah
016: I don’t have problems with my vision, other than wearing glasses but that’s nothing to do with MS
016: And I definitely don’t have problems eating and drinking
016: Sometimes I struggle with speaking, especially if I’m tired, so I would say you can put that as important
016: And I think number 16 is important, because I struggle with my left hand
016: Number 17 is most important
016: And the same for number 18 and number 19
016: Number 20 as well
016: I think I’ve already got enough (pain) management from my GP with the tablets that I’m on
016: No, I’m not not mobile
016: So 23 doesn’t affect me either
016: Yep definitely number 24, most important
016: And 25, because I do struggle with concentration
016: Yep 26 is a problem, and 27 and 28
016: Umm no I don’t think 29 is an issue
016: 30 is definitely an issue sometimes, and same with 31
016: 32, sometimes yes so you can put that as important
016: Number 33 is not a problem
016: I think I’ve already had what adaptations I need so I don’t need any help doing that, that’s all been done by my OT
016: Um, I think you can put 35 as most important
016: Um no that’s not a problem, 36
016: 37 I would say that’s important
016: I’m sure my partner does get frustrated with me but that’s probably just me not my illness
016: No he definitely understands so that’s not an issue
016: I think 40 is most important, because I don’t feel like work colleges understand it
Interviewer: yeah
016: I suppose 42 is quite important, you never know what they’re feeling do you
016: 45 I would say that’s most important
Interviewer: ok
016: And put 46 as important too
Interviewer: so are there any of these that you think are currently a problem for you
016: Well fatigues a problem but I have got, I have done stuff with the OT
Interviewer: any of the other ones?
016: Not on there no
016: I suppose cognitive would be a current problem
Interviewer: So 27 and 28 both of them?
016: Yeah
016: And 40 I think that’s a problem
016: None of those
Interviewer: just those last two
016: No I don’t think so
Interviewer: so what did you think of the questionnaire in general was is easy enough to understand all the questions?
016: Yeah the questions were all easy to understand but I’m not sure about the most important and currently a problem, I would say that it would be better doing something like a scale you know what I mean?
Interviewer: yeah, well what we’re trying to do is get an idea which questions out of these 40-45 are most important and then we are going to reduce it down to about 20 for the final questionnaire and then it will be yes no answers instead, so it will be like yes this is a problem, no this isn’t
016: Yeah that will be easier, but other than that I think everything made sense
Interviewer: Do you think there are any other problems that you’ve faced that we haven’t included in this
016: No I think you’ve included everything, its all just work, home and then treatments and everything is covered in that
Interviewer: And some of the questions for example Q1 and 2 bolded the key words, do you think this makes it easier to read and see what each question is talking about
016: Yeah
Interviewer: Okay I’m just going to go through some details on the front with you now, so how old are you?
016: 51
Interviewer: And you have RRMS?
016: I do yeah
Interviewer: And you’re on a DMT
Interviewer: Ok I’m going to stop the recording now if that’s okay with you
016: Right thank you
Interviewer: Thank you

Think-aloudtranscription_STH20247_StudyID017
11/05/2018

Interviewer: Ok so just to confirm you are okay with me recording you whilst you complete this questionnaire
017: Yeah, I’m fine with that.
Interviewer: Ok so I’m just going to go through a few things on the front with you, so how old are you?
017: 28, I’m pretty certain 28….yeah we’ll go with 28
Interviewer: And you have RRMS, yeah?
017: Yeah
Interviewer: Ok so if you just want to look through and talk me through the different questions
017: I’d like more information about my MS…..to be fair, I think I’m pretty much clued up about my MS, and
the information is out there I know I can get it quite easily ummm I’m trying to think if there’s anything I need
to know now
Interviewer: ok that’s fine we’ll leave that one blank then
017: Again I would say a very similar thing with the second one because I think everyone has been quite helpful
with all the treatments that are available and I’ve never felt that I didn’t understand that
I’m not too sure about health and social support services in my areas, I don’t really know anything about that, to
be honest that’s probably mainly because I’m new to Sheffield so I don’t know about anything I Sheffield
Interviewer: so do you think that’s something that’s important to you? Knowing where you would be able to
get extra support services if you needed it now or in the future say
017: Umm well yeah if I did need it….I cant think of what I would need…I assume you wont until you need
it…but yeah I think that’s probably going to be an important thing in the future
Interviewer: but yeah that’s not something that’s currently a problem for you is it?
017: No its not currently a problem
Interviewer: Information about support from charity and other people with MS….umm I don’t actually know anything
about support from charities…. I am aware of MS charities…people like the MS trust….ummm the MS society but
I’m not too sure if that’s a charity or not…I was under the impression that the support was more providing
information rather than actual support and to be fair there is a lot of stuff…because when I was first diagnosed
and I was hospitalised …ummm I lost my main source of income……I’ld gone to college and university to study
music….studying a teaching degree and started teaching and then lost the ability to use my hands so then I had
to go on benefits and its quite difficult to get hr benefit system to take you seriously when you have MS……and
there was not really any help I had to figure that out myself …and to be honest a lot of people aren’t aware of
anything to do with that…even GP's haven’t heard of things like (the drug I’m on)…..so I’m not saying anything
I need but it would be good if more people understood this information so that I didn’t need to tell medical
professionals
Interviewer: so you don’t need to teach people
017: Yeah , but yeah I’d say it’s important but again not currently a problem (question 4)
017: Ummm...again information about looking after yourself, that’s something I do find quite important but it’s
not that it’s not available and its fairly simple things as far as I understand….eating healthy, staying
active….ummm doing it while you’re in a relapse in quite difficult ….if there is help available with that then it
would be a good thing but I’m not sure there is any way you could help or anyone could help give me energy
when I haven’t got it
Interviewer: yeah
017: So yeah im not really sure about that particular one…I’d probably say leave that blank
Interviewer: The diet one…cause you hear lots of conflicting information about diet….some people say fish is good for
whatever reason…I’ve found lots of information about nuts are suppose to be good for the regenerating
myelin…but again I haven’t been given anything specific about you’ve got MS, this diet stuff will help you
have to find all this online from various different sources that I’m not sure I can trust
Interviewer: yeah yeah of course
017: Umm it would be handy having more access to this is a diet that would help you, I generally go under the
impression that salad is good and junk food is not but I get that obviously certain things…I’m not a scientist or a
food scientist so I don’t really understand it…it would be nice if it was more available and clear from the
off…again I wouldn’t say its currently a problem because this information is already out there but it would help
if it was more easily accessible
Interviewer: ok so shall we tick that as most important then
017: I would say that’s most important yeah
017: Um I don’t know about new trials in MS…um yeah I’ve heard a lot about new trials but I’ve never had anyone approach me for one…things like the ….I’ve heard people are doing research with things like stem cells…..
Interviewer: Yeah there is some stem cell research going on
017: And I think there was also a big one that got approved a while ago that was essentially chemo…but I don’t really understand that…but I haven’t been approached for that so I’m assuming that my neurologist has seen that maybe I’m not the right fit so maybe there is no point approaching me
Interviewer: Yeah those studies that are going on at the moment here have a very strict inclusion and exclusion criteria so that’s probably why
017: Yeah that makes sense
Interviewer: But I don’t know about smaller trials or anything like that
017: I like to go by the opinion that if I don’t know a lot about something and someone has been to university and studied it for years then I’ll put my trust that they know what they’re doing more than me….so with stuff like that I would say its not a problem in the slightest…if someone says that I am not a fit or I don’t need to know this then im not going to waste someone’s time
Interviewer: ok
017: A place where I can find out all the information I need….umm again not really a problem because I assume the place would just be here…or…..I mean I can’t expect that a GP would just have all of that information available but I’m assuming that once I start seeing the neurologist I would just be given all of the information on things like diet, exercise….I mean I know I’ve had lots of explanations on reasons I shouldn’t smoke but I’ve still ignored that
Interviewer: I think what a lot of people that I’ve spoke to have found is that they get the different information from different places and they have to put it all together
017: Yeah, compile it …you get so much that is just conflicting that clearly people have put stuff across as fact when its based on their own opinions and its hard to tell quite when that’s happening…so yeah I think it would be good if someone that knows what they’re talking about compiles all the information and puts it all together ….I would say that’s some of the most important stuff out of the lot of it for an MS patient umm again it’s not something that’s bothering me at the second but its what I imagine would be the most important
017: Umm no I think whenever I’ve had a problem there has always been specialists available
017: Again I know what to do when I have a new symptom or problem..
017: I can’t think of a single problem of MS that I can’t have solved quickly ummm the MS nurses always fairly available
017: To be fair I haven’t had a relapse since I was in Sheffield so I’m not aware of how quickly Sheffield reacts to it but I was in Milton kenes before and whenever I have a relapse within a couple of hours of being on the phone with my neurologist I’d have steroids and all sorts….so it was never an issue
017: No I don’t have any problems that don’t get solved quickly enough….in fact I would say I’m the one messing you guys around because I’m always missing appointments and things like that so the fact that I’ve not been kicked off this treatment is a nice thing..
017: I do have problems with vision, but I cant say I need help with it…I understand the problems and I think the fact that I understand makes me very comfortable….I had some issue a number of years ago when I couldn’t see anything but that fact that I knew what was going on stopped me from being potentially terrified to something I had to do…I knew it would come back so yeah
017: Again, I do have problems with eating and drinking but I don’t know if I need any help with it
017: Again, yeah I often have problems trying to find the right words for things but it’s not an issue…I know generally people are fairly patient
017: Ummm yeah I do get problems with using my hands…that’s one of the most irritating parts of MS for me…but I’m not sure what help that…or what things anyone could do about it ….I can use my hands…but for what I want to use them for requires a lot of dexterity and I’m not sure anyone could improve that but me ….if there is help available then I wouldn’t turn it down but I can’t see any way anyone could help
Interviewer: But would you say that’s something that is currently a problem for you then because say that help was out there
017: Umm the issue that I get at the second is because I’m trying to get back to the stage of …my..musical side of things that I was at before the MS started….it can stress me out not being able to do things that years ago I would find very simple, and if there is a new approach that people would give me…because stress will lead to more relapses and its just a vicious circle….so yeah it is one of the main problems for me but again I cant see any way anyone could help with that ….i wouldn’t say it’s a problem anyone else needs to sort out…it’s a problem for me that isn’t really anyone’s fault….yeah I don’t know really what to put to that….i’d say leave that one blank as well.
017: No I don’t have difficulty walking, I’ve got a walking stick just in case
017: Managing spasms and stiffness…no…no that’s fine
017: Managing fatigue would be awesome but…I signed up to the other thing the lady was coming round for…I’ll try anything

Interviewer: shall I tick that one then?
017: Yeah yeah…just constantly knackered…I don’t think I’ve had energy in the last 5 or 6 years…but I think a lot of that is down to sleep…. sleep is another thing that gets to me but I’m not sure if that’s down to MS or not

Interviewer: I think there is a relationship between MS and sleep disturbances
017: But that’s not really…the thing is I’ve sort of got used to all these things…its an issue at first but after years of it you learn to make do
017: No again bladder is fine
017: Help managing pain…umm…yeah managing pain would be nice when it comes because I don’t really like painkillers…but I don’t know if there is…techniques to manage certain types of pain…my understanding was that neurological pain cant really be touched as easy as anything else

Interviewer: yeah
017: So it’s the sort of thing where I just have to deal with it…I find scotch helps occasionally…doctors and that would argue with me …umm…
017: Problems because I’m not very mobile…yeah…I wouldn’t say swollen feet and skin problems but my mobility annoys me

Interviewer: So it causes frustration?
017: I want to be more mobile because I have things like massive muscle waste because as much as I want to be active and exercise more…when I do for say maybe half an hour that would put me out for a very long time and then I’m not able to function normally and do things like assisting general cleaning and stuff like that.
017: No I’ve never found issues with skin sores
017: Yeah my brains always working slow….my memory is a major problem..ummm to the point where I’m going to have to phone up my ex to apologise…she was insisting that I have paid her before in a certain way….i was saying I couldn’t have done that…she was saying I paid her before through pay pal but I said I couldn’t have done that because I haven’t got a paypal and never have done…until last night I discovered that I did have a pay pal that I was using last year and she was right I had paid her…and I had no memory of that…so yeah the memory is getting slightly annoying

Interviewer: Shall I put that as currently a problem then?
017: No again,. More emotional support no I’m alright
017: Now yes I have low mood but that seems like a really unfair questions asking that someone should help me with it…because I think tis a very personal thing…its very circumstantial as well and I cant expect that just because my mood is low that there is a professional medical answer to it and that’s someone else’s responsibility…so no, although its applicable that my mood can be low I don’t think I should have help with it
017: I sometimes feel worried or anxious…again yes…but I don’t need help with it
017: Same for 32
017: Well I’m not even going to get started on finances…that’s not a medical issue but tis a constant struggle living between 3 cities and 2 countries…especially on benefits…umm…but again not a medical issue I don’t think there is any way my doctor could help me with that

Interviewer: but in terms of other services so we aren’t just thinking about what help a doctor can give but that other services might be able to help you with that, say like people who worked in the benefits system is they understood more about MS
017: Its not just the benefit system, I think a lot of systems could do with understanding more about MS, especially the fact that I went through court a fair few years ago now to gain access to my daughter…and part of the court’s decision about whether or not I was able to have my daughter over night…the judge out in certain restrictions and put it down to the fact that I have MS and felt that I wasn’t capable of looking after her and would not listen to the fact that it doesn’t mean anything about my capability of looking after my daughter and certain places they don’t seem to understand from the point of view that MS is a neurological disease but it doesn’t mean you’re mental…or it doesn’t mean at any second I will ….like when I am with my daughter shes aware and my ex is aware and most people that although a relapse can come on at any time I will have a certain amount of warning its not like one second I’m fine and next second I’m on the floor….I will feel a relapse
coming on and I’ll be able to make appropriate… but yeah it would be nice if more people understood
information especially people like law courts….. but again I’m not really sure that’s the hospitals responsibility

Interviewer: But if say there was a way that you could get that information across to those people…so it’s not
necessarily the hospital that would have to do it…but someone else who specialises in MS… if they could better
communicate that information to those people or create more public engagement in MS and what it is and what
it means to have MS so that people did better understand

017: Yeah… well yeah that would be ideal but I think the issue is, based on my own perspective, is that MS sort
of gets lumped in alongside other things like….what people are referring to as invisible diseases
recently….conditions that you wont be able to tell someone has based on seeing them…but people tend to just
 lump them all in together as something that you could have or you could just be faking …and I don’t take
offense to that if someone wants to say I’m faking that’s fine its not my problem and I have no reason to need to
prove that to anyone….um but sometimes it does get a bit annoying when people involved in law and
benefits…the amount of time I’ve had the benefits people say well this isn’t possible….and I’m like well it is
because I’m doing….but it’s just individuals…I think that’s the problem its not really tackling an issue that
comes from an industry or people as a whole…they’re individuals and unfortunately sometimes if you’re
inclined to be close minded then you’re going to stay that way unless there is a strong catalyst to convince you
otherwise….so yeah if there is any way medical professionals can help with things like that to change that…but
I’m not really sure that is that viable an option to change people attitudes...

017: But yeah I’d say put it as important, but I just don’t know what you can do about it

017: I know there is stuff out there to help with that

017: Advice on how to do things I used to enjoy….um no…I don’t need advice on how to do things

017: That one….one how to do things I know find difficult…I’d quite like to look into driving again because
when I was younger I had a choice to learn to drive a car or a motorbike and I chose a motorbike and I …after
the 4th time I hit the concrete I didn’t really want to do it anymore….and now I’m sort of at the stage where I
miss my motorbike…but I don’t really trust driving on two wheels with MS….cause I know what it feels like to
hit the deck from a motorbike and its not fun …but if there is any advice on driving….because I don’t know if you
have to take your test again or something?

Interviewer: I’m not sure what the driving restrictions are for MS in this country

017: No see that’s the problem…..you’re actually working in this industry and you don’t know so I would say
that’s pretty important and sort of goes hand in hand with things like fatigue and the need to get around

017: Plans for the future…no who cares….I’ll just take it as it comes

017: Current partner, no….previous partners yes but a lot of it it could be down to my own dispositions

017: Understands my MS….yeah that’s fine

017: Other people like my boss and friends don’t understand MS….well again that’s an issue…it would be nice
for people not to consistently say that I’m lazy all the time but at the same time its not really an issue….again its
down to changing people’s outlooks and opinions…it’s not important…I would just be nice

017: My partner doesn’t care for me…. I’m not saying she does nothing….she’s helpful…

017: Do I think my partner would benefit for emotional support…so now it would be quite selfish of me to say
she wouldn’t need emotional support while caring for me…i mean for one she doesn’t care for me…but then I’ve
only been with her for just over 2 years and I haven’t had a relapse in that time so I don’t know….i imagine if I do
have one then she might want support

Interviewer: so shall we put that as important then? It’s not currently important but if you had a relapse she
might

017: Well yeah, its not currently important….if she was left needing to care for me….I’d hate to think….because
she is constantly stressing about the responsibilities she has….and I don’t want to add to that….so yeah I
would like to know that supporting me isn’t going to put her out

017: Strain on relationship…no

017: Physical/sexual relationship…no, I mean it used to worry me but conversations tend to just….more because
of the fatigue and stuff as well….sometimes I might want something that my body doesn’t…and…she’s
understanding so

017: Worried about my family members ….ummm yeah I mean that might be another quite selfish thing….but
then again a lot of my family don’t really understand MS….when I was diagnosed I sort of kept it to myself and
its just my daughter and my partner…my partner knows….my daughter has a brief understanding but she’s only
like 9….so she knows that I come for this every month…she knows that for the next day after having this I’m
going to be shattered….and I’ll explain more to her as she grows up….so no I don’t think that’s an issue

017: Umm hobbies no….because I have enough hobbies that I want to get back into….holidays….I haven’t put
any thought into holidays since I was a kid really….ummm so no there’s nothing really there

Interviewer: Ok so did you find all the questions easy to understand?

017: Yeah yeah, they were all easy to understand

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Interviewer: Was there any other problems that you think should be included…anything else you can think of that we haven’t spoken about
017: Umm no I mean to be fair majority of what I was fairly passionate about that we did speak about were things like other peoples understanding. Especially when it comes to GPs and courts and stuff but again we had already sort of discussed that…and I cant think of anything else…I’m pretty satisfied with that
Interviewer: ok thank you, I’m going to turn that recorder off now

Think-aloudtranscription_STH20247_StudyID018
15/05/2018

Interviewer: Ok so just to confirm you’re okay with my recording you whilst we complete this questionnaire today?
018: Yeah
Interviewer: Ok I’m just going to go through a few details on the front with you, how old are you?
018: 42
Interviewer: Do you know your EDSS score by any chance?
018: Umm no I don’t think so, I think it’s around 2
Interviewer: And you have RRMS yeah?
018: Yeah
Interviewer: And you’re on a DMT?
018: Yeah
Interviewer: Okay that’s great
Interviewer: So if you want to just take a quick look through these first few questions and let me know which ones you think are important
018: Yeah, so is that relative within these 7?
Interviewer: Yeah so these first few are all about information, so I’m looking to reduce these ones down to maybe 2 or 3, so if you think some of them could be combined as one question or which ones you think are more important
018: For myself that would be probably treatment, because obviously there is always new treatment coming out on the market, so it would be good to see which ones are maybe more suitable so at the moment I’m just on this and I don’t know about anything else that comes out unless I find out or ask but I only see my consultant every 12 months
Interviewer: Ok so we’ll tick that one then
018: Trials…that may be something that is worth knowing more about…I know of people involved in trials, but I never know who to…
Interviewer: How to get involved in them?
018: Yeah
Interviewer: Do you think…we were considering putting those two into one question…do you think that would work as one question as well?
018: Yeah
Interviewer: Ok, any of the other ones for you
018: Umm no I mean I’m pretty much…I keep myself personally informed by just checking on the internet for things as well so and um I’m aware of charity and I do kind of within reason keep on top of exercise because I know that it’s a benefit …so I think with regards to the others I’m kind of…. I’ve got enough information I think
Interviewer: Ok, so let’s just turn over
018: With regards to those, I don’t think personally they…there is anything there that I need any more information on or would like to get any more information on because I’m quite…like I said before…I’m quite up to speed with things and in my own personal circumstances I’ve tried to keep myself on top of things…and I know I’ve always got he MS nurses who are a good point of contact…and in the other areas I don’t have problems with any of the other areas that are mentioned…so with regards to those I think I’m fully informed enough at the moment with regards to those…is that the right kind of thing?
Interviewer: Yeah thanks
018: That one
Interviewer: Managing fatigue yeah?
018: Yeah
Interviewer: Is that something that’s currently a problem for you as well then?
018: That…combined with that…is that like cognitive?
Interviewer: Yeah
I've geared my life towards knowing my condition and dealing with it really well within the constraints of what I can do. Something to look at is that in terms of the other things again I think because I've been in the situation for so long, I've also geared my hobbies and things more towards my capabilities so maybe that's something to look at. In terms of output of work because it's less... and they're aware of it and don't over expect things from me and are more supportive in place... I get time off to attend appointments and so they're aware... so burdens aren't placed upon me in those right... Maybe that's something I could find out and discuss.

Interviewer: Do you know who you would go to too ask about that? Is that something you would ask your neurologist or MS nurse?

Interviewer: Yeah, because it's not something that happens that often... But when it does its just something I take as is.

Interviewer: So that's during relapses right?

Interviewer: Yeah during a relapse... I think that others are ok, I'm on... I've already got control over them I think.

Interviewer: I sometimes think to myself... about the top 2... but maybe I'm aiming a bit too high... but I used to play football 3 times a week before I got diagnosed and go running and stuff and now I can't do it... and now I... maybe I don't put myself in those situations because I think that's going to be a problem if I do that so I just don't do it for that reason... perhaps I could... but I don't want it to make things flare up... and the other things I think my partner sometimes get frustrated with me because I can't sometimes... referring back if I let myself get down because I'm having a relapse... I think because I've had the condition for so long I think it's something that I'm already aware of the potential support that is out there... I don't know if I'm answering these right...

Interviewer: Yeah, that's absolutely fine... so we are trying to again have one or two questions about partners because a lot of things about strains on relationships has come up in the focus groups that I've done... more maybe in cases of more serve MS than yourself... but in terms of the wording of these do you think the frustration is a good way to describe it?

Interviewer: Yeah I think frustration is definitely a key word... and personally I'm very frustrated so personal frustrated and... not that she does... She gets frustrated because maybe I'm not coping as well as I could... but like you say as well I think I'm quite fortunate in one respect that my symptoms aren't too severe... when I was younger I had one episode of flair up when I couldn't walk for a week to ten days... and that was hugely frustrating... but since then the symptoms I encounter are more severe fatigue and confusion and foggy headedness... but I don't think they're as bad as what potentially could be.

Interviewer: And what about in terms of, so you say your still working and everything, but you might get tired by the end of the day... do other work colleagues understand that? Are they aware of the situation and everything?

Interviewer: Yeah they are aware, my boss is, the company I work for are very supportive actually... so I've got things in place... I get time off to attend appointments and so they're aware... so burdens aren't placed upon me in terms of output of work because its less... and they're aware of it and don't over expect things from me and are aware of my condition... my output is going to be less than someone who isn't in the same situation and has more good health... so they are really supportive.

Interviewer: Yeah, that's good... ok so just the last few.

Interviewer: Maybe the bottom one... Just because I can't... I don't think I can do things that I used to do... like hobbies and things so maybe its gearing my hobbies and things more towards my capabilities so maybe that's something to look at... in terms of the other things again I think because I've been in the situation for so long I've geared my life towards knowing my condition... you know I deal with it really... within the constraints of what I can...
do, what I can’t do and again my partner she is fully aware of things so yeah… its kind of just knowing what I can do now that I couldn’t do 20 years ago and its learning to stay within constraints

Interviewer: Yeah, so learning to adapt?
018: Yeah exactly… just knowing I’m not the same person I was maybe when I was younger

Interviewer: Yeah, okay… so just in terms of the questionnaire… do you think all the questions were easy enough to understand? Do you think any of the questions could be worded differently?

018: Yeah I think they were fine…. It’s maybe the more difficult thing is because like you mentioned people who go worse condition can maybe apply those questions more… whereas someone who’s not got… the conditions not such a key thing…. Even though you still have situations where you feel rubbish, or you feel bad.. sometimes those ones where you feel well for more times than not, it’s difficult to apply those… because you think I’m don’t have a problem with this or that because for all sense and purposes I want to get it into my head that I’m as normal as I can, so you don’t think you have to face those barriers you know…. Obviously there are… when I go through bad patches but yeah

Interviewer: Yeah ok, sometime else that’s been mentioned as I’ve been doing these questionnaires which I haven’t included is sleep disturbances, I don’t know if that’s something the affects you at all?

018: Yeah it does sometimes

Interviewer: So I guess that would contribute to the fatigue you feel throughout the day as well

018: Yeah probably, last night for example I was woken up at about… 5 times to go to the toilet… so yeah broken sleep … so yeah I suppose I could look into different treatments specifically looking at fatigue and sleep

Interviewer: Yeah that’s definitely something that’s come up a lot.. so are there any other issues or difficulties that you can think of that we might have missed?

018: Ummm…. No I don’t think so no, I think that is definitely a huge one the sleep and the fatigue and cognitive problems that develop from that… so maybe they’re all interlinked… so if I looked at dealing with one that may have a positive impact on others… so it’s just finding out which one can be looked at, if there is anything else that can be another treatment for those

Interviewer: Yeah ok that’s great I’m going to stop the recording now if that’s okay with you

018: Ok, yeah thanks

Interviewer: Thank you

Think-aloudtranscription_STH20247_StudYID019
16/05/2018

Interviewer: ok so just to confirm you are okay for me to record you while we are going through this questionnaire?

019: No problem at all

Interviewer: okay I’m just going to go over some details on the front with you, so how old are you?

019: Umm 68

Interviewer: 68, and do you know your EDSS score?

019: I don’t even know what an EDSS is

Interviewer: Ok no worries, and what type of MS do you have

019: Well um I wish I knew but in principle its in my spine, but there are some issues with my brain as well

Interviewer: Ok and are you on any disease modifying treatment

I have had a course of…some years ago now…it was a disease modifying drug that I was given but your only allowed to have once in your life… and I had 6 courses of once in my life which was designed to slow down the progressive of my MS

Interviewer: but you’re not on that now?

019: No no, as I say I’m only allowed it once, because it’s a cancer drug

Interviewer: Ok so basically if you want to just take a quick read of the questions

019: No, I don’t, you just ask me the questions

Interviewer: Ok so the first few are about getting more information, so I’ve split them up into 7 questions here

019: Just ask the questions

Interviewer: I’m looking to reduce them down to less, so I’d like more information about my MS

Yes

Interviewer: Yeah so is that sometime that you think is important to you or you think you need more of

019: What I would say is that the MS …it seems to me that MS is well resources compared to certain other issues that people might have, but on the other hand there is still a shortage of people doing MS…and by that, I mean that I have an abnormal system that people see a MS doctor once a year..but in fact its been nearly two years since I was last here
Interviewer: Ok
019: And the way I get round that is I go private, and I’m in the happy situation where I can afford to go private, not on a continuous basis but occasionally I’ve seen oddly enough prof sharrak privately, when I see doctor Nair here on the NHS and one of the issues that I’ve raised with them…and they’ve reassured me that there is no issue…is that the linkage between being private and the NHS…but that’s okay they’ve got that sorted out …sorry I’ve wondered off the subject a bit
Interviewer: No, no worries that’s fine …so what about number 2…so information about different treatments available
019: No I am not aware of that…I depend on the doctors here…doctor Nair has in fact suggested that I change the one and only drug that I’m on to another one which is less damaging to my brain basically …so I’ll definitely follow that up and do it…and if I hadn’t of come I wouldn’t have known about that…I don’t have access to that sort of information
Interviewer: Yeah ok, so do you think that’s something that you would like access to
019: I think it all comes back down to …you know I cant do that on my own and if I was aware of that I wouldn’t know how to do with it …my GP wouldn’t know what to do with it… I need an MS specialist to do it and that’s why I come back to it its so good…this system works …and there’s a lot I could say about my experience at kalo, in chesterfield which is where I’m based, I’m a chesterfield person…and I went into kalo several weeks ago now when I was in a right mess…and I came out a bigger mess than when I went in because they don’t understand MS…and it was unfortunate that they weren’t prepared to bring me here for that treatment and in the end I had to go private to see prof sharrak which is not through coming here…so there is an issue here which is sort of a mechanical issue rather than being to do with MS…again we’ve wondered off the subject haven’t we
Interviewer: Yeah, no worries, so what about number 3; I’d like more information about extra health and social support services in my area
019: I am blessed with an excellent support system, prof sharrak again was instrumental in getting that, not organised, but enabling that to happen …the care system that I have at home is superb, except that, there aren’t enough resources to do what I’m supposed to have…so I’m well-funded..in fact I’ve got I think in my accounts, because I actually run the accounts myself …I think I’ve got about 4 or 5 thousand pounds unused in my account because there aren’t enough carers to use up all the money…umm so there’s an issue there…but that said the carers are very good and they do the best they can ….does that answer the questions
Interviewer: Yeah
Interviewer: So, what about number 4…I’d like more information about other charities or people with MS? I suppose you say you’re quite well funded
019: Yes, but in the past I have done charitable aspects as well …in the past I was…the MS society has branches all over the place..and there is a relatively knew branch, well not so knew now, but 10 years ago there was a relatively new branch in chesterfield which I was sort of one of the founder group and I was the person that looked after newly diagnosed people with MS so that I could steer them in the right direction…but one of the things that I fell out with them over is that I had a certain amount of funding that came through the MS society that I could give to people to help with their non-medical aspects, if you see what I mean and they basically stopped giving me that money and as a result of that…I objected strongly to that loss and I resigned my role as a consequence ….so looking now at the branch, which is still relatively underfunded and compare that with derby, I don’t know if you know about the derby branch?
Interviewer: No
019: It would be worth asking about the derby branch if your particularly interested because that is very well funded, they have a room which is an MS room, which is in the middle of an industrial estate…and they have activities…I think it’s 4 time a week or something..but they have all sorts of activities, its really dynamic whereas in chesterfield there isn’t a history of that funding and it becomes a bit cliché and I don’t approve of that…it’s got to be open and inviting…and I felt that I was unable to do what I wanted to do and so I stopped being active..I still pay by subs and that but I don’t stay active…also it’s an interesting aspect of it which I’m very aware of, is that Ms seems to be more female than male orientated and women are different and so I am quite content to stay at home and really look after myself with my carers…whereas I’m aware that the women have a sort of group…all sorts of group activities which they do…and they’ve invited me to go to these but I choose not to do it…and I just sort of note that and its interesting
Interviewer: Yeah ok, um so how about number 6 …so I’d like more information about exercise lifestyle of diet …do you think that’s something that’s important to you
019: It is…but only because I’ve taken the initiative myself..I’ve got a dietician ….I was in a right mess…when I went to the hospital I was in a right mess…my daughter god bless her found a dietician..who herself has got MS..and she has steered me and I feel that has made quite a difference to my condition in that I’m eating a lot better than I used to …cause I live alone my wife died 12 years ago its been very easy to eat rubbish and not eat properly, but the dietician has got me on the straight and narrow and I do recognise that that has helped
Interviewer: So that’s something that you kind of found yourself
019: Yeah, but I do believe that there is…I don’t know how it could be done with in the NHS…but just to alert people that it can make a difference would be a valuable thing for others
Interviewer: Yeah okay, so number 7 I’d like to know about new trials for MS and how I can get involved
019: Absolutely yeah, include me in
Interviewer: Yeah okay, do you hear much about new trials?
019: No its only when I come here that I hear about these things you see today they’ve suggested that I…I only take one tablet for my MS and he said that there is another tablet that is better than the one I’m on at the moment so I didn’t know about this until he explained it all to me this morning…so I’m very pleased that he’s done that and his going to get my GP to prescribe this new or alternative drug …so that’s good but I think there is a danger more generally in people that think they know everything about MS but in practice just completely get it wrong…and therefore I’m not quite sure what the answer is…we’re all, we the community of people with MS, we’re all looking for answers, but I have this suspicion that sometimes the answer is more wrong than right and I don’t know how you deal with that other than with experts so you know…I don’t know if that answers your question or not but that is the issue as I see it
Interviewer: Ok so, number 8 I would like there to be one place where I can find out all the information I need
019: Yeah, that’s here, and that is back to my experience again in chesterfield where I went into the hospital there at kalo and the experience was awful and I believe to this day that they misdiagnosed me..they thought I have things wrong with me that I don’t believe I do have wrong….and this place is…I get quite emotional about this place…because I really believe it’s fantastic…and to go to kalo where they didn’t know anything about MS was just a backwards step and that’s down to the limitations of the NHS..that they wouldn’t let me come here..and I asked them
Interviewer: So, number 9 so we’ve kind of touched on this already, but I’ve got lots of problems and would like more opportunity to talk to a specialist about them …so obviously you say you have yearly neurologist appointments
019: Yes, but the yearly appointments have fallen back, so it’s really getting on for 2 years since I was last here…so I would say it’s very important that those yearly appointments do happen…that’s about resources in the NHS at the end of the day
Interviewer: Ok so number 10, I would like to know more about what to do if I have a new symptom or problem
019: Yeah, its an interesting one that, because back to this place and access to this place..and on the other hand the resources that they have here are clearly limited and there’s a balance that has to be struck…that’s a difficult question and I don’t know what the answer is..because what you don’t want is people wasting professional time..on the other hand I suppose the answer is that it comes back to the GP and for the GP to make a judgement about how to take an issue forward but my experience with my GP..there is a GP allegedly  in chesterfield that knows all about MS…and I tried to track him down and failed basically..so the doctors that I used who are very good I can’t criticise them..but when you mention MS to them they just sort of back off….its not within their comfort
Interviewer: Yeah ok, so number 12 I have lots of different problems and they don’t get solved quickly enough
019: I think its under control to be honest
Interviewer: Ok, um I have problems with my vision and need some help with this
019: Vision…I’m very lucky that my sight is good..but I’ll tell you a story now and this happened several years ago..but I had been diagnosed but I was in better condition than I am now and I think I was actually driving so that really does go back a few years..and suddenly the core of my eyes stopped working, and extraordinarily my body corrected it so here I was driving and I couldn’t see the number….I was looking at the um..umm
Interviewer: Dashboard?
019: Yeah thank you..I was looking at the number and the middle number was missing..but my body put in a blank so it knew what was on both sides and filled in the gap even though it got it wrong..and I thought that was astonishing..that mechanism in your brain that does that…a couple of days later my sight returned to normal and its been normal ever since but it was quite an extraordinary teaching
Interviewer: Yeah, I bet, that’s interesting
019: I don’t drive anymore though
Interviewer: Ok so question 14, I have problems eating and drinking and need some help with this
019: I suppose I do in a minor sort of way, there is a limit because I’m stuck in a wheelchair to what I can and can’t do in the house and the carers take care of that but even eating…I do eat by myself so that’s good, but I’m aware that it’s not quite as easy as it used to be
Interviewer: Okay so 15, I have problems speaking or making my voice heard
019: The only problem I have that’s an MS sort of thing, my memory is shot, my immediate memory is shot and its quite interesting that I sort of test myself everyday and I’m aware that I can remember things for seconds, but if I go back I can’t remember…so specifically…just to explain what that’s all about…I self-manage all my
finances and I’ve learned an awful lot about how to manage my funds, which I do via…err…you’re now experiencing not a memory loss but a gap I’m having to fill to explain to you…I…my source of income is through shares, which I manage all myself and it’s been very successful and so it funds visits and doctors and things that I have to pay for, it funds my lifestyle and I keep on top of it very carefully…I’ll tell you the numbers so that you understand… I have a normal income of about £600 per month…over and above my state pension and things like that…and I can take that out of my personal funds…but over the years, my personal funds have not depleted…and that’s because I have kept on top of my financial arrangements…and that is a thing that keeps my brain going….I think its important that I keep my brain going….I produce a magazine every quarter…I’ve got one that I’m about to do now…and again that’s another thing that I’ve learned that I have to do a formal process to produce this magazine…so I do it in stages…and it works, but I’ve learned that I have to do it mechanically…mentally mechanically…but it does work and I’m determined to keep that going, to keep my brain going

**Interviewer:** What’s the magazine on

**019:** Well, sorry its very boring, it’ll be boring for you umm..there is a proper London bus…a group called the route master association, which I’m a founder member of and I produce their quarterly magazine..and I’m very pleased to say that its quite a professional magazine..it’s not just a knock it out on a piece of paper thing…it looks good..and I produce that every quarter…it takes me about 2 weeks to assemble all the information and then make it right…and I’m quite comfortable about doing that..I’m in the process of taking out a second magazine..which is proving to be much more difficult because they want me to use technology that I don’t want to use…and I’ve got to fight that battle I will use the same technology that I use for the other magazine which will be ok…but I’m afraid I’m up against people that just have a different view about it

**Interviewer:** Ok so 16, I have problems with my grip or using my hands and would like help with this

**019:** Umm…I agree to the first half and don’t agree to the second half so yes, I have problems but no I don’t need help

**Interviewer:** So, 17, I have difficulty walking and would like help with this

**019:** I can’t walk

**Interviewer:** Yeah

**019:** Well that’s one of the reasons I’ve come today, because I want to see if there is anything I can do about it, so…it would be very easy just to accept the situation, but I don’t like accepting the situation

**Interviewer:** So that is something that you would want more help and advice on

**019:** Well yes, I’ve spoken to the doctor about it today and he is well aware of my comment..so the system works its just the balance of once a year…how often do you do these things…so I’m content

**Interviewer:** I would like help managing spasms or stiffness

**019:** I would say that I’m not that bad that I need help..so yes, I recognise the question, but I don’t at this point in time need assistance

**Interviewer:** I would like advice on managing fatigue

**019:** I don’t think so I think I’ve got it under control

**Interviewer:** Ok that’s fine, I would like advice on bowel/bladder management and care

**019:** Again, I’ve got it under control….when I was bad a…I was going to say doctor but he wasn’t a doctor I don’t know what he was…a lesser doctor …made me…use all sorts of items of plumbing which eventually I just ripped it all off and said I’m not doing this and reverted to self-catheterisation, which is what I still do now ..and that was the best thing I ever did…so he was trained in the use of all this technology which was inappropriate

**Interviewer:** Was it an occupational therapist?

**019:** Yeah

**Interviewer:** Ok, so 21, I would like help managing pain

**019:** No, no its ok because I don’t have pain

**Interviewer:** Ok so 22, I have problems because I’m not very mobile, for example swollen feet and skin problems, and would like help with this

**019:** Skin problems…. I have had skin problems and I’ve put them right….so no that’s it really

**Interviewer:** I have problems with skin sores or pressure sores and need help with this

**019:** No

**Interviewer:** My brain sometimes works slower than usual, and I would like help with this

**019:** Oh, tell me about it, I don’t know about help..I don’t know what help there could possibly be….so again it’s a case of yes but so what

**Interviewer:** I often find my mind wondering and would like advice on how to deal with this

**019:** This is all back to…I can only deal with one thing at any time…and if I wonder then I find it difficult to get back to where I was

**Interviewer:** Because of the memory?

**019:** Yes, but my analysis is that there is nothing you can do about it..it’s just me
Interviewer: So, 26, we’ve touched on already…but I feel my memory has worsened since being diagnosed with MS
019: Oh, no doubt
Interviewer: Yeah okay…I feel that my cognitive abilities have decline since my diagnosis and would like help with this
019: Well again its, I accept that things have got worse…I’m not sure what help there can be …I would love to have help but I don’t recognise a solution there…make of that what you wish..
Interviewer: Umm I would like more support or advice on the cognitive aspects of MS
019: Hmm…well I suppose I have to say yes, I’m not sure that its feasible or what there is that would do it..but yeah anything that would help potentially you’ve got to accept…you’ve got to go for
Interviewer: Ok so 29, I would like more emotional support
019: Hmmm no
Interviewer: Okay
019: Sorry I….its quite an interesting subject that…my wife died 12 years ago and my family even to this day are still recovering from that …and my…and that in turn makes it difficult for them to deal with me…and I’m overstating all of this but I am aware that there is an undercurrent that they wouldn’t admit to of the loss of my wife …and for that reason they have some difficulty in dealing with me….and I recognised that and I accept that…I don’t push you know….that’s the way it is
Interviewer: Ok so 30 I sometimes have low mood and would like help with this
019: I’m lucky that I don’t…I’m lucky..I recognise that
Interviewer: Ok 31 kind of similar...sometimes feel worried or anxious
019: Hmm…I don’t
Interviewer: Yeah okay…33 I’m guessing this isn’t going to apply to you, but I need some help or advice organising my finances?
019: No …no… I deal with that
Interviewer: It sounds like you’ve got that under control
Interviewer: Umm again 34 I need help making adaptations to my home
019: Well I cant do them…so yes I do yes…but I’ve tried to keep ahead of the game…quite an important point really as a general comment to anticipate the next step down and to try and keep ahead which is what I’ve done…so can’t go up the stairs obviously…and it’s a two floor house…everything now is organised on the ground level…so that works…but it was all done in anticipation to keep ahead
Interviewer: Okay yeah that makes sense
Interviewer: Okay, so 35 I would like advice on how to do the things I used to enjoy but now find difficult
019: That’s a very general comment that…. I don’t think so, yes there are things that I would love to do but I’m not sure that advice would make the slightest difference
Interviewer: Okay, I would like advice on planning for the future to ensure my wishes are met
019: That is a good one, yeah, I tick that one
Interviewer: So 38…well 38 and 39 are more about partners who might be caring for you but obviously you’ve got carers who come in
019: Yeah
Interviewer: Number 40, so I feel other people like my boss or friends don’t understand MS and I’d like advice how to cope with this
019: No, they do, they’re not stupid, they’re very caring
Interviewer: Yeah okay good…
019: You might say one of the curiosities of my lifestyle, is although I’ve lived in chesterfield for whatever it is…25 years…my social life is not based in chesterfield…and therefore I have relatively few friends in chesterfield…I have some…but I have friends all over the place, elsewhere….north, south, east, west I’ve got friends..but not in chesterfield…it’s a curiosity…anyway carry on
Interviewer: Ok, so 45 I’m worried about how other family members are affected by MS and would like some advice on this
019: When you say by MS what do you mean
Interviewer: So how other family members are affected by the fact that you have MS
019: Well exactly that’s the point, that they haven’t got MS…it’s me that’s got MS and yes, they do struggle to deal with it….I’m sure of that…but you know they’ve got their own lives….a family…I’m a grandparent and I’ve got to allow them to deal with matters their own way…. I don’t interfere
Interviewer: Do you think they struggle to understand it as well?
019: No, I think they understand it fine, but they struggle to deal with it
Interviewer: So just the last one here, I would like to find out about hobbies or holidays that I would be able to take part in
019: Yeah that’s a very big issue that for me...and the issue there is that no two people have the same MS...and therefore it is very difficult to generalise on what a group of MS people can do and can’t do...and I would love to go abroad and it would be really good if I went with a group of people with MS...the trouble is people who have got MS up here and down there and because there are no two people with the same MS, its hard to group them together to cater for everybody so in theory a wonderful thing in practice cant be done...in my analysis

Interviewer: Ok yeah that’s fair enough ...ok so we’re done with the questionnaire then...so what did you think in general...were all the questions easy enough to understand?

019: Yeah

Interviewer: Are there any things in particular that stood out as being really really important to you?

019: I would say that I am very bad at local communication..and its because I’m inactive in that respect..having given up on the MS society...and that is a definite weakness

Interviewer: And are there any other problems that you’ve faced in the past or are facing now that we haven’t covered

019: No, I don’t think so, I think the system in its broadest sense is very good ...I think when you’ve got MS you’re actually quite lucky in that the system is really good... it could be better of course

Interviewer: Okay that’s great thank you, so I’m going to stop the recording now, thank you

019: Ok, thank you

Think-aloudtranscription_STH20247_StudyID020
16/05/2018

Interviewer: So just to confirm you’re okay with me recording you while we go through this questionnaire?

020: That’s fine

Interviewer: Ok, so I’m just going to go through some details on the front first, so how old are you?

020: I am 59

Interviewer: Ok and what type of MS do you have?

020: Well apparently,.. from what I’ve what doctor Nair was saying its secondary progressive, he said it probably is that...but no body has actually told me that before...I just sort of made it up reading about what people say you know

Interviewer: Ok that’s fine thank you

020: So you know I don’t know my label yet

Interviewer: Okay so the first 7 or so questions are about information about different parts of MS. If you want to take a quick look through them and let me know which ones you think are the most important to you or I can read it out for you if you want

020: Maybe I’ll put my glasses on that might help, keep forgetting I’m long-sighted...it’s age

020: I think information is always important, am I supposed to say whether it’s a problem?

Interviewer: Yeah so if you think it’s currently something that’s currently a problem, or something that hasn’t yet been met by the MS service...so some people I’ve spoken to have said they have lots of information about MS but that’s because they themselves have gone to fine that information

020: Yes absolutely, I’ve done a lot of that myself as well

020: I think maybe the thing about the treatments as well, I found out about those from different websites follow really..I don’t hear it particularly...well if things are on the news you find out about them and then you can research them more...and speaking to Dr. Nair then...otherwise I wouldn’t know...but it’s difficult because people don’t want to be bombarded but at the same time you want to know stuff....so it’s very varied..but obviously there are some positive things happening as well

Interviewer: So, what about number 3?

020: Oh absolutely, I mean that’s absolutely vital for everybody...and at the moment it’s so hard.... the assessment process the trying to reduce the amount of hours I get from hospital appointments now..I’m supposed to do it without a PA with me...stuff like that...it’s just impossible to do really ....

Interviewer: So do you go to any extra classes or anything else extra outside of the hospital?

020: Umm physiotherapy...I have a social worker and all that sort of things, and I have the council for information about...you know to connect the information you get from the council and the hospital and they can fit together...and nobody really does that

Interviewer: So one place where everything is? A more connected service?

020: Well yeah, the things I’m doing with disability Sheffield is sort of connected to that and I think ...the university asked me to do stuff as well and Hallam university. But it’s not all in the same place so its hard...but that whole sharing loads of information thing its not that simple really is it

Interviewer: So are there any of the others that jump out at you as something that’s really important

020: I think that one about diet, I think diet is really important, and exercise

Interviewer: Is that something you have information about already?
Well, after I was first diagnosed and I came to see my GP, they’d done a lumbar puncture, so he just didn’t really know what to do with me in 1987...but he said one of my patients has MS and he went to the homeopathic hospital in London...and I went there...and they talked a great deal about diet and exercise and they gave my physio as well as the homeopathic remedies and the things that are like caring for your health as well as your physical health...so that was a really good start and then...trying to carry that on to keep going there and then also my recent GP said he’d rather believe in miracles than homeopathy...so he wasn’t very keen...but hat approach that they were doing there was fantastic...you were getting a lot of information about caring for your whole self...and they gave me a proper idea about diet and trying to reduce yeast in your body and talked about all different sorts of diet studies and even gave me primrose oil on prescription until that was stopped on prescription...and that sort of thing is really important

Interviewer: So, what about number 7, I’d like to know about new trials for MS and how I can get involved

020: Well umm yeah I would...I’ve...but I don’t know about anything that’s...I wouldn’t really like to have any injections of things that take away my immune system or anything like that...because I think that’s not the way to deal with things...but there are plenty of trials going on about other things

Interviewer: And are you given information about that?

020: Yes, absolutely and I have done some...I participated in one...they’ve just published a paper now I think from the university...it’s about research and movement in MS and trying to make a similar way of doing research...so that was non-invasive

Interviewer: Ok shall we go onto the new page then, so we’ve already touched on the first one...is that something you think is important

020: I think that’s very important really because people...I’m looking for information at could be a place that everybody else can get to as well as find it out...including people in physiotherapy department and...there’s a thing between whether its MS related or other parts of the body related...and they say oh can’t touch that because that’s neurology...ooo can’t touch that because that’s physio...so it would be nice for them to make more connections there...I don’t know how you do that really...but communication between departments more I think...I think its vital but I don’t know how much people know about...you know just simple sign posts might help I don’t know...communication is key

020: Ahh umm I think that is always relevant to know

Interviewer: Number 9 yeah?

020: Yeah...because I mean sometimes I think I can ring the MS nurse about this...but sometimes I forget about the MS nurse being the go to person really and I can’t always talk to the MS nurse about all my problems can I...but there are so many different specialists that you’re connected with...so I’ve seen a lot of specialists recently, but I don’t feel like they connect..

Interviewer: Yeah so do you think it would be good to have one person

020: Well yeah maybe you could have a picture of my body and point to the different parts...would that work

Interviewer: So, what about number 10 then, what to do if you have a new symptom or problem...is the MS nurse your first port of call if something new happens or if something progresses?

020: Yeah...I think so...but its very hard to know if things are new or if things are that different because they are so gradual...so you don’t always realise and then you suddenly think oh this has been like this for ages maybe I should do something about it...its not just a new one but its about recognising that things have changed somehow...so I suppose that it’s probably not new but I suppose it counts as you’re newly trying to do something about it...so what to do then I don’t know

Interviewer: What about 11 or 12 so know more about how to solve problems quickly

020: Um yeah absolutely. That would be great...because if you’ve got a problem you normal speak to somebody and you have to wait to speak to this person and that person so yeah if there was a way of doing that easier

Interviewer: So 13, problems with vision...is that something that is important to you or currently an issue

020: Well I have got some yeah...I’m...I was short sighted, and I had a laser

PA: laser

020: Yes, laser treatment on my eyes...then I started getting longsighted and now I have to wear glasses to read again...and also I have a bit of double vision and stuff as well...what did Dr Nair say something about that...oh no that was my swallowing sorry

Interviewer: Ok so you just get a bit of double vision in terms of MS related problems

020: Yeah because I get too hot quite a lot and I get tired and so that effects it more

Interviewer: So it gets worse when your warm or tired

020: Yes it gets worse then

Interviewer: Ok, so 14 I have problems eating or drinking and need some help with this?

020: Umm oh yeah that’s what I was talking to...I have some swallowing problems...and also I can’t cut things with a knife and fork so I have to eat with a spoon or have things cut for me or...I have a smoothie I bought with me today for my breakfast...so trying to eat enough...I have to eat little and often so I need to have a little bit
of an organised plan for it but that’s just another thing that needs organising you know ...and Dr. Nair said something about speech therapist for problems with swallowing...so he’s going to write that in a letter to my GP

Interviewer: Ok yeah so they’ll look at things like swallowing for you ...so what about number 15, making my voice heard?

020: I do yeah, being tired, being not very loud, being low down...and also I get a bit short of breath and...I can’t get words. I keep forgetting words...or just run out of steam...I find it quite tiring as well

Interviewer: Ok so 16...problems with my grip

020: Yeah I do yeah

Interviewer: So that’s something that’s currently an issue for you?

020: Yeah I drop things all the time and sensations things like that...and I have been given some exercises to do from the physio

Interviewer: Ok yeah so does the physio help with that?

020: I have had some exercises but I think maybe I need to refresh them now seen as my hands aren’t getting any better really so I think there could be a different way to do it...and also I get a lot of pain in my bones and joints that I didn’t have as well...and my hands so I don’t know if that’s to do with the osteoarthritis or ...

Interviewer: How often do you see a physio?

020: I’ve been seeing one over the past...since last year was it?

PA: I think so

020: Yeah I’ve been seeing her for quite a while but she’s leaving so the next time I’ll see somebody else...but I saw her quite a bit maybe...

PA: every other week or so I think

020: Yeah, over a while ...so maybe 3 weeks and then ...they tend to say you can only have so long and then you’ve got to go ...I used to have physio that came every week just to do some leg stretches with me and that just ...but they stopped that so

Interviewer: Ok so shall we go over to the next page

020: Yes, I do have difficulty walking...and I’m having some help with this with the physio at the moment and she’s given me exercises and she’s also tied to get a walker for me just to have at home to try and use at home...because I used to walk with my crutches..but she said stop walking with them because they’re not safe really

Interviewer: Ok so that’s important but something you’re getting help with at the moment?

020: Yeah but I don’t know how long it will go on, so I’m hoping it will last longer

Interviewer: Ok so what about 18?

020: Umm yes somewhat that one...I have sativex and that does help a lot and the physio gave me some leg stretch exercises to help with my leg, but I also have stiffness and spasm in fingers and arms and things, so I probably want something to help with that as well...because that’s quite difficult

Interviewer: Ok so how about 19?

020: Well yeah I’ve had quite a lot of contact with...I saw the psychotherapist about my...because my memory was really bad...and he said that’s a result of mostly fatigue more than anything else but the effects everything...so my daily life is so effected by it...so I’ve got information about it and I try to implement it ....I try to manage it but any more information would always be useful...and I was wanting to...they were talking about a fatigue management course ...I think the MS nurse were talking about it...that they were running one...but going to a course itself is quite hard

PA: by the time you get there you’re tired

020: Yeah, so it’s quite difficult really

Interviewer: Do you find that you have sleep disturbances as well?

020: Yeah a lot

Interviewer: So do you think that potentially contributes to the fatigue as well?

020: Yes definitely, and overheating does...

Interviewer: Yeah it makes symptoms worse

020: Yes, so if I’m too hot it makes me feel heavy as well and I can’t move my body as well and you know...it slows me right down

Interviewer: Yeah...so number 20...

020: Um yeah that’s always useful I mean I have Botox for that, so I’m connected to urology...so I have, and I do intermittent self-catheterisation...so that’s all I have really...more information might be more helpful

Interviewer: Is what you’re doing at the moment working for you?

020: That’s working yeah

Interviewer: So we’ve spoken a little bit about pain but what about 21? Is that something that’s currently a problem?

020: Yes it is, I go to the pain clinic at northern general and they’ve been treating for arm and shoulder pain a lot and neck...but now I have a lot of pain in my hips now as well because I’ve been told recently that its
arthritis…so I’ve got pain in my hips and my back as well so trying to monitor that better…I don’t know how to do it at the moment because I’ve only just found out about it…so Dr. Nair said he would talk to my GP about it because apparently MS and arthritis impact quite a lot on each other …so that’s more stuff to find out …to know what to do

Interviewer: Ok so 22, is about secondary problems due to being not as mobile so swollen feet, skin problems, pressure sores..is that something that’s a problem for you?
020: Not at the moment no..I suppose justs postural problems and stuff like that…continually cold feet..I don’t know what else…and just like…I don’t know…when it says problems with not being very mobile….does it just mean like physical problems or does it mean general life problems as well?

Interviewer: No, so more of the questions later on address more emotional, psychological problems …so 24….my brain sometimes works slower than usual, and I would like help with this
020: Yes, well I was saying to the psychologist I’ve had some input from him for that umm so obviously more help would be useful….probably need to put it together in a different order don’t you..it’s all mixed up

Interviewer: Ok so what do you think about the wording of these two questions? 24 and 25…does one of those apply more so to you or are they both relevant
020: I think both, they are absolutely both relevant ..because it’s also about …its connected with the fatigue again…it’s all about the fatigue really

Interviewer: Yeah ok, so we are getting onto more of the memory and cognitive things now
020: So..this is what I was saying about seeing the clinical psychologist….because I was worried about it…so he wrote a big long report….because we did serval assessments and everything….and then he said it was down to fatigue mostly….my memory and brain works fine but it just …the fatigue effects it

Interviewer: So, did they give you strategies to deal with that?
020: I’ve got a book about fatigue management…and that’s quite useful…I’m trying to sort of use those techniques…but its quite difficult…I do a lot of stopping and lying down between stuff,,,so that is important

Interviewer: So, what about 27, 28, advice and support on cognitive aspects of MS
020: Yeah I think so yeah

Interviewer: So that’s something that’s important to you?
020: Yes it is

Interviewer: And is that something that’s currently a problem too?
020: Yeah I think it is really yeah..and I don’t know if its partly not hearing properly, or not listening properly or just being too tired….all of those things

Interviewer: Do you think you’ve received, over the years, less support on the cognitive aspects compared with the physical aspects?
020: Oh yeah I think so, because its all about…and obviously the physical is the stuff that you see first and feel first but the cognitive….that’s just in you head you know….so no one else really knows what’s happening….or they hear what you say and just think oh they’ve lost it now….so you know just more information about why…the thing about the fatigue was so important for me to know….also apparently you are loosing brain cells more….so knowing more about that and how does that effect you as well….will I get dementia….you know all those things

Interviewer: So sort of more information about that stuff would be helpful?
020: Yeah yeah

Interviewer: So going onto 29?
020: Well that’s vital for everybody, I think so yeah

Interviewer: Is that something that’s currently a problem for you?
020: I think its always been a problem really….from when I was first diagnosed….and there was very little information about it then….I knew very little ..and the things I read told me that well my life is probably finish….and also its very frightening because I couldn’t walk properly and then I could walk again….and all that stuff…and I got really depressed for quite a long time…..and the hospital ….the homeopathic hospital actually was quite good because they did some emotional stuff as well and I did used to go to ….someone from the MS society used to come and talk to me….which was really useful actually in telling you stuff you had no idea about

Interviewer: Have you ever been to any support groups with other patients with MS? Has that ever been something that you’ve done or heard of doing?
020: No, occasionally I’ve been to councillors, when I’ve managed to get seen..I think 6 weeks is the time you can have…probably not even that now….yeah…but also one of the thing about going to the MS society was..when I first new I got MS I didn’t know how I could be now ..and I didn’t want to spend time with other people with MS just because we’ve got MS but on the other hand maybe something where it felt like it was just part of everybody’s life to just connect with each other somewhere…not like an official thing…but provided so that you could go…I don’t know…it’s a weird thing really…I think it might help….or even to have an outing to the woods, spend the time in the trees…I don’t know
Interviewer: Ok so the next 3 are all based around emotional support...are there any of those that you think are more or less relevant or more or less important or would you say they're all things that you’ve experienced?
020: Yeah definitely...I think MS has affected me massively for the last ...all through this assessment type period...ever since the new government...ever since the Tories got in here...so you know that I think has affected my blood pressure and you know stress can affect osteoarthritis apparently you know...so they’re killing me quicker ...and that you know sometimes I feel I get snappy with people and its frustration as well as tiredness you know...but you cant spend your time shouting at people who are supposed to be there for you so that’s really quite difficult to ...and maybe that’s a thing I could do ...with something with my PA’s so they could I don’t know how a signal, or shut me in a room or put a bag on my head ...or give me a tequila or something
Interviewer: So what about 33?
020: Oh yeah I think so, I’m actually regarded as a small business due to some of my ..because I employ people, so I have to do all the contract stuff, payment stuff, or you have to get an agency to do it for you...so there is a lot of work about that...it’s not just...so that
Interviewer: So that’s something that important?
020: Yes it’s very important
020: And finances, yeah
Interviewer: Is that something that’s currently a problem for you or have you got it all...?  
020: Well I think not at the moment because.these years have been so chaotic recently...and we are still trying to work out things that the council still have to pay in and writing another letter
PA: a lot of work
Interviewer: Yeah ok, so how about 34 help making adaptations
020: I’m hoping at the moment I am ..I’m hoping to get an electrical rising floor/sink put in ...the thing about them is that the people who turn up to do it don’t connect with...they don’t look at the whole picture of what they’re doing...they look at what they’re putting it and fit it around what’s there already ...and I just think ...if you take a little bit longer just to work on the design of it to start with you know...it’s really important I think that they collect with each other..so its communication again
Interviewer: So do you want to turn over then
020: Oh that’s really important too I think ...but that’s a lot to do with ...access as much as anything...also...places being made more accessible...or easier to get to ...sorry I’m a bit...
Interviewer: No its fine don’t worry, so how about 36 then advice doing things you used to be able to 
Yeah I think all those things are important you know...driving a car maybe...maybe I should get a car again and I could have my PAs to drive it...and I could drive it occasionally you know if I felt like it...so that sort of thing might be a possibility
Interviewer: So it would be useful if you had someone to talk about it or give you advice on the best thing to do?
020: Yeah, if I could just like use those car schemes when you pick one up and use it for a certain amount of time...but you have to sign up to do that...so how do you work out how to do that
Interviewer: Yeah okay...so 37...I’d like advice on planning for the future to ensure my wishes are met
020: That’s really important I think
Interviewer: Is that something you’ve had already? Have you had people to speak to about that?
020: No, not really...that doesn’t come in to it does it...the assessment is not about that sort of thing at all ...social services, health services...yeah that’s a big one isn’t it
Interviewer: So the next couple are about partners or relationships because some people have partners who are also caring for them...I don’t know if that applies to you or not?
020: Well I don’t have a partner...I have PA’s...and I think it’s really important to ensure our relationships is properly looked after as well...because I’m having to employ them and they’re having to be my employee and so I have to ask them for things...and I need them to do things for me...but I don’t what it all the time...you know it’s a very difficult thing...trying to work out our...sometimes I think it would be good to have a bit more support for everybody ..
Interviewer: I suppose it’s more than just an employee-employer relationship
020: Yeah and it’s the communication between all of us as well...
Interviewer: So how about 40? I feel like other people like my boss or friends don’t understand MS? How have you found other people that have been around you
020: Well I think that’s true...yeah coping with that...well just dealing with it or...its difficult really that one...because its quite hard to do...
Interviewer: Do you think other people, or I guess the general public would benefit from knowing more about MS?
020: Yeah I think so really… I mean …because its …a lot of people have it don’t they …and a lot of people don’t know that you can be walking and whatever… or you can use a wheelchair one day and not another day …all those things… it education yeah

020: And also the idea that they should make reasonable adjustments you know, they should actually do it…my sister worked in a place for quite a long time …in derby I think…and she started to have to use a wheelchair for some of the time or walk with a stick or something… and they had a lift which was broken and they didn’t fix the lift… for like over a year… and just… that is so poor… I mean she should have sued them or taking them to court and I said to her she should do that but she’s like oh no its alright but that should never happen should it

Interviewer: No of course not… ok 41, 42 again about partner/careers

020: I think that’s what I was saying about my PA’s need support too… but obviously they work for me so trying to fit that in with work time you know… it’s difficult

Interviewer: Yeah difficult to do… ok so if you go over there is just the last few there… nearly done

020: Oh I tell you what emotional support, I think about my sister now more than myself… both my sisters have MS and they both have partners who support them, who care for them… and I think they need some sort of support you know… but they would probably say they wouldn’t so I don’t know you know… it’s quite a difficult thing but I do think it’s important… but its how to word it so that it doesn’t feel like they’re being you know?

Interviewer: So they’re not being made to feel they’re not doing a good enough job?

020: Yeah I think so and then you can have a conversation that isn’t just about their relationship but how they can support each other or help each other more to do some of the things… nothings ever going to be perfect though is it

Interviewer: So yeah these two again are about relationships

020: Yeah I think that is true of all relationships I’ve had really because you know, so big strains some not so big, because in my head as well as the connection with other people… I don’t know many people now, apart from the family… there is very few of my friends that I still know since the diagnosis… I know some different people, I’ve met different people but…

Interviewer: Do you think that’s due to a lack of understanding?

020: Yeah and a bit of fear I think and also not knowing what to do and also you know I think I was… I went into a very internalized phase where I didn’t particularly want to …

Interviewer: So what about 45? Other family members

020: Well both my sisters have MS, my youngest sister has 2 daughters and I’m sure she’s worried about them, and they are probably worried too… you know… my parents have been worried since forever… they’re trying to find ways of dealing with it… and us being able to share stuff with them without worrying about them… 46, yeah I would love it… I do some things now, I do life drawing once a week but you know I’d like maybe to do a bit more stuff in the university now… I used to I did an access course to the arts… I would like to try and do that again maybe in Sheffield… but it’s a huge undertaking you know… but I would like to find out more about how I could do that… how to make it easier or if its possible…

Interviewer: Yeah okay, so that’s the end of the questionnaire, so I’m just going to ask you a few questions about it if that’s okay with you?

020: Okay

Interviewer: How did you find it? Did you find it easy enough to understand and take part it?

020: Yeah although I was getting quite tired and confused and also because its quite nosy round here it’s quite distracting

Interviewer: I know ideally we would have had one of the rooms but they’re all booked out… but what I’m doing for the final questionnaire I’m quite significantly reduce the length of it because I’m aware its often quite difficult to concentrate for long periods of time… so hopefully I’ll be able to get it down to 25 or so

020: Well yeah you might be able to combine some of the questions because it covers some things twice

Interviewer: Yeah so I’ve been working at combining the questions and which ones are worded better so that’s what I’m working on at the moment… do you think there was any other problems that you’ve experiences that I haven’t covered?

020: I mean probably you’ve said most of the things…

Interviewer: What about in terms of… obviously MS is more prevalent in women and often are diagnosed quite young… what about in terms of information and advice on pregnancy and family planning because I know that’s a problem that can be quite difficult for people

020: Oh yeah because what I did actually is decided I was going to have a sterilisation, so I had that… and they were saying you’re too young why are you wanting to do this… and I said because I don’t want any babies its hard enough managing my own life without a baby as well… and I don’t want to accidently become pregnant

Interviewer: Were you given enough support and information when you were making that decision and going through that process, did people talk to you about pregnancy and MS or was that something you decided yourself
020: Umm I think I decided it myself, but I’d always thought I don’t want children…so that was fine for me…my sister has daughters…and I don’t know how much support she had actually…

Interviewer: Did she have them after her diagnosis?

020: Um no, she was diagnosed after she had her children…so that was also very hard for her to tell her children…you know really hard…and she didn’t know how to do it because they knew my sister and I both had it…so its also how do you talk to your children about your MS…and what do you say about the likelihood you might have a child with MS…and does it matter you know…Don’t make MS into such a terrible thing…but at the same time its like yeah

020: So yeah information or advice about that I guess is something that’s important

Interviewer: -Yeah, ok that’s great that’s everything…so I’m going to stop the recording now if that’s okay with you?

020: Yeah that’s fine
Appendix M:

Phase 3
Time point 1

To be filled in by the study investigator

Date ____________
Age _______
Gender ____
EDSS ____
Type of MS ________
DMT Y/N
Time taken to do the LUN-MS ______

LUN-MS

Please read each statement and answer it as follows
✓ Tick ‘YES’ if you agree with the statement
✓ Tick ‘NO’ if you do not agree with the statement or it doesn’t apply to you

1. I would like more information about the different treatment or trials available for MS

2. I would like more information about extra MS support services in my area

3. I would like more information about how to look after myself, such as exercise, diet and lifestyle

4. I would like more information about MS and pregnancy/family planning

5. I would like to know more about what to do if I have a new symptom or problem

6. I have difficulty walking and would like help with this

7. I have problems because I’m not very mobile (e.g. swollen feet, pressure sores) and would like help with this

8. I have problems eating and drinking and need some help with this

9. I have problems with my vision and need some help with this

10. I have problems speaking or making my voice heard and need some help with this

11. I would like help on bowel/bladder management and care

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**Please read each statement and answer it as follows**
- Tick 'YES' if you agree with the statement
- Tick 'NO' if you do not agree with the statement or it doesn't apply to you

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<td>12.</td>
<td>I would like help for managing <strong>pain</strong></td>
<td>Yes</td>
<td>No</td>
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<td>13.</td>
<td>I would like help managing <strong>spasms</strong> or <strong>stiffness</strong></td>
<td>Yes</td>
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<td>14.</td>
<td>I have problems with my <strong>grip</strong> or using my hands and would like help with this</td>
<td>Yes</td>
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<td>15.</td>
<td>I have <strong>fatigue</strong> and would like advice on how to manage this</td>
<td>Yes</td>
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<td>16.</td>
<td>I have <strong>sleep disturbances</strong> and would like advice on how to manage this</td>
<td>Yes</td>
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<td>17.</td>
<td>I need some help/advice on organising my <strong>finances</strong> (work/benefits)</td>
<td>Yes</td>
<td>No</td>
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<td>18.</td>
<td>I need help making <strong>adaptations to my home</strong></td>
<td>Yes</td>
<td>No</td>
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<td>19.</td>
<td>I find it difficult to <strong>get around</strong> and would like some help with this (i.e. wheelchair, access to transport etc.)</td>
<td>Yes</td>
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<td>20.</td>
<td>I would like advice on <strong>planning for the future</strong> to ensure my wishes are met</td>
<td>Yes</td>
<td>No</td>
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<td>21.</td>
<td>I sometimes have <strong>low mood</strong> and would like help with this</td>
<td>Yes</td>
<td>No</td>
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<td>22.</td>
<td>I sometimes feel my <strong>emotions</strong> are out of control and would like help with this</td>
<td>Yes</td>
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<td>23.</td>
<td>I sometimes feel <strong>worried or anxious</strong> and would like help with this</td>
<td>Yes</td>
<td>No</td>
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<td>24.</td>
<td>I find my <strong>memory</strong> has worsened since being diagnosed with MS and would like help with this</td>
<td>Yes</td>
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<td>25.</td>
<td>I would like advice on how to adapt to be able to do the <strong>things I used to enjoy/need to do</strong> but now find difficult (e.g. leisure or work activities)</td>
<td>Yes</td>
<td>No</td>
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<td>26.</td>
<td>I am worried about my <strong>physical and/or sexual relationship</strong> with my partner and would like some advice on this</td>
<td>Yes</td>
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<td>27.</td>
<td>I feel like MS has put a <strong>strain on my relationship</strong> with my partner and would like advice on how to cope with this</td>
<td>Yes</td>
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<td>28.</td>
<td>I am worried about how <strong>other family members</strong> are affected by MS and would like some advice on this</td>
<td>Yes</td>
<td>No</td>
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<td>29.</td>
<td>I feel other people like my <strong>boss or friends</strong> don’t understand MS and I’d like advice on how to cope with this</td>
<td>Yes</td>
<td>No</td>
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### Satisfaction questionnaire

Think about the LUN-MS questionnaire you've just answered and tick the box that best describes what you thought.

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<th>Neither agree or disagree</th>
<th>Agree</th>
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<td>3</td>
<td>The questionnaire covers all of the problems I have that are caused by my MS.</td>
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<td>The questionnaire is</td>
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Are there any other questions we've missed?

You can use this space to write any other comments.

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### MSIS-29 (Multiple Sclerosis Impact Scale)

- The following questions ask for your views about the impact of MS on your day-to-day life during the past two weeks.
- For each statement, please circle the number that best describes your position.
- Please answer all questions.

#### In the past two weeks, how much has your MS limited your ability to...

<table>
<thead>
<tr>
<th>Not at all</th>
<th>A little</th>
<th>Moderately</th>
<th>Quite a bit</th>
<th>Extremely</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Do physically demanding tasks?</td>
<td>1</td>
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<td>3</td>
<td>4</td>
</tr>
<tr>
<td>2. Grip things tightly (e.g., turning on taps)?</td>
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<td>4</td>
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<tr>
<td>3. Carry things?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

#### In the past two weeks, how much have you been bothered by...

<table>
<thead>
<tr>
<th>Not at all</th>
<th>A little</th>
<th>Moderately</th>
<th>Quite a bit</th>
<th>Extremely</th>
</tr>
</thead>
<tbody>
<tr>
<td>4. Problems with your balance?</td>
<td>1</td>
<td>2</td>
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<td>4</td>
</tr>
<tr>
<td>5. Difficulties moving about indoors?</td>
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<td>4</td>
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<td>4</td>
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<td>4</td>
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<td>9. Tremor of your arms or legs?</td>
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<td>4</td>
</tr>
<tr>
<td>12. Having to depend on others to do things for you?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

Please check that you have answered all the questions before going on to the next page.

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STH 20247 LUN-MSTimepoint1 CRF 16/05/2018 Page 5

STH 20247 LUN-MSTimepoint1 CRF 16/05/2018 Page 6
### MSIS-29 (Multiple Sclerosis Impact Scale)

<table>
<thead>
<tr>
<th>Question</th>
<th>Not at all</th>
<th>A little</th>
<th>Moderately</th>
<th>Quite a bit</th>
<th>Extremely</th>
</tr>
</thead>
<tbody>
<tr>
<td>13. Limitations in your social and leisure activities at home?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>14. Being stuck at home more than you would like to be?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>15. Difficulties using your hands in everyday tasks?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>16. Having to cut down the amount of time you spent on work or other daily activities?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>17. Problems using transport (e.g., car, bus, train, taxi, etc.)?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>18. Taking longer to do things?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>19. Difficulty doing things spontaneously (e.g., going out on the spur of the moment)?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>20. Needing to go to the toilet urgently?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>22. Problems sleeping?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>23. Feeling mentally fatigued?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>24. Worries related to your MS?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>25. Feeling anxious or tense?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>26. Feeling irritable, impatient, or short tempered?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>27. Problems concentrating?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>28. Lack of confidence?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>29. Feeling depressed?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

Please check that you have circled ONE number for EACH question.

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### EQ 5D – 5L

Under each heading, please tick the ONE box that best describes your health TODAY:

- **MOBILITY**
  - I have no problems in walking about
  - I have some problems in walking about
  - I am confined to bed

- **SELF-CARE**
  - I have no problems with self care
  - I have some problems washing or dressing myself
  - I am unable to wash or dress myself

- **USUAL ACTIVITIES** (e.g. work, study, housework, family or leisure activities)
  - I have no problems doing my usual activities
  - I have some problems doing my usual activities
  - I am unable to do my usual activities

- **PAIN / DISCOMFORT**
  - I have no pain or discomfort
  - I have moderate pain or discomfort
  - I have extreme pain or discomfort

- **ANXIETY / DEPRESSION**
  - I am not anxious or depressed
  - I am moderately anxious or depressed
  - I am extremely anxious or depressed

- **DIGNITY**
  - I feel that I live with dignity
  - I feel that I live with some dignity
  - I feel that I live with very little dignity
EQ 5D – 5L

- We would like to know how good or bad your health is TODAY.
- This scale is numbered from 0 to 100
- 100 means the best health you can imagine.
- 0 means the worst health you can imagine.
- Mark an X on the scale to indicate how your health is TODAY.
- Now, please write the number you marked on the scale in the box below.

YOUR HEALTH TODAY =

---

You are finished!
Please return this to the study team
Thank you for taking part
Appendix N:

Dear Participant,

I spoke to you about 4 weeks ago at the Royal Hallamshire Hospital about the LUN-MS study (STH20247) being run by the University of Sheffield. We are aiming to develop a questionnaire to identify the difficulties faced in Multiple Sclerosis and look at whether the MS service is currently doing enough to help with these difficulties. In order to do this we are asking people to complete 2 questionnaires 4 weeks apart. You already completed the first questionnaire when you signed up to the study at the Royal Hallamshire Hospital. The second questionnaire is contained within this envelope and should take you no longer than 10 minutes to complete. Once completed please return it in the post using the freepost envelope provided or bring it with you to your next appointment at the Royal Hallamshire Hospital if this is within the next week.

If you have any questions please don’t hesitate to email me on: c.kirkland1@sheffield.ac.uk

Thank you for participating in this study.

Best Wishes,

Charlotte Kirkland

(MSc. Clinical Neurology, Sheffield Institute of Translational Neuroscience)
Appendix O:

Part 3 Time point 2

Dear participant,

Thank you for taking part in our study.

Your questionnaire is due to be completed on this date:

_______/_______/_________

Please complete each questionnaire and check to make sure you've filled in every box.

When you have finished you can either return it at your next appointment if it is in the next week or put it in the stamped addressed envelope.

If you have any problems with the study please contact the study team on telephone number 0114 22 22230 and ask for Dr Esther Hobson to return your call or email e.hobson@sheffield.ac.uk or dkirkland1@sheffield.ac.uk

Have you had a relapse or other major problem with your physical or emotional health since the last time you completed this questionnaire?

Yes
No

Since you completed this questionnaire in hospital four weeks ago do you feel your MS is....?

Much worse
A little worse
About the same
A little better
Much better
Please read each statement and answer it as follows

- Tick ‘YES’ if you agree with the statement
- Tick ‘NO’ if you do not agree with the statement or it doesn’t apply to you

<table>
<thead>
<tr>
<th>Statement</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. I would like more information about the different treatment or trials available for MS</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. I would like more information about extra MS support services in my area</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. I would like more information about how to look after myself, such as exercise, diet and lifestyle</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. I would like more information about MS and pregnancy/family planning</td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. I would like to know more about what to do if I have a new symptom or problem</td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. I have difficulty walking and would like help with this</td>
<td></td>
<td></td>
</tr>
<tr>
<td>7. I have problems because I’m not very mobile (e.g. swollen feet, pressure sores) and would like help with this</td>
<td></td>
<td></td>
</tr>
<tr>
<td>8. I have problems eating and drinking and need some help with this</td>
<td></td>
<td></td>
</tr>
<tr>
<td>9. I have problems with my vision and need some help with this</td>
<td></td>
<td></td>
</tr>
<tr>
<td>10. I have problems speaking or making my voice heard and need some help with this</td>
<td></td>
<td></td>
</tr>
<tr>
<td>11. I would like help on bowel/bladder management and care</td>
<td></td>
<td></td>
</tr>
<tr>
<td>12. I would like help for managing pain</td>
<td></td>
<td></td>
</tr>
<tr>
<td>13. I would like help managing spasms or stiffness</td>
<td></td>
<td></td>
</tr>
<tr>
<td>14. I have problems with my grip or using my hands and would like help with this</td>
<td></td>
<td></td>
</tr>
<tr>
<td>15. I have fatigue and would like advice on how to manage this</td>
<td></td>
<td></td>
</tr>
<tr>
<td>16. I have sleep disturbances and would like advice on how to manage this</td>
<td></td>
<td></td>
</tr>
<tr>
<td>17. I need some help/advice on organising my finances (work/benefits)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>18. I need help making adaptations to my home</td>
<td></td>
<td></td>
</tr>
<tr>
<td>19. I find it difficult to get around and would like some help with this (i.e. wheelchair, access to transport etc.)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>20. I would like advice on planning for the future to ensure my wishes are met</td>
<td></td>
<td></td>
</tr>
<tr>
<td>21. I sometimes have low mood and would like help with this</td>
<td></td>
<td></td>
</tr>
<tr>
<td>22. I sometimes feel my emotions are out of control and would like help with this</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
LUN-MS

Please read each statement and answer it as follows

- Tick 'YES' if you agree with the statement
- Tick 'NO' if you do not agree with the statement or it doesn’t apply to you

<table>
<thead>
<tr>
<th></th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>23.</td>
<td>I sometimes feel <strong>worried</strong> or <strong>anxious</strong> and would like help with this</td>
<td></td>
</tr>
<tr>
<td>24.</td>
<td>I find my <strong>memory</strong> has worsened since being diagnosed with MS and would like help with this</td>
<td></td>
</tr>
<tr>
<td>25.</td>
<td>I would like advice on how to adapt to be able to do the <strong>things I used to enjoy/need to do</strong> but now find difficult (e.g. leisure or work activities)</td>
<td></td>
</tr>
<tr>
<td>26.</td>
<td>I am worried about my <strong>physical</strong> and/or <strong>sexual relationship</strong> with my partner and would like some advice on this</td>
<td></td>
</tr>
<tr>
<td>27.</td>
<td>I feel like MS has put a <strong>strain on my relationship</strong> with my partner and would like advice on how to cope with this</td>
<td></td>
</tr>
<tr>
<td>28.</td>
<td>I am worried about how <strong>other family members</strong> are affected by MS and would like some advice on this</td>
<td></td>
</tr>
<tr>
<td>29.</td>
<td>I feel other people like my <strong>boss or friends</strong> don’t understand MS and I’d like advice on how to cope with this</td>
<td></td>
</tr>
</tbody>
</table>

Satisfaction questionnaire

Think about the LUNS questionnaire you’ve just answered and tick the box that best describes what you thought.

<table>
<thead>
<tr>
<th></th>
<th>Strongly disagree</th>
<th>Disagree</th>
<th>Neither agree or disagree</th>
<th>Agree</th>
<th>Strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>I’d be happy to use this questionnaire again as part of a research study</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2.</td>
<td>I’d be happy to use this questionnaire again as part of my routine MS clinic appointment.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3.</td>
<td>The questionnaire covers all of the problems I have that are caused by my MS.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4.</td>
<td>The questionnaire is</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Much too long</td>
<td>Too long</td>
<td>About right</td>
<td>Too short</td>
<td>Much too short</td>
</tr>
</tbody>
</table>

Are there any other questions we’ve missed?

You can use this space to write any other comments.
### MSIS-29 (Multiple Sclerosis Impact Scale)

- The following questions ask for your views on the impact of MS on your day-to-day life during the past two weeks.
- For each statement, please circle the number that best describes your position.
- Please answer all questions.

#### In the past two weeks, how much has your MS limited your ability to...

<table>
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<tr>
<th>Not at all</th>
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<td>1. Do physically demanding tasks?</td>
<td>1 2 3</td>
<td>4 5</td>
<td></td>
<td></td>
</tr>
<tr>
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<td>4 5</td>
<td></td>
<td></td>
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<tr>
<td>3. Carry things?</td>
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<td></td>
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</tbody>
</table>

#### In the past two weeks, how much have you been bothered by...

<table>
<thead>
<tr>
<th>Not at all</th>
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<tbody>
<tr>
<td>4. Problems with your balance?</td>
<td>1 2 3</td>
<td>4 5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. Difficulties moving about indoors?</td>
<td>1 2 3</td>
<td>4 5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. Being clumsy?</td>
<td>1 2 3</td>
<td>4 5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>7. Stiffness?</td>
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<td></td>
<td></td>
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<td>4 5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>12. Having to depend on others to do things for you?</td>
<td>1 2 3</td>
<td>4 5</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Please check that you have answered all the questions before going on to the next page.

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You've finished!

Please check through and make sure you've filled in every box. Please return the questionnaire by post or at your next visit if you are coming in the next week.
Appendix P:

### q1 * q1t2 Crosstabulation

<table>
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<td>q1 no</td>
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<td>2</td>
<td>4</td>
</tr>
<tr>
<td>q1 yes</td>
<td>4</td>
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### q2 * q2t2 Crosstabulation

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<td>Total</td>
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### q3 * q3t2 Crosstabulation

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<td>6</td>
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</tr>
<tr>
<td>q3 yes</td>
<td>1</td>
<td>9</td>
<td>10</td>
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<tr>
<td>Total</td>
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<td>15</td>
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### q4 * q4t2 Crosstabulation

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<td>21</td>
</tr>
<tr>
<td>q4 yes</td>
<td>0</td>
<td>1</td>
<td>1</td>
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<tr>
<td>Total</td>
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<td>22</td>
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### q5 * q5t2 Crosstabulation

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<th>Total</th>
</tr>
</thead>
<tbody>
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</tr>
<tr>
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<td>11</td>
<td>14</td>
</tr>
<tr>
<td>Total</td>
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<td>13</td>
<td>22</td>
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</table>
### q6 * q6t2 Crosstabulation

Count

<table>
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</thead>
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<td>yes</td>
<td></td>
<td></td>
</tr>
<tr>
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<td>Q2 I would like more information about extra MS support services in my area</td>
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<tr>
<td>Q15 I have fatigue and would like advice on how to manage this</td>
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<td>Q13 I would like help managing spasms or stiffness</td>
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<td>Q5 I would like to know more about what to do if I have a new symptom of problem</td>
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<td>Q24 I find my memory has worsened since being diagnosed with MS and would like help with this</td>
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<td>Q3 I would like more information about how to look after myself such as exercise, diet and lifestyle</td>
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<td>Q14 I have problems with my grip or using my hands and would like help with this</td>
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<td>Q11 I would like help on bowel/bladder management and care</td>
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<td>Q12 I would like help for managing pain</td>
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<td>Q16 I have sleep disturbances and would like advice on how to manage this</td>
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<td>Q23 I sometimes feel worried or anxious and would like help with this</td>
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<td>Q21 I sometimes have low mood and would like help with this</td>
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<td>Q22 I sometimes feel my emotions are out of control and would like help with this</td>
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<td>Q20 I would like advice on planning for the future to ensure my wishes are met</td>
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<td>Q25 I would like advice on how to adapt to be able to do the things I used to enjoy/need to do but now find difficult (e.g. leisure or work activities)</td>
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<td>Q28 I am worried about how other family members are affected by MS and would like some advice on this</td>
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<td>Q29 I feel other people like my boss or friends don't understand MS and I'd like advice on how to cope with this</td>
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<td>Q4 I would like more information about MS and pregnancy/family planning</td>
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<td>Q9 I have problems with my vision and need some help with this</td>
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<td>Q17 I need some help/advice on organising my finances (work/benefits)</td>
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<td>Q27 I feel like MS has put a strain on my relationship with my partner and would like advice on how to cope with this</td>
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<td>Q6 I have difficulty walking and would like help with this</td>
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<td>Q7 I have problems because I’m not very mobile (e.g. swollen feet, pressure sores) and would like help with this</td>
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<td>Q8 I have problems eating and drinking and need some help with this</td>
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<td>Q26 I am worried about my physical and/or sexual relationship with my partner and would like some advice on this</td>
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<td>Q10 I have problems speaking or making my voice heard and need some help with this</td>
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<td>Q27 I feel like MS has put a strain on my relationship with my partner and would like advice on how to cope with this</td>
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<tr>
<td>Q29 I feel other people like my boss or friends don’t understand MS and I’d like advice on how to cope with this</td>
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<tr>
<td>Q30 I would like more information about how to look after myself such as exercise, diet and lifestyle</td>
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<tr>
<td>Q3 I would like more information about bowel/bladder management and care</td>
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<tr>
<td>Q11 I would like help managing spasms or stiffness</td>
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<tr>
<td>Q12 I would like help for managing pain</td>
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<td>Q13 I would like help on bowel/bladder management and care</td>
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<td>Q19 I find it difficult to get around and would like some help with this (i.e. wheelchair, access to transport etc.)</td>
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<td>Q21 I sometimes have low mood and would like help with this</td>
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<td>Q23 I sometimes feel worried or anxious and would like help with this</td>
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<tr>
<td>Q24 I find my memory has worsened since being diagnosed with MS and would like help with this</td>
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<tr>
<td>Q25 I would like advice on how to adapt to be able to do the things I used to enjoy/need to do but now find difficult (e.g. leisure or work activities)</td>
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<tr>
<td>Q10 I have problems speaking or making my voice heard and need some help with this</td>
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<tr>
<td>Q14 I have problems with my vision and need some help with this</td>
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<tr>
<td>Q16 I have sleep disturbances and would like advice on how to manage this</td>
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<tr>
<td>Q17 I need help making adaptations to my home</td>
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<tr>
<td>Q18 I need help making adaptations to my home</td>
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<tr>
<td>Q20 I would like advice on planning for the future to ensure my wishes are met</td>
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</tr>
<tr>
<td>Q21 I sometimes have low mood and would like help with this</td>
<td>7</td>
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<tr>
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<td>LUN-MS Item (EDSS &gt;6)</td>
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<td>Q2  I would like more information about extra MS support services in my area</td>
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<td>Q12 I would like help for managing pain</td>
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<td>Q15 I have fatigue and would like advice on how to manage this</td>
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<td>Q1  I would like more information about the different treatment or trials available for MS</td>
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<td>Q24 I find my memory has worsened since being diagnosed with MS and would like help with this</td>
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<td>Q5  I would like to know more about what to do if I have a new symptom of problem</td>
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<td>Q6  I have difficulty walking and would like help with this</td>
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<td>Q7  I have problems because I’m not very mobile (e.g. swollen feet, pressure sores) and would like help with this</td>
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<td>Q14 I have problems with my grip or using my hands and would like help with this</td>
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<td>Q4  I would like more information about MS and pregnancy/family planning</td>
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<td>Q10 I have problems speaking or making my voice heard and need some help with this</td>
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<td>Q17 I need some help/advice on organising my finances (work/benefits)</td>
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<td>Q19 I find it difficult to get around and would like some help with this (i.e. wheelchair, access to transport etc.)</td>
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<td>Q8  I have problems eating and drinking and need some help with this</td>
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Appendix R:

This table demonstrates the sample size calculated for the Kappa statistic to have 80% power in testing intra-rater (test-retest) reliability ($k_1=0.5$, $k_0=0$, $\alpha=0.0017$)

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