

A large, stylized orange graphic that resembles a speech bubble or a callout box. It has a gradient from light orange to dark orange and is filled with a pattern of overlapping, semi-transparent orange triangles. The text is centered within this graphic.

My MS My Needs 3
Methods document

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1. Introduction

My MS My Needs is a self-reported experience survey of people with MS across the UK. The survey was carried out in 2013 (My MS My Needs) and 2016 (My MS My Needs 2). In the past the results of the My MS My Needs surveys have provided an opportunity to understand in detail how people with MS feel about their treatment, care and support. This helps us identify areas of need where policy influencing and campaigning can have a real impact on what matters most to people with MS.

The My MS My Needs study in 2013 demonstrated that a national survey can provide quantitative data on the extent to which many of the needs of people with MS are met. That is also of a sufficient quality and scale to allow for comparison between areas and over time. The project provided robust evidence to drive us to campaign to stop the MS postcode lottery and to enable people with MS to access the right treatment at the right time. Following on from this the results of the 2016 My MS My Needs survey were the driving force behind a number of campaigns, including End the Care Crisis, MS Enough and Treat me Right.

2. Survey design

2.1 Cross organisational research aims

In order to build on these successes, and to make sure our work is based on both evidence and the voice of our community, we had input from teams across the organisation. This included teams from Policy, External Relations, Regional External Relations, Services and Support, and Strategy and Impact.

We held a number of workshops to determine the research aims and objectives of the 2019 My MS My Needs survey project. We determined that the overarching aim is to get a representative voice of people with MS across the UK to gain an understanding of their lived experience. More specific aims are detailed below:

- Inform and build on the development of our internal segmentation work by identifying the characteristics of those who fit within the different segments as they are currently defined.

- Gather up to date information on the health and social care needs of people with MS across the UK; on a national and local level.
- Determine the economic status of people with MS across the UK and what support is in place to help them remain economically active, if desired, and above the poverty line.
- Gain a view of the access to healthcare and services at a local level and how this compares across the UK.
- Gather demographic characteristics from the respondents and increase, wherever possible, responses from previously under-represented groups (e.g. Ethnic minorities, newly diagnosed, etc. – see UK MS Register EDI report).
- Obtain comparative data to enable us to determine whether the MS landscape in the UK has changed since 2013+/2016.

2.2 Previous survey review, additions and changes

The number of questions in the My MS My Needs survey has increased from 32 questions in 2013 and 2016 to 61 questions in 2019. The main reasons for this are learnings from previous versions and identification of the current gaps in our knowledge. These changes will allow us to gain more valuable information as well as improve our accessibility to a wider audience. There are some disadvantages to these changes, as it means that some parts of the questionnaire are either not at all or less comparable over time. We hope to increase the sample base to include a broader demographic reach. This will in turn will reduce the comparability to previous samples. The risk was considered worth the gains provided by these changes. We also hoped that broadening the sample base and increasing topic interest would offset any negative effects of a longer questionnaire on response rates. Please see appendix 1 and 2 to view the 2016 and 2019 questionnaires.

Some of the main changes are highlighted below:

- The order of the sections has been changed to put the demographics section at the end (Q56 – 60) as this should require a low cognitive load and therefore be less tiring to complete.
- The 'Your care needs' section (Q30-41) has been moved to later in the survey as this may be confronting to those who have been more recently diagnosed and discourage them from completing the survey

- A number of questions around benefits, social care and employment have been updated including adding and removing items
- Questions were added to the 'Healthcare and community services' section to support local influencing activities. One major concern is the distance people have to travel to access services and the impact this has (it is understood that the usefulness of this will depend on the response rate but numbers can be collated to make it useful at larger regional areas where necessary)
- Question 44 on Sativex was changed to make it more useful as the previous question did not account for the appropriateness of this treatment for the individual concerned
- Two questions on powered wheelchairs were removed as this information was not used from previous versions
- Questions were added to assess the cannabis and HSCT treatment landscapes
- A number of demographic questions were added
- Questions were added to determine how to categorise respondents into segments based on perceived coping now and in future
- A question was added to assess what services provided by the MS Society are used by respondents
- The 2019 surveys were given a unique identifier number in order to link completed surveys to post code. This allowed us to map responses geographically. It also allowed us to track responses, and reduce reminder mailings to only those that haven't completed the survey.

2.3 Thinking aloud survey testing

To test the survey with people affected by MS and make sure that the questions are clear, appropriate and easily understood, we used the Thinking Aloud methodology described by Fonteyn et al (1993)¹.

Thinking aloud is conducted via a one on one interview method in an agreeable setting. In this case the interviews were carried out over the phone. One hour was allocated for each interview. People with MS were invited to participate through our Research Network co-production group. 12 people in total participated in the Thinking Aloud interviews in 3 groups.

Participants were provided with a copy of the survey shortly prior to the beginning of the interview and were asked not to review the survey before the interview. At the beginning of the interview participants were asked to work through the survey and verbalise their thoughts as they went through. If they paused for longer than a few seconds the interviewer quietly reminded them to 'keep thinking aloud'. The interviewer reminded participants to stay on task if they started to discuss the survey or other matters during the session, saying that 'there will be time at the end to talk through any comments or questions you have but for the moment can you please continue to complete the survey and think aloud'. Aside from these two interruptions, all interaction between the participants and the interviewer were kept to a minimum so as not to interfere with the subjects' flow of thoughts. Once data collection was complete the interviewer conducted a brief follow-up interview to further clarify the participants thinking and reasoning strategies and allow them to add any comments and questions.

In the first session participants were given one of two different versions of the survey. One with the demographics questions at the beginning and the other with these at the end. Following review of these sessions the decision was taken to put these questions at the end, and the following sessions were conducted with the survey in this format. Amendments were made to other questions in the survey and then re-tested with a new group of participants. The interviews were carried out by two independent researchers. Sessions were audio recorded and notes for each question were collated to inform survey development.

2.4 Alternative survey versions

A complete copy of the survey was available in large print and in Welsh.

An abridged version of the survey was also available in Easy Read. It was not possible or advisable to convert the entire survey into Easy Read. Key questions were identified, and a shorter 37 question version was created.

The three alternative versions of the survey were available on request. There were 3 requests for large print, 1 request for Welsh and 0 requests for Easy Read versions of the survey.

There was also the option to complete the survey over the phone. Many people with MS find it difficult to complete a paper or online survey. Three members of the evidence team at the MS

Society were available to complete the survey on behalf of a person with MS over the phone. 19 surveys were completed over the phone.

3. Sample selection

The survey was provided in both paper and online form. The online version of the survey was hosted on the UK MS register site. A mix of sampling methods were used to recruit people with MS to complete the survey.

- A copy of the survey was sent out to all registered members of the MS Society.
- If we had a postal address a paper survey was sent (22,025 people), but if only an email address was listed an email was sent with a link to the online survey.
- An email was sent to all registered users of the UK MS register
- Email communications were sent out through our professional networks
- The survey was promoted via our social media channels
- A promotional flyer was used by our regional external relations officers to promote the survey regionally in GP surgeries, MS therapy centres, clinics and other places where people with MS may frequent. This flyer had a link to the online survey and details to contact the MS Society by phone or email to request a paper copy if necessary.
- A reminder mailing was sent to those people who had not returned their survey after 6 weeks, and an email was sent via the MS register.

Interim response data was collected 6 weeks into the survey period in order to evaluate regional response rates. These were used to focus efforts to increase sample size in these areas.

Targeted social media posts were used in Scotland and Northern Ireland. We also used our social media to reach out to under-represented groups.

4. Collecting responses

Survey mailing and collection of returned surveys was carried out by Pureprint. PurePrint are a print and marketing solutions provider. PurePrint are an NCVO trusted supplier with a certificate ISO 27001 Security Management.

Via addressed and reply paid envelopes enclosed with the survey Pureprint received completed surveys directly.

Pureprint collated the responses to the survey using automatic scanning and applied to a data dictionary provided by the UK MS Register. This ensured that the results of the paper and online survey could be easily collated. Pureprint provided us with three data files. One containing interim data – as referred to above, one final data file containing results from all respondents, and a third data file linking the URN to the respondents post code.

Surveys completed over the phone by our evidence team were coded manually and appended to the file containing postal returns.

Responses to the online survey version were collated by the UK MS register team and provided to us.

The online and postal results were collated into one master file.

5. Data Cleaning

To ensure that anomalies in the data were identified and processed a plan was created. The cleaning and processing plan addressed factors such as:

- Duplicate surveys – where people may have filled in the survey twice either in paper form, or in a mix of paper and online
- Straight liners – A survey that contains responses to all answers on the left or right of the page, or all answers in a single location (e.g. only selecting the first answer for every question)
- Inconsistent responses – where the answer to one question negates the answer of another
- Invalid responses – selecting more than one response where only one is requested
- Matching the logic routing of the online survey with the paper survey – e.g. if selecting one answer online means that respondents are not shown certain follow up questions, these would need to also be removed from the paper response data
-

Following the data cleaning process 158 whole survey responses were removed from the data set.

Full completion of the survey was not a requirement of valid response. Where there were inconsistent answers to specific questions these were removed from the result for those questions, but where logical responses to the other questions in the survey were included in the data set.

See appendix 3 for the full data cleaning plan

6. Response rate and representation

It is difficult to determine the response rate to the survey based on those that were contacted. Direct contact was made by sending a paper copy of the survey to our 22,025 members and by email to the 12,782 registered users of the UK MS register. Unfortunately, we don't collect 'relationship to MS' from members at this time so we don't know how many members are people living with MS, and therefore eligible to complete the survey. There is also likely to be significant crossover between the people with MS that are members of both the MS Society and the UK MS register. Additionally, the survey was promoted indirectly via leafleting. Leaflets were distributed via the Regional External Relations Officers and Local Network Officers to service locations and healthcare professionals likely to be in contact with people with MS.

In the final dataset there are 8,281 responses to the survey. Responses to individual questions varies due to appropriateness of the question and data cleaning. We received 4,554 responses to the paper version and 3,727 responses via the online survey, and 19 response by telephone. Assuming no crossover in contacts, that all members of the MS Society were eligible to complete the survey and completed a paper version, and that no responses came from further snowball sampling that equates to a 24% combined response rate (21% MS Society membership and 29% UK MS register membership).

Investigating the characteristic structure of the respondent profiles and comparing these to known data sources helps to identify where the data is likely to be a good representation of the experiences of people with MS and where there may be bias in the data. Demographic data for people with MS is not comprehensive but where population estimates have been published we have compared the survey respondent profile.

Across the four nations of the UK representation was good and within 5% of the current prevalence estimate.

Diagnosis of MS Type is relatively close (although this is a very rough estimate within the literature), but we might be slightly overestimating people with Primary Progressive MS. The respondent profile underrepresents people who were diagnosed less than 12 months ago and those that are younger.

More females and less males completed the survey than the current prevalence estimates suggest.

There is no good data on the prevalence of MS within different ethnic groups or of different sexual orientation.

Type of MS	MMMN3	MS Population (based on available prevalence est)
Relapsing remitting MS	42.1%	Rough est. 43%
Secondary progressive MS with relapses	12.7%	
Secondary progressive MS without relapses	23%	
Primary progressive MS	16%	Est. 10-15%
I don't know	6.1%	
Time since diagnosis		
Less than 12 months ago	1.9%	5%
1-5 years ago	13.6%	
5-10 years ago	17.3%	
More than 10 years ago	67%	
Don't know	0.1%	
Gender		
Female	75%	72%
Male	25%	28%
Non-binary	<1%	NA
Prefer not to say	<1%	
Age		
Up to 34	3.5%	7.5%
35-44	10.3%	14.4%
45-54	23.4%	24.4%
55-64	32.4%	24.2%
65-74	23.8%	20.9%
75+	6.6%	8.6%
Ethnicity		
Asian/Asian British	1%	Not available
Black/African/Caribbean/Black British	<1%	
Mixed/Multiple ethnic groups	<1%	
Other ethnic group	1%	
White	97%	
Prefer not to say	1%	
Sexual orientation		
Bisexual	2%	Not available
Gay man	1%	
Gay woman	1%	
Heterosexual/straight	93%	
Prefer to use my own term	1%	
Prefer not to say	3%	
Nation		
England	83.0% (n=6913)	80%
Scotland	8.2% (n=683)	12%
Wales	5.4% (n=452)	4%
NI	3.3% (n=274)	4%

Based on the proportions identified for the respondent profile as well as the data that we currently have on the demographic profile of people with MS it was decided to weight the data on age alone. Weighting was calculated and carried out using SPSS.

The table below shows that weighting the data on age has an effect on the proportion of people diagnosed in the last 12 months and type of MS indicating that these are age linked factors in this population. The data was separated by gender prior to weighting on age as the age profiles for males and females differed.

	MMMN3 unweighted	MMMN3 weighted	MS Population (based on available prevalence est)
Time since diagnosis			
< 12 months	2%	3%	5%
Type of MS			
Relapsing remitting MS	42%	48%	Rough est. 43%
Secondary progressive MS with relapses	13%	11%	
Secondary progressive MS without relapses	23%	20%	
Primary progressive MS	16%	15%	Est. 10-15%
Gender			
Female	75%	75%	72%
Male	25%	25%	28%

7. Further analysis and reporting of results

Following data cleaning and weighting the full dataset was exported to a SQL database for further analysis. The results of further analysis were carried out and presented using Power Bi. Validation of all response outcomes and spot checking of statistical analysis was carried out in SPSS.

8. References

1. Fonteyn et al, A Description of Think Aloud Method and Protocol Analysis, Qualitative Health Research, Volume: 3 issue: 4, page(s): 430-441, November 1993

9. Appendix 1

My MS My Needs 2 (2016) questionnaire

Background information

1. Are you male or female?

- Female
- Male
- Prefer not to say

2. How old are you?

- 18-29
- 30-39
- 40-49
- 50-59
- 60-69
- 70 to 79
- 80 or over
- Prefer not to say

3. What type of MS do you have?

- Relapsing remitting MS
- Secondary progressive MS with relapses
- Secondary progressive MS without relapses
- Primary progressive MS
- I don't know

4. How long ago were you diagnosed as having MS by your neurologist?

- Less than 12 months ago
- 1-5 years ago
- Between 5-10 years ago
- More than 10 years ago
- I don't know

Your care needs

Care and support (social care) can enable you to remain independent and carry out the practical tasks of everyday living, like washing and dressing, or getting out and about. This might be provided by family, friends, social services, or a combination of these.

5. In the past 12 months, have you received social care support? i.e. support from someone for the kind of practical tasks

described above

- Yes, I have received all the support I needed
- Yes, I have received some support but not enough
- No, and I have not needed to
- No, but I needed to
- I am not sure

If you have not needed any social care support, please go to **Question 11**. Otherwise continue to the next question

6. What sort of practical tasks do you NEED support with? (Tick all that apply)

- Getting up in the morning
- Going to bed
- Washing/bathing/personal care
- Meals/eating
- Cooking
- Getting out of the house

- Shopping
- Cleaning/laundry
- Other
- Not sure

6b. What sort of practical tasks do you RECEIVE support with? (Tick all that apply)

- Getting up in the morning
- Going to bed
- Washing/bathing/personal care
- Meals/eating
- Cooking
- Getting out of the house
- Shopping
- Cleaning/laundry
- Other
- Not sure

7. In the past 12 months, have you received care and support in relation to your MS for practical tasks from any of the following?

(Tick all that apply)

- Your local council (or Trust in Northern Ireland) or social services
- A charity or voluntary sector organisation
- Friends or family (unpaid)
- An occupational therapy service
- A private home care company
- A private individual e.g. cleaner or cook
- A care home or nursing home
- Other
- I am not sure

8. Who pays for your social care? For example this could be paid for by the government i.e. your local council or social services, or the NHS.

- The government does
- I do/my family does
- Partly the government and partly me/my family
- I am not sure

9. In the past 12 months, have you had a social care assessment and/or review from your local council (or Trust in Northern Ireland) for your care and support needs?

- Yes
- No, but I needed one
- No, but I did not need one
- I am not sure
- I only receive unpaid care and support from family or friends

10. In the past 12 months, have you been offered a care plan and/or care plan review for your social care? A care plan is a plan made with social services that sets out what your care and support needs are and how they will be met. A review is where your needs are re-assessed and changes can be made to the plan.

- Yes, I have been offered a care plan
- Yes, I have been offered a care plan review
- No
- I am not sure

Employment

11. Are you currently in paid employment?

- Yes, employed / self employed full time
- Yes, employed / self employed part time
- No, looking for work
- No, not looking for work
- No, retired
- No, student

If you are not looking for work or are retired please go to **Question 16**. Otherwise continue to the next question.

12. In the past 12 months, have you received support to help you find employment?

For example government programmes such as Work Choice, support from Job Centre advisors etc.

- Yes
- No, and I have not needed support
- No, but I needed support
- I am not sure

13. If yes, where have you received support from? (Tick all that apply)

- Job Centre
- A charity or voluntary sector organisation
- Your local council (or Trust in Northern Ireland)
- Friends or family
- Other

14. In the past 12 months, have you received support to remain in employment? For example the Access to Work Scheme, adapted working arrangements or workplace adaptations

- Yes
- No, and I have not needed support
- No, but I needed support
- I am not sure

15. If yes, where have you received support from? (Tick all that apply)

- Government e.g. 'Access to Work'
- My local council (or Trust in Northern Ireland)
- NHS or health service
- A welfare or money advice service
- My employer
- A charity or voluntary sector organisation
- Other
- Not applicable

16. Have you done any of the following as a result of your MS? (Tick all that apply)

- Changed working hours
- Changed jobs or roles
- Retired early
- Left work entirely
- Changed location
- Made physical changes / adaptations to my work environment
- Other
- I haven't had to change anything in relation to my work

Income and benefits

17. Which would you say comes closest to your feelings about your current household income?

- Living really comfortably on current income
- Living comfortably on current income
- Neither comfortable nor struggling on current income
- Struggling on current income
- Really struggling on current income

18. Do you currently receive any of the following disability benefits? (Tick all that apply)

- Employment Support Allowance (ESA)
- Incapacity Benefit (IB)
- Disability Living Allowance (DLA)
- Personal Independence Payment (PIP)
- None of the above
- I am not sure

19. In the last 12 months, have you used the Motability Scheme? The Motability Scheme provides access to adapted vehicles, wheelchairs, and scooters and is available to those receiving the higher rate mobility component of DLA or PIP

- Yes
- Yes, but I have now lost my entitlement and am no longer able to access the Scheme
- No, I have needed support from the Scheme but have been unable to access it
- No, and I have not needed to access the Scheme
- I am not sure

Powered wheelchairs

20. Do you use a powered wheelchair to help with your mobility?

- Yes
- No, and I do not need one
- No, but I would benefit from one

21. If you use a powered wheelchair, did you/your family pay for it?

- Yes, I/we paid the entire cost
- Yes, I/we paid part of the cost
- No

Healthcare and community services

22. In the past 12 months, have you seen an MS specialist nurse in relation to your MS?

- Yes
- No, and I have not needed to
- No, but I needed to
- I am not sure

23. If yes, was this (Tick all that apply)

- In a specialist clinic in a hospital setting
- In an outreach clinic in a community setting
- In your home
- By telephone
- By email

24. In the past 12 months, have you seen a neurologist in relation to your MS?

- Yes
- No, and I have not needed to
- No, but I needed to
- I am not sure

25. In the past 12 months, have you seen a specialist about continence advice in relation to your MS? (e.g. bladder or bowel advice)

- Yes
- No, and I have not needed to
- No, but I needed to
- I am not sure

26. In the past 12 months, have you received sufficient support for mood or emotional issues? i.e. from health or community services rather than friends or family

- Yes from the NHS
- Yes from a charity or voluntary organisation
- Yes from a private company or individual
- Yes from somewhere else
- No, and I have not needed support
- No, but I needed support/more support
- I am not sure

27. In the past 12 months, have you seen a physiotherapist in relation to your MS?

- Yes, from the NHS
- Yes, privately
- Yes, from a charity or voluntary organisation
- Yes from somewhere else
- No, and I have not needed to
- No, but I needed to
- I am not sure

28. If you have needed to be seen by a physiotherapist in the past 12 months, have you been able to contact them directly (i.e. self referral)?

- Yes
- No, I need to be referred by another healthcare professional
- I am not sure

29. In the past 12 months, have you received support so that you can keep physically active?

For example, help to attend exercise classes, or use sports and leisure facilities

- Yes from the NHS
- Yes from my local council (or Trust in Northern Ireland)
- Yes from a charity or voluntary organisation
- Yes from somewhere else
- No, and I have not needed to
- No, but I needed to
- I am not sure

Care coordination

30. Who is the key contact for any healthcare or support in relation to your MS?

- My GP
- My MS nurse
- My neurologist
- My carer / a member of my family
- No one
- I am not sure

31. In the past 12 months, have you been offered a care plan and/or care plan review for your healthcare? A care plan is a plan made with your health professional that sets out what your care and support needs are and how they will be met. A review is where your needs are re-assessed and changes can be made to the plan.

- Yes, I have been offered a care plan
- Yes, I have been offered a care plan review
- No
- I am not sure

Access to therapies

This section asks about some therapies that are specifically licenced for MS and are possible treatment options for some people with MS. These will not be suitable for everyone with MS and there may be other therapies or drugs not listed.

33. Below is a list of disease modifying therapies that are licensed specifically for MS at present. Please select from the list all of the drugs you are currently taking:

- Aubagio (Teriflunomide)
- Avonex (beta interferon 1a)
- Betaferon (beta interferon 1b)
- Copaxone (glatiramer acetate)
- Extavia (beta interferon 1b)
- Gilenya (fingolimod)
- Lemtrada (Alemtuzumab)
- Plegridy (peginterferon beta 1a)
- Rebif (beta interferon 1a)
- Tecfidera (Dimethyl fumarate)
- Tysabri (natalizumab)
- I am not currently taking any of the drugs listed

34. Below is a list of symptom management therapies that are licensed specifically for MS at present. Please select from the list all of the drugs you are currently taking:

32. To what extent do you feel that the professionals who help plan your care work well together? E.g. from your GP, hospital, social care

- Completely
- To some extent
- Not at all
- I am not sure
- Not applicable

- Sativex (delta-9-tetrahydrocannabinol, cannabidiol)
- Fampyra (Fampridine)
- Botox (onabotulinumtoxin A)
- I am not currently taking any of the drugs listed

35. In the last 12 months, have you requested sativex?

- Yes, and my request was accepted
- Yes, and my request was turned down
- No
- I am not sure

36. In the last 12 months, have you requested functional electrical stimulation (FES)? FES is a treatment that uses the application of small electrical charges to improve mobility

- Yes, and my request was accepted
- Yes, and my request was turned down
- No
- I am not sure

37. Have you received enough information from your health professionals about drugs available to support the treatment of your MS?

- Yes, I have been provided with enough information
- No, I have not been provided with enough information
- No, I have not sought this information from health professionals

Information and advocacy

38. In the past 12 months, have you received sufficient information in relation to your MS?

- Yes, I've received sufficient information
- No, I have not needed any information
- No, I needed more information

39. In the past 12 months, have you used an advocacy service? Advocacy services help people to put forward their views or speak or act on their behalf, for example to help them access the services they need

- Yes
- No, and I have not needed to
- No, but I needed to
- I am not sure

Before you go

40. Could we contact you in the future to take part in further research we think may be relevant to you, based on your responses to this survey?

Your personal information will be handled securely and your responses would be anonymised before analysis.

- Yes, and I understand this does not mean I would have to take part in any future research
- No, I would prefer you not to contact me in this way

10. Appendix 2

My MS My Needs 3 (2019) Questionnaire

MS family & friends survey: If you have a family member, partner, or friend that supports you with your MS please ask them to consider going online to complete the MS family & friends survey at <https://tinyurl.com/ms-family-friends>

This survey opened on March 1, 2019. It is available in paper copy and on the UK MS Register. If you have already completed the survey please do not complete it again. Thank you.

For each question please cross clearly inside one box using a black or blue pen. Don't worry if you make a mistake, simply fill in the box and put a cross in the correct box.

Please put an X in the box if you are completing this survey on behalf of someone with MS

Living with MS

1. What type of MS do you have?

We understand that these categories may not be personally relevant to you, but please complete to the best of your knowledge as this information helps us to influence change.

- Relapsing remitting MS Primary progressive MS
- Secondary progressive MS with relapses I don't know
- Secondary progressive MS without relapses

2. How long ago were you diagnosed as having MS by your neurologist?

- Less than 12 months ago 16- 20 years ago
- 1- 2 years ago 21- 50 years ago
- 3-5 years ago More than 50 years ago
- 6-10 years ago I don't know
- 11- 15 years ago

Care coordination

3. Who is the key contact for any healthcare or support in relation to your MS?

(e.g. Decisions about treatment, arranging support with daily living, support with lifestyle changes, etc.) Please only select one response.

- My GP Other specialist nurse My neurologist
- My MS nurse
-
-
-

4. Since diagnosis, have you developed a plan for your healthcare with a health professional?

This is a plan made with a healthcare professional that sets out what is important to you, and what support you need to achieve this. The details may be recorded in a letter or other document.

- Yes I don't know what a care plan is
- No, but I would like one I am not sure
- No, and I have not needed one

5a. To what extent do you feel that the professionals who help plan your care, work well together? (e.g. your GP, hospital and social care)

- Completely I am not sure
- To some extent Not applicable
- Not at all

If the professionals who help plan your care, work well together please go to question 6. If they do not please answer Question 5b.

5b. If the professionals who help plan your care do not work well together has it resulted in any of the below experiences? (Tick all that apply)

- I have had to regularly repeat information about my treatment and care to different professionals
- I have had to chase professionals for information or appointments about my treatment and care
- Other
- Chasing health professionals to arrange care has caused stress that has exacerbated my MS symptoms
- I believe mistakes have been made in my treatment and care
- Decisions about my treatment or care have not reflected my needs

Information and advocacy

6. In the past 12 months, have you received sufficient information in relation to your MS?

- Yes, I've received sufficient information No, I needed more information
- No, I have not needed any information

7. In the past 12 months, have you used an advocacy service?

Advocacy services help people to put forward their views or speak or act on their behalf, for example My social worker My speech and language therapist My My physiotherapist or occupational therapist My psychologist

-
-

Employment

8. Are you currently in paid employment? (Tick all that apply)

- | | |
|---|---|
| <input type="checkbox"/> Yes, employed full time | <input type="checkbox"/> No, retired and receiving pension/occupational pension |
| <input type="checkbox"/> Yes, employed part time | <input type="checkbox"/> No, medically retired early due to ill health |
| <input type="checkbox"/> Yes, self-employed full time | <input type="checkbox"/> No, student |
| <input type="checkbox"/> Yes, self-employed part time | <input type="checkbox"/> I do volunteer work |
| <input type="checkbox"/> No, looking for work | |
| <input type="checkbox"/> No, not looking for work | |

If you are not looking to find or remain in employment please go to Question 13

9. In the past 12 months, have you received support to help you find employment?

For example government programmes such as support from Job Centre advisors etc.

- | | |
|--|---|
| <input type="checkbox"/> Yes | <input type="checkbox"/> I am not sure |
| <input type="checkbox"/> No, and I have not needed support | <input type="checkbox"/> Not applicable |
| <input type="checkbox"/> No, but I needed support | |

10. If yes, where have you received support from? (Tick all that apply)

- | | |
|---|--|
| <input type="checkbox"/> Job Centre | <input type="checkbox"/> Employment Agency |
| <input type="checkbox"/> Charity/Voluntary organisation | <input type="checkbox"/> Friends or family |
| <input type="checkbox"/> Your local council | <input type="checkbox"/> Not applicable |
| <input type="checkbox"/> Healthcare Professionals | |
| <input type="checkbox"/> Other | |

11. In the past 12 months, have you received support to remain in employment?

For example the Access to Work Scheme, adapted working arrangements or workplace adaptations

- | | |
|--|---|
| <input type="checkbox"/> Yes | <input type="checkbox"/> I am not sure |
| <input type="checkbox"/> No, and I have not needed support | <input type="checkbox"/> Not applicable |
| <input type="checkbox"/> No, but I needed support | |

12. If yes, where have you received support from? (Tick all that apply)

- | | |
|---|---|
| <input type="checkbox"/> Government e.g. 'Access to work' | <input type="checkbox"/> Healthcare Professionals |
| <input type="checkbox"/> Charity/Voluntary organisation | <input type="checkbox"/> My employer |
| <input type="checkbox"/> Your local council | <input type="checkbox"/> Friends or family |
| <input type="checkbox"/> Other | <input type="checkbox"/> Not applicable |

13. Have you ever done any of the following as a result of your MS? (Tick all that apply)

- | | |
|---|---|
| <input type="checkbox"/> Changed working hours | <input type="checkbox"/> Changed job location |
| <input type="checkbox"/> Reduced working hours | <input type="checkbox"/> Made physical changes/adaptations to my work environment |
| <input type="checkbox"/> Changed jobs or roles | <input type="checkbox"/> I haven't had to change anything in relation to my work |
| <input type="checkbox"/> Retired early/Medically retired | |
| <input type="checkbox"/> Left work entirely (without pension) | |
| <input type="checkbox"/> Other | |

14. If you retired early or left work entirely: Do you feel you were properly supported by your employer, and able to stay in work as long as you wanted to?

- | | |
|---|--|
| <input type="checkbox"/> Yes, I feel my employer offered sufficient support to help me stay in work as long as I wanted | <input type="checkbox"/> No, I was offered support but it was not sufficient to support me to stay in work as long as I wanted |
| <input type="checkbox"/> Yes, I did not wish to stay in work | <input type="checkbox"/> No, I wanted to stay in work but my employer did not support me |
| | <input type="checkbox"/> Not applicable |

Income and benefits

15. Which of these describes your gross combined household income last year? This includes any benefits received

- | | |
|---|---|
| <input type="checkbox"/> £0 | <input type="checkbox"/> £75 000 to £99 999 |
| <input type="checkbox"/> £1 to £9 999 | <input type="checkbox"/> £100 000 to £149 999 |
| <input type="checkbox"/> £10 000 to £24 999 | <input type="checkbox"/> £150 000 and greater |
| <input type="checkbox"/> £25 000 to £49 999 | <input type="checkbox"/> Prefer not to answer |
| <input type="checkbox"/> £50 000 to £74 999 | |

23b. If yes, where was this? (Tick all that apply)

- In a specialist clinic in a hospital setting
- In an outreach clinic
- In a community setting
- In your home
- By telephone
- By email
- By Video conference

23c. Northern Ireland only: If yes, what was the nature of this appointment?
(If you have had more than one appointment tick all that apply)

- Neurology Recall by Belfast Trust
- Regular MS review
- I am not sure

24. The last time you saw a nurse or neurologist how far did you have to travel?

- 0-5 miles
- 6-10 miles
- 11-20 miles
- 21-30 miles
- 31-40 miles
- 41-50 miles
- 51+ miles
- I am not sure

25. What impact, if any, does the distance you have to travel for treatment have on you?
(Tick all that apply)

- Have had to take time off work
- Difficulty arranging childcare or other caring responsibilities
- Significant time spent travelling
- Have missed appointments
- Have been unable to access preferred treatment options
- Unable to see certain healthcare professionals
- Other
- I travel further so that I get to see my preferred healthcare professional
- I have moved home/not been able to move home in order to stay close to services
- There has been no/very little impact
- I am not sure

26. In the past 12 months, have you seen a specialist about continence advice in relation to your MS? e.g. bladder or bowel advice

- Yes
- No, and I have not needed to
- No, but I needed to
- I am not sure

27. In the past 12 months, have you received support for mood or emotional issues? e.g. from health or community services rather than friends or family (Tick all that apply)

28. In the past 12 months, have you seen a physiotherapist in relation to your MS?
(Tick all that apply)

- Yes from the NHS
- Yes from a charity or voluntary organisation
- Yes from a private company or individual
- Yes from somewhere else
- Yes, but I needed more support
- No, and I have not needed support
- No, but I needed support
- I am not sure

29. In the past 12 months, have you received support so that you can keep physically active?

For example, help to attend exercise classes, or use sports and leisure facilities. (Tick all that apply)

- Yes from the NHS
- Yes from a charity or voluntary organisation
- Yes from a private company or individual
- Yes I/My family paid for it
- Yes from somewhere else
- Yes, but I needed more support
- No, and I have not needed support
- No, but I needed support
- I am not sure

Your care needs

Care and support can enable you to remain independent and carry out the practical tasks of everyday living, like washing and dressing, or getting out and about. This might be provided by family, friends, social services, or a combination of these.

30. In the past 12 months, have you received care and support to assist with daily living? i.e. support from someone for the kind of practical tasks described above

- Yes, I have received all the support I needed
- Yes, I have received some support but not enough
- No, and I have not needed to (please go to Question 41)
- No, but I needed to
- I am not sure

31. If you have not received all the care and support you need in the past 12 months have you experienced any of the following?

- I have felt lonely and/or isolated
- I have been unable to work
- I have had to reduce the hours I work
- My health has deteriorated
- I have needed hospital treatment
- I have not been able to leave hospital because alternate care was not in place
- Not applicable

32. If you receive care and support with daily living, does the person who provides this receive carer's allowance?

- Yes
- No
- I am not sure
- Not applicable

47. Have you received enough information from your health professionals about drugs available to support the treatment of your MS?

- Yes, I have been provided with enough information
- No, I have not sought this information from health professionals
- No, I have not been provided with enough information

49. How do you feel about the future of treatment for MS? This includes disease modifying therapies and symptom management therapies.

- I believe that in the future we will be able to stop MS
- I am worried for my future, because we need more and better treatments for MS
- I am unsure how I feel about the future of MS treatment
- I don't know
- Other

Please tell us a little more about you

50. Do you currently provide help and support, without payment, to a partner, disabled child, close relative or friend, who could not manage without your help?

- Yes
- No
- Prefer not to say

51. Do you currently live with any long term condition other than MS?

Long-term conditions are conditions for which there is currently no cure, and which are managed with drugs and other treatment, for example: diabetes, chronic obstructive pulmonary disease, arthritis and high blood pressure.

- Yes, one other condition
- Yes, two or more other conditions
- No
- I am not sure

52. In the last 12 months, what information, support and/or services provided by the MS Society have you used? (Trick all that apply)

- MS Society Helpline
- MS Society Grant
- MS Society produced information leaflet/booklet (online & print)
- Information from the MS Society website
- MS Society online forum
- Information from the MS Society by email
- Other

53. Of the following statements, which ones most closely describe how you feel right now? (Trick all that apply)

- I feel I am living as well as I can with my MS
- I feel I could live better with MS if I had more support to manage my MS
- I feel I could do more to manage my MS and live my life, but I don't know how or cannot access the support I need
- I have recently been diagnosed with MS and have not yet worked through what that means for my life
- I have taken deliberate steps to reduce the impact of MS on my future
- I've had MS for some time and have had to make major adjustments to my life to manage my symptoms

54. In the last 12 months, how often have you been able to overcome the challenges of MS?

- Almost always or always
- Often
- Sometimes
- Not at all
- I have not experienced any challenges
- Prefer not to say

55. Do you feel confident that you can overcome the challenges MS brings in the future?

- Very confident
- Somewhat confident
- Not sure
- Doubtful
- Very doubtful
- Prefer not to say

56. What is your gender?

- Female
- Male
- Non-binary
- Prefer not to say

57. How old are you?

- 16-24
- 25-34
- 35-44
- 45-54
- 55-64
- 65-74
- 75-84
- 85 or over
- Prefer not to say

58. How would you describe your sexual orientation?

- MS Society magazine (eg. MS Matters and/or Research Matters)
- Local MS Society group Living Well with MS sessions
- My MS, My Rights, My Choices information and support service in Wales
- The Active Together Project in Scotland
- None

11. Appendix 3

Data cleaning plan

1. Duplicates		
		Answer code
Select	ALL postcodes	
Action 1	group by postcode having count > 1	
Action 2	partition by postcode	
Action 3	order by time (earliest first)	
Action 4	Look through for duplicates (or if too many Action 5)	
Action 5	Check & Delete if needed	
2. Straight liners		
		Answer code
Select	ALL WHERE answer is a (= '1')	e.g. WHERE mmn_1 = '1'; mmn_2 = '1'; mmn_3 = '1'; mmn_4 = '1'; mmn_5a = '1'; mmn_5b_1 = '1'
Action 1	If any exist then delete	
		Answer code
Select	ALL WHERE answer is b (= '2')	e.g. WHERE mmn_1 = '2'; mmn_2 = '2'; mmn_3 = '2'; mmn_4 = '2'; mmn_5a = '2'; mmn_5b_2 = '1'
Action 1	If any exist then delete	
		Answer code
Select	ALL WHERE answer is c (= '3')	e.g. WHERE mmn_1 = '3'; mmn_2 = '3'; mmn_3 = '3'; mmn_4 = '3'; mmn_5a = '3'; mmn_5b_3 = '1'
Action 1	If any exist then delete	
		Answer code
Select	Register surveys WHERE answer is last (= 'X')	e.g. WHERE mmn_1 = '5'; mmn_2 = '9'; mmn_3 = '12'; mmn_4 = '5'; mmn_5a = '5'; mmn_5b_6 = '1'
Action 1	If any exist then delete	

		Answer code
Select	Paper surveys WHERE answer is first on right (= 'X')	e.g. WHERE mmn_1 = '4'; mmn_2 = '6'; mmn_3 = '7'; mmn_4 = '4'; mmn_5a = '4'; mmn_5b_3 = '1'
Action 1	If any exist then delete	
		Answer code
Select	Paper surveys WHERE answer is last on right (= 'X')	e.g. WHERE mmn_1 = '5'; mmn_2 = '9'; mmn_3 = '12'; mmn_4 = '5'; mmn_5a = '5'; mmn_5b_5 = '1'
Action 1	If any exist then delete	
		Answer code
Select	Paper surveys WHERE answer is last on left (= 'X')	e.g. WHERE mmn_1 = '3'; mmn_2 = '5'; mmn_3 = '6'; mmn_4 = '3'; mmn_5a = '3'; mmn_5b_6 = '1'
Action 1	If any exist then delete	
3. Inconsistent responses		
		Answer code
Select	SELECT Q2 is 16-20 years ago	mmn_2 = '6'
Action 1	WHERE age 16 - 24	
Action 2	Check and delete	
		Answer code
Select	SELECT Q2 is 21-50 years ago	mmn_2 = '7'
Action 1	WHERE age 16 - 24	
Action 2	Check and delete	
		Answer code
Select	SELECT Q2 is 2more than 50 years ago	mmn_2 = '8'
Action 1	WHERE age 45 - 54 or under	WHERE age = '16-24'; age = '25-34'; age = '35-44'; age = '45-54'
Action 2	Check and delete	
		Answer code
Select	SELECT Q3 = 'no one'	mmn_3 = '11'
Action 1	WHERE Q4 = 'Yes'	mmn_4 = '1'
Action 2	check and DELETE	
		Answer code

Select	SELECT Q17 = 'no'	mmn_17 = '4' OR '5'
Action 1	WHERE Q18 = any except none	Q18 Agg 'On benefits' = '1'
Action 2	check and DELETE	
		Answer code
Select	SELECT Q18 = 'PIP'	mmn_18_5 = '1'
Action 1	WHERE Q19 = 'I receive...'	mmn_19 = '1' OR '2' OR '3' OR '4'
Action 2	check and DELETE	
		Answer code
Select	SELECT Q18 = 'UC'	mmn_18_7 = '1'
Action 1	WHERE Q20 = 'I receive...'	mmn_20 = '1' OR '2' OR '3' OR '4'
Action 2	check and DELETE	
		Answer code
Select	SELECT Q18 = 'DLA' OR 'PIP'	mmn_18_4 = '1' OR mmn_18_5 = '1'
Action 1	WHERE Q21 = Yes	mmn_21 = '1' OR '2'
Action 2	check and DELETE	
		Answer code
Select	SELECT Q30 = 'Yes, all the support needed'	mmn_30 = '1'
Action 1	WHERE Q31 = any except NA	Q31 Agg 'Any except NA'
Action 2	check and DELETE	
		Answer code
Select	SELECT Q30 = No	mmn_30 = '3' OR '4'
Action 1	WHERE Q32 = any except NA	mmn_32 = '1' OR '2' OR '3' OR '4'
Action 2	check and DELETE	
		Answer code
Select	SELECT Q30 = 'no and not needed'	mmn_30 = '3'
Action 1	WHERE Q33 = any except none or NA	Q33 Agg '33_need'
Action 2	check and DELETE	
		Answer code
Select	SELECT Q30 = 'no and not needed'	mmn_30 = '3'
Action 1	WHERE Q34 = any except none or NA	Q34 Agg '34_need'
Action 2	check, flag and delete	

		Answer code
Select	SELECT Q30 = 'no and not needed'	mmn_30 = '3'
Action 1	WHERE Q35 = any except no or not sure	Q35 = '1' OR '2' OR '3' OR '4'
	WHERE Q35 = no or not sure	Q35 = '5' OR '6' OR '7' OR '8'
Action 2	check, flag and delete	
		Answer code
Select	SELECT Q30 = 'no and not needed'	mmn_30 = '3'
Action 1	WHERE Q36 = any except no or not sure	Q35 = '1' OR '2' OR '3'
	WHERE Q36 = no or not sure	Q35 = '4' OR '5' OR '6'
Action 2	check, flag and delete	
		Answer code
Select	SELECT Q30 = 'no and not needed'	mmn_30 = '3'
Action 1	WHERE Q37 = any except no or not sure	Q37 = '1' OR '2' OR '3'
	WHERE Q37 = no or not sure	Q37 = '4' OR '5'
Action 2	check, flag and delete	
		Answer code
Select	SELECT Q30 = 'no and not needed'	mmn_30 = '3'
Action 1	WHERE Q38 = any except not sure or NA	Q38 = '1' OR '2' OR '3' OR '4'
	WHERE Q38 = not sure or NA	Q38 = '5' OR '6'
Action 2	check, flag and delete	
		Answer code
Select	SELECT Q30 = 'no and not needed'	mmn_30 = '3'
Action 1	WHERE Q39 = any except none, not sure or NA	Q39 = '1' OR '2' OR '3' OR '4'
	WHERE Q39 = none, not sure or NA	Q39 = '5' OR '6' OR '7'
Action 2	check, flag and delete	
		Answer code
Select	SELECT Q30 = 'no and not needed'	mmn_30 = '3'

Action 1	WHERE Q39 = any except none, not sure or NA	Q39 = '1' OR '2' OR '3' OR '4'
	WHERE Q39 = none, not sure or NA	Q39 = '5' OR '6' OR '7'
Action 2	check, flag and delete	
Action 2	check and DELETE	
		Answer code
Select	SELECT Q45a = No	mmn_45a_5 = '1' OR mmn_45a_6 = '1' OR mmn_45a_7 = '1' OR mmn_45a_8 = '1' OR mmn_45a_9 = '1'
Action 1	WHERE Q45b = any except NA	mmn_45b = '1' OR '2' OR ... '6'
Action 2	check and DELETE	
4. Logic Testing – Delete single responses		
		Answer code
Select	SELECT Q9 = No or NA	mmn_9 = '2' OR '3' OR '5'
Action 1	WHERE Q10 = any except NA	Q10 Agg 'Any except NA'
Action 2	check and DELETE	
		Answer code
Select	SELECT Q11 = No or NA	mmn_11 = '2' OR '3' OR '5'
Action 1	WHERE Q12 = any except NA	Q12 Agg 'Any except NA'
Action 2	check and DELETE	
		Answer code
Select	SELECT Q16a = not struggling	mmn_16a = '1' OR '2' OR '3'
Action 1	WHERE Q16b = any except none	Q16b Agg 'Any except none'
Action 2	check and DELETE	
		Answer code
Select	SELECT Q22a = No	mmn_22a = '2' OR '3'
Action 1	WHERE Q22b = any	Q22b Agg 'All'
Action 2	check and DELETE	
		Answer code
Select	SELECT Q22c	mmn_22c
Action 1	WHERE not Northern Ireland	
Action 2	DELETE	
		Answer code
Select	SELECT Q23a = No	mmn_23a = '2' OR '3'

Action 1	WHERE Q23b = any	Q23b Agg 'All'
Action 2	check and DELETE	
		Answer code
Select	SELECT Q23c	mmn_23c
Action 1	WHERE not Northern Ireland	
Action 2	DELETE	
		Answer code
Select	SELECT Q36	mmn_36
Action 1	WHERE not England OR Wales	
Action 2	DELETE	
4. Invalid responses – delete single response		
		Answer code
Select	SELECT QX and count responses	repeat for mmn_1; 2; 3; 4; 5a; 6; 7; 9; 11; 14; 15; 16a; 17; 19; 20; 21; 22a; 22c; 23a; 23c; 24; 26; 30; 32; 35; 36; 37; 38; 39; 40; 42; 44; 45b; 46; 47; 48; 49; 50; 51; 54; 55; 56; 57; 58; 59; 60; 61
Action 1	count > 1	
Action 2	check and DELETE	

We're the MS Society.

Our community is here for you through the highs, lows and everything in between.

We understand what life's like with MS.

Together, we are strong enough to stop MS.

mssociety.org.uk



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 **Let's stop MS together**

