healthwatch Devon

healthwatch Torbay

Living with Multiple Sclerosis in Devon & Torbay

Insight Report

July 2025

Contents

Executive Summary

Over the course of 2023 – 2024, accounts reported via our online and telephone 'Have your say' portal from people living with Multiple Sclerosis described patients experiencing difficulties with various aspects of their care. Complaints centred on the availability of care, communication issues, medication access, appointment scheduling, and unresolved grievances.

It became clear that the everyday issues faced by these patients deserved closer examination with an engagement insight concentrating on Devon and Torbay, comprising both face-to-face focus group work and an online survey.

What we concluded from examining the results of this research

There are inconsistences in care for many people living with MS, notably in:

- obtaining a diagnosis
- waiting for treatment
- ongoing care
- communication with clinicians.

We therefore recommend:

1. Efforts should focus on standardising diagnostic processes for MS, including setting targets from symptom onset to diagnosis.
2. Research is needed on how diagnostic delays impact patients emotionally and physically.
3. A 12-week treatment initiation goal post-diagnosis, as advised by the National Neurosciences Advisory Group, should become a benchmark.
4. Further investigation is warranted into apparent regional disparities in MS care quality.
5. Annual comprehensive patient reviews, as recommended by the National Institute for Health and Care Excellence (NICE), should be universally adopted, with advocacy groups promoting patients' rights to request them.

About Us

Healthwatch in Devon, Plymouth, and Torbay (HWDPT) are the local independent consumer champions for people using health and social care services across Devon.

Local Healthwatch organisations were established as independent bodies run by local people, for local people. They are part of a national network of Local Healthwatch in England that was set up under the Health and Social Care Act 2012.

Healthwatch engages with the local community to give residents of Devon, Plymouth & Torbay a stronger voice to influence and challenge how health and social care services are provided for them.

Devon County Council, Plymouth City Council and Torbay Council jointly commission local Healthwatch in Devon, Plymouth and Torbay. This jointly commissioned Healthwatch service is provided by Citizens Advice Devon, Colebrook Southwest Ltd & Engaging Communities Southwest Ltd.

Introduction

Multiple sclerosis (hereafter referred to as MS) is a condition that affects nerves in the body's central nervous system. This causes a range of symptoms such as blurred vision and problems with how people move, think and feel. Once diagnosed, MS remains for life, but treatments and specialists can help to manage the condition and its symptoms.

It is estimated that there are over 150,000 people with MS in the UK, and each year over 7,000 people are newly diagnosed. This equates to around 3,000 Devon residents living with MS - approximately 1 in every 400 people in the UK.

MS affects about two and half times as many women as men. In the UK, people are most likely to find out they have MS in their thirties and forties. But the first signs of MS often start years earlier and many people notice their first symptoms years before they receive a confirmatory diagnosis of their condition.

Everyone's MS is different. No two people, even if they're closely related, will have the same type of symptoms, or have them to the same degree. This means that there is no "one size fits all" approach to treating and caring for people with MS. What is universal is that, as one of our feedback correspondents described: *"Patients and their families live with the disease over many years, and it has a profound effect on every aspect of our lives."*

This insight, compiled from a range of feedback from people living with MS, attempts to provide a snapshot of those profound effects and point to ways that life can be made easier for people living with the condition.

Background

The impetus for this report originated by reviewing our website and information line feedback received over the past two years related to MS from which we collated accounts of people living with MS experiencing difficulties accessing care, failure of communication from NHS providers and long waits for appointments or results of diagnostic procedures. A picture emerged of some people living with MS enduring rising anxiety caused by problems accessing the care and advice they need. Feedback describes how some felt "*brushed under the carpet*" or "*overlooked by the MS department*".

Based on these trends, we decided to undertake research for this insight into the lived experience of MS patients.

Methodology

Feedback from people living with MS was gathered in a variety of ways:

- Cases referred to our Healthwatch Champions working through Citizens Advice offices across Devon.
- Face-to-face discussions with people attending MS specific therapy sessions and social groups, conducted by Healthwatch Champions and Engagement Officers.
- Accounts received through our online 'Have your say' form between 2023 and 2025.
- Calls taken by our Freephone Information Line during the same period.
- Respondents to an online survey, distributed through Healthwatch contacts and social media.

Key Findings

This section highlights a summary of the key themes gathered from our research.

Summary of Key Themes

- **Diagnosis** – Many participants described the diagnostic process as "stressful", "complicated" or "difficult" with a wide variance of time taken from first reporting symptoms to receiving an MS diagnosis.
- **Treatment and Referral Satisfaction**– When asked about satisfaction with the time it took to be referred to a specialist and beginning treatment, 8 of 33 survey respondents (24.24%) reported being dissatisfied.
- **Clinic Appointment Convenience -** Most respondents found appointment times and locations convenient.
- **Positives** – Praise was given to individual staff and services.
- **Negative experiences** - These included inadequate follow-up after diagnosis, difficulty navigating services and feeling uninformed or dismissed by professionals.

Detailed Findings

Our findings are derived from a combination of online survey responses, web form feedback, face to face discussions and calls to our Information Line. Combining all these interactions, a total of 89 individuals living with MS fed into the data for this insight. The findings are segmented by the themes of questions posed in the online survey.

Please Note: *All commentary featured in this report is included as verbatim to illustrate the themes identified from the data analysis. Not all comments are included in this report, and some comments relate to more than one theme.*

Survey demographics

Demographic data was not gathered in focus group sessions but was taken as part of the online survey. Of the 33 people who responded to our online survey, 25 (75.8%) were female and 8 were male (24.2%), which closely resembles the UK national gender ratios of MS patients of 72% and 28% respectively. Nearly all respondents were aged between 45 and 74, with the largest proportion - 12 (36.4%) - aged between 55 - 64 (the highest prevalence for MS in the UK occurs in the 60 to 69 years age group for both sexes[1]). The great majority, 87.9%, identified their ethnic origin as White - English, Welsh, Scottish or Northern Irish.

The bulk of the responses came from residents in the Devon area, with only 3 contributors from Torbay and 1 from Plymouth (3 declined to give their postcode).

[1] Multiple sclerosis: prevalence, incidence and smoking status - data briefing https://www.gov.uk/government/publications/multiple-sclerosis-prevalence-incidence-and-smoking-status/multiple-sclerosis-prevalence-incidence-and-smoking-status-data-briefing> Published 4 February 2020

Diagnosis

Evidence indicates that early diagnosis of MS and early treatment improves long-term outcomes. However, the MS diagnostic pathway is increasingly complex, and delays may occur at several stages. Factors causing delays remain understudied[2].

Accounts given to us of patients' diagnostic journey demonstrate a wide variance in time taken from reporting symptoms to receiving a diagnosis of MS. In some instances, familiarity with the symptoms of the condition appear to have facilitated a quicker diagnosis; one respondent recognised his symptoms as being similar to those of his mother who had MS, and his journey to diagnosis was approximately 1 month. Another patient had the advantage of medical training and effectively diagnosed himself, whilst a survey response detailed: "*As a sufferer with another MS sufferer in the family I knew enough about the condition that my symptoms could be indicative of MS. My GP took my concerns seriously and I was diagnosed within 12 months of my first symptoms*."

Such cases appear to be the exception rather than the rule in our findings. Only 12 of 33 online survey respondents (36.36%) reported their diagnosis as "straightforward", with the majority describing the experience as "complicated", "confusing", "difficult" or "stressful." Proportionately more women than men found the experience stressful, with 11 of the 25 female respondents (44%) choosing that descriptor as opposed to 1 out of 8 (12.5%) of the men. The greater difficulty of the experience for women is also reflected in the percentages of those describing the process as straightforward; 28% of female patients as opposed to 62.5% of males.

Diagnosis delays ranged from several months to 20 years, "*symptom by symptom at the GP. Eventually, someone joined up the dots*." One survey respondent complained they were given no information and felt they were simply "*left in the dark and … told to carry on working for as long as I*

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[2] Kuri, A., Henshall, D.E., Chaudhry, D. *et al.* Delays in Multiple Sclerosis diagnosis (DIMES): protocol for a multicentre, observational study of multiple sclerosis diagnostic pathways in the United Kingdom and Republic of Ireland. *BMC Neurol* **24**, 105 (2024)."

could." This variance in people's experience indicates a lack of consistency in diagnostic pathways.

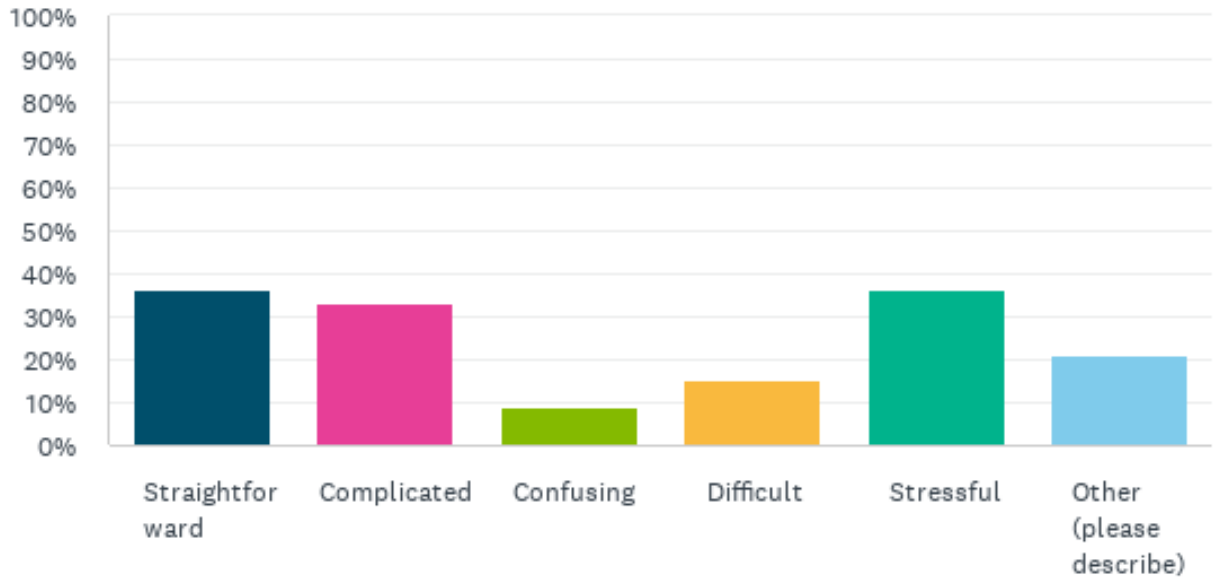

Figure 1: Survey responses to the question "What was your experience of diagnosis like?" (Tick all that apply)

Diagnosis to treatment

Unlike the 62-day target applied to cancer patients beginning treatment following diagnosis, there is no statutory instruction in the UK for how quickly someone diagnosed with MS should start receiving treatment. However, there are guidelines and recommendations aimed at ensuring timely access to care. NHS England has a treatment algorithm for MS therapies to streamline decision-making and reduce delays, whilst the National Neurosciences Advisory Group (NNAG) has developed an optimal clinical care pathway for MS, recommending that treatment should ideally begin within 12 weeks of diagnosis.[3]

As with the diagnostic journey, our research pointed to wide variance in how satisfactory people found waiting times for treatment following being diagnosed. Whilst 12 (36.36%) of 33 survey respondents were "very

[3] Optimal clinical pathway for adults with multiple sclerosis (MS): National Neurosciences Advisory Group (NNAG) November 2024 https://www.nnag.org.uk/optimal-clinical-pathway-adults-ms

satisfied" with the time it took to be referred to an MS specialist, a further 8 (24.24%) were dissatisfied.

Of those 8, one respondent described how it took 12 months to be seen by any clinician at all post diagnosis, whilst another recounted: "*I have only had brief opportunities to speak to the specialist. My treatment was delayed by 6 months due to lost and subsequently ignored blood work. During which [time]my condition deteriorated with no contact or help from anyone.*"

In instances where treatment has started in a timely fashion, one person in the survey felt that they were rushed into it without being given time to consider what it entailed: "*I was offered drugs straight away and when I said I needed more time and information I was pretty much told that drugs are the only option and lifestyle changes would make no difference. I did not feel supported or listened to, almost as though the consultant was annoyed with me.*" A similar feeling of not being included in decision making is found in the following account: "*I have questions about my condition that I can't get answers to, so I look them up, then I am told I shouldn't be 'researching' my condition but am not offered any alternative as to who to speak to.*"

Ongoing care

The most concerning feedback in this research centres on the experience of MS patients' ongoing care. Although most survey responses indicated satisfaction with times and locations of appointments, problems reported revolve around:

- the frequency of **appointments**
- the inadequacy of **virtual and phone consultations**
- difficulty in **communications** with specialists and nursing staff
- an apparent **inconsistency** in care.

The NICE MS guideline recommends that people with MS have annual review **appointments** with a healthcare professional with expertise in MS.

This will usually be with a neurologist or MS nurse.[4] However, we received feedback from our survey, information line and engagement sessions from patients for whom that was not the case.

We received comments such as "*I can't even remember the last time I saw a neurologist*," and "*I don't hear from the MS Nurse unless I contact her with a query*," whilst a common complaint of those attending a focus group engagement in Torbay complained they had not been seen "for years". Another respondent complained that "*No one has ever checked in with me to find out how I am, now that I'm a wheelchair user*" which is not an unreasonable expectation. It is not surprising, therefore, that only 10 of 33 survey respondents felt that all their needs were being met by clinicians, whilst the same number felt that their needs were not being satisfied at all.

An examination of the demographics of survey respondents suggests that women living with MS express the most dissatisfaction with their ongoing care. 9 (36%) of women surveyed felt that their needs were not being met, whereas only 1 (12.5%) of the male respondents reported this. Similarly, 50% of the men surveyed felt all their needs were being met as opposed to only 24% of women.

Whilst the use of **virtual or telephone consultations** might be facilitating more appointments, only 11 of 24 survey participants experienced that as a satisfactory option. One patient who had a poor mobile signal at home was forced to hold her telephone appointment in a supermarket café - with an unavoidable lack of privacy. Another respondent has difficulties holding their phone, whilst one patient described how upsetting it was to be told they had MS over a video link and reported that subsequent telephone consultations with MS nurses felt "rushed", concluding that "*things I am trying to say get overlooked*."

This account reflects a theme emerging from our research of difficulties for some around **communication** between MS patients and clinical staff.

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[4] Multiple sclerosis in adults: management – NICE guideline Reference number:NG220 Published: 22 June 2022 https://www.nice.org.uk/guidance/ng220

There are guidelines for NHS staff in the UK on responding to patient enquiries, though the specifics can vary depending on the nature of the enquiry and the NHS trust or service involved. Although 16 (81.25%) of survey respondents were either 'very' or 'reasonably' happy with their communications with health professionals, reports from our feedback centre and the information line includes many accounts of emails and phone calls to clinicians not being acknowledged or responded to. One person diagnosed with MS in 2023 reported to our information line that they had tried on several occasions to contact their neurologist or MS nurse as they had concerns regarding their health and medication. After leaving several messages and emails without any reply they called Healthwatch for help to register a complaint.

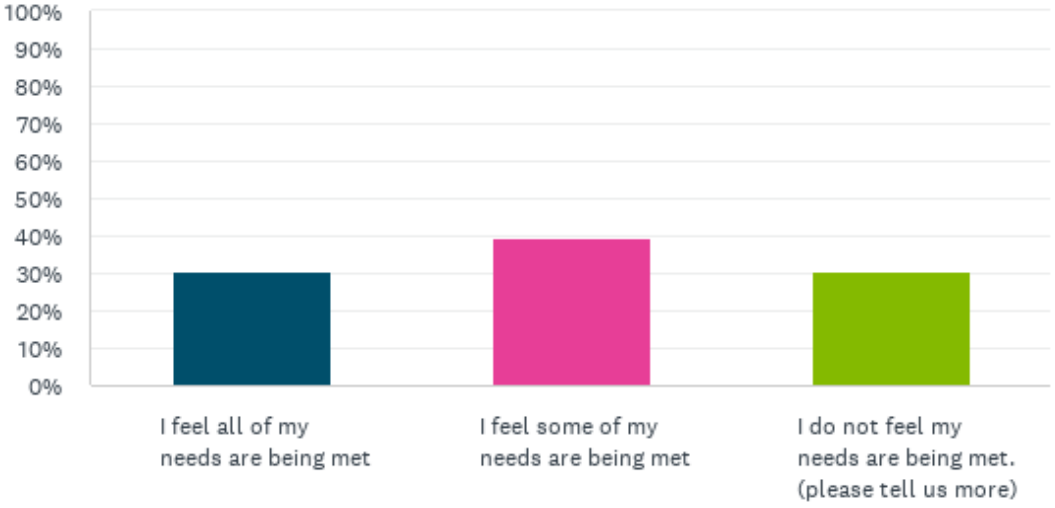


Figure 2: Survey responses to the question "Do you feel your needs are being met by ongoing reviews from clinicians?"

An MS patient with an eye condition had tried unsuccessfully to speak to the Ophthalmology department at Torbay hospital, but two months after their MS nurse and GP had also written to the department they had still not heard anything. Two months was also the time it took for one person to receive the results of an MRI scan on their spine, whilst another reported having to write Freedom of Information requests to see clinical notes about their scans. One patient complained: "*I have not had regular contact with a specialist, the MS nurse I have been assigned ignores my emails, is difficult to contact via phone, makes suggestions of more regular*

meetings but doesn't follow up with them."

The patchiness of communication quality is illustrated in the following account: "*When received, communications are ok but my emails to the team have not always been acknowledged nor answered*." These accounts and other feedback we have received suggest that more work needs to be done in standardising communication procedures and response time guidelines.

Elsewhere in our results we found accounts that pointed to an **inconsistency of care** experienced by some individuals living with MS, often revolving around changes to MS nursing staff or consultants. One respondent, themselves a medical practitioner, expressed the opinion that although they valued their current "excellent" neurologist, the quality of consultants is "variable". One survey response cited a difference in consultant care between hospitals: "*Previous specialists via Torbay were non-verbal and I was ignored many times when requesting help. Now I have changed to Exeter MS specialists they do communicate with me via phone but [they are] not really helpful as they are unable to visit me due to my postcode*." Similarly, a focus group patient told us that the MS Nurses at Royal Devon & Exeter were excellent, but that services in North Devon are generally difficult to access.

Anyone living with MS will generally be in contact with an MS Nurse more frequently than a neurology consultant. As their main point of contact, specialist nurses are someone that MS patients come to rely on, so it is not surprising that changes in staff can be uncomfortable for them: "*My first MS nurse was brilliant, but new ones, I always get a different one who doesn't really know me and my difficulties, they are all very good at their jobs, but I feel I'm repeating myself.*"

Observations

Summary of Observations

- **Diagnosis** – The wide variance in diagnosis pathway times illustrated in our feedback highlights a need for statutory guidelines on how long the process from a clinical suspicion of MS to definitive diagnosis takes. In addition, more thought needs to be given to the support needs of patients on their diagnosis journey to avoid unnecessary stress that will only worsen their condition.

- **Treatment** – We were told of significant variation in the time patients waited between diagnostic confirmation and the start of treatment. This is unacceptable given that early diagnosis of MS and early treatment has been shown to improve long-term outcomes.

- **Ongoing care** – Feedback to Healthwatch indicates that many patients are not being well served due to a lack of specialist attention and scarcity of appointments, numerous difficulties communicating with health staff (or even having patient communication acknowledged) and reported inconsistency in the quality of care between individual regional services.

- **Positive experiences** - Several people consulted in this research praised individual health service staff, including consultants, nurses and secretarial staff, and particular praise was given to the MS Therapy Centre in Exeter, about which one patient declared: "*Without this charity and all that it offers I would have felt very lost as help and support from the NHS does not compare in any way.*"

- **The Plymouth experience** – Although this report focuses on the experiences of Devon and Torbay service users, we have also picked up similar themes from MS patients in Plymouth, largely about capacity

problems at Derriford Hospital. As one of our survey respondents summarised: "*Neuro Derriford is really short staffed*."

An account to our feedback centre detailed being diagnosed in 2022 after having the condition for 13 years, following which "*I waited 10 months for treatment as our hospital withdrew the space it gives the MS team for treatment. Even current patients missed their infusions despite already being on a treatment programme.*"

In 2024, another account detailed how accessing care or support for her MS diagnosed mother had been "*an uphill battle*", concluding that "*I think the main problem is there is basically no MS service in Plymouth. There are 1 or 2 consultants, a handful of nurses (our main nurse only works part time) and we have been told that the Co-ordinator role no longer exists… we really are at the end of our tether and seek alternative provisions whenever possible*."

A contributor to our feedback centre complained in 2023 of the decision by Derriford not to continue the funding of the MS Team Service Coordinator and considered that "*By not agreeing to fund the Service Co-ordinator's post through the NHS, the Trust is driving a coach and horses through the work of the Plymouth MS team and causing immense stress to patients who will no longer have the support they have been used to*."

In response to a Healthwatch Plymouth enquiry in February 2024 about the future of the MS Coordinator post, we were informed that a business case for continuing and recruiting the MS Coordinator role was underway. It is a matter for further investigation as to whether the post was reinstated.

We conclude that the situation in relation to MS treatment and support at Derriford Hospital deserves separate research to capture the experiences of people living with MS who depend on services in the Plymouth area.

Recommendations

Healthwatch have the following recommendations:

1. Consideration needs to be given to improving the uniformity of diagnostic pathways. Targets should be devised for the time taken from patients' initial reporting of symptoms to definitive MS diagnosis.
2. Further research should be undertaken into the physical and emotional effects that long waits have on patients during their diagnostic journey.
3. The 12-week optimal clinical pathway for treatment to begin following diagnosis, as recommended by the National Neurosciences Advisory Group, should be adopted as a standard target.
4. Further research and / or investigation should be carried out into the reported variance in quality of MS care between regional services and providers.
5. According to the National Institute for Health and Care Excellence (NICE) guidelines in 2022, everyone living with MS should receive a comprehensive review of their care at least once a year. This guidance should be adopted by all MS teams, whilst MS support and advocacy organisations should be encouraged to promote the right of MS patients to make formal requests for an annual review.

Stakeholder Response

The MS service at the Royal Devon University Healthcare NHS Foundation Trust said:

"MS is a complex disease and it is important the NHS is able to provide a person-centred approach.

This feedback from patients is valuable learning as we seek to continuously improve the care we offer."

Acknowledgements

Healthwatch Devon Plymouth and Torbay would like to thank everyone living with MS, their families and carers who contributed their experiences to this report via either the online survey or in face-to-face meetings, including;

- Katie Head, Administrator, and the patients, staff and volunteers at the MS Therapy Centre in Exeter.
- MS patients and MS Society volunteers at the Neuro Physio-led exercise classes in Paignton.
- Members of the MS Social group and coffee morning in Barnstaple.
- The MS Society South Devon and MS Society Exeter groups.

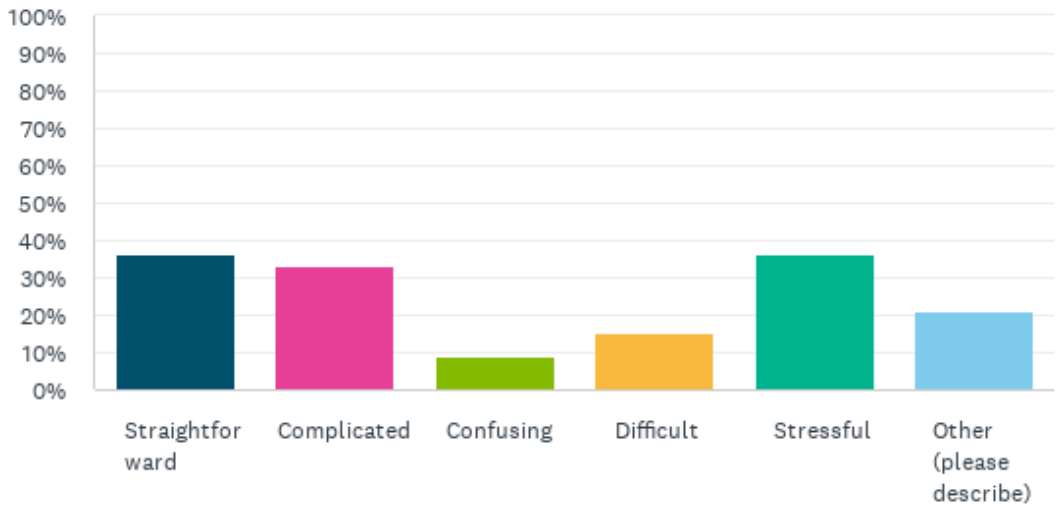
Appendix A

Survey Questions

1. Diagnosis

Getting a diagnosis for MS can be a complex process. What was your experience of diagnosis like? (Tick all that apply)

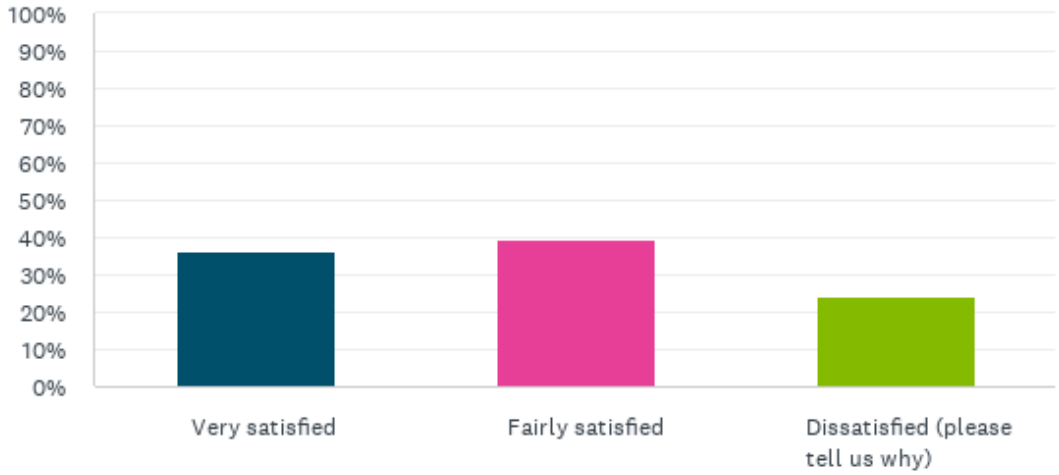
- Straightforward
- Complicated
- Confusing
- Difficult
- Stressful
- Other (please describe)



2. Treatment

MS treatment typically involves a combination of therapies following consultation with a MS specialist. Were you satisfied with the time it took to be referred to a specialist and subsequent treatment?

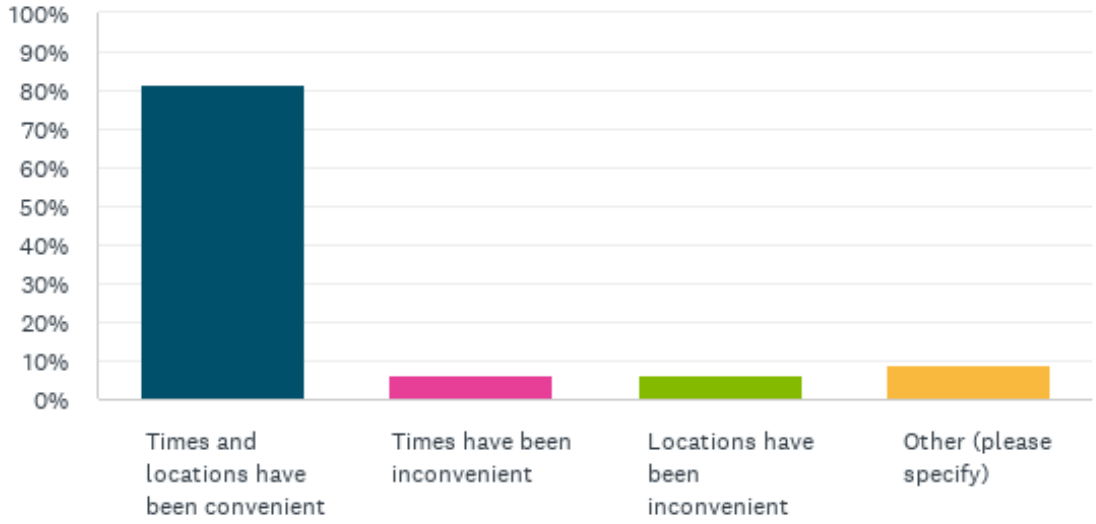
- Very satisfied
- Fairly satisfied
- Dissatisfied (please tell us why)



3. Clinic Appointments

When attending your appointments, how convenient have the locations and times offered usually been? (Tick all that apply)

- Times and locations have been convenient
- Times have been inconvenient
- Locations have been inconvenient
- Other (please specify)

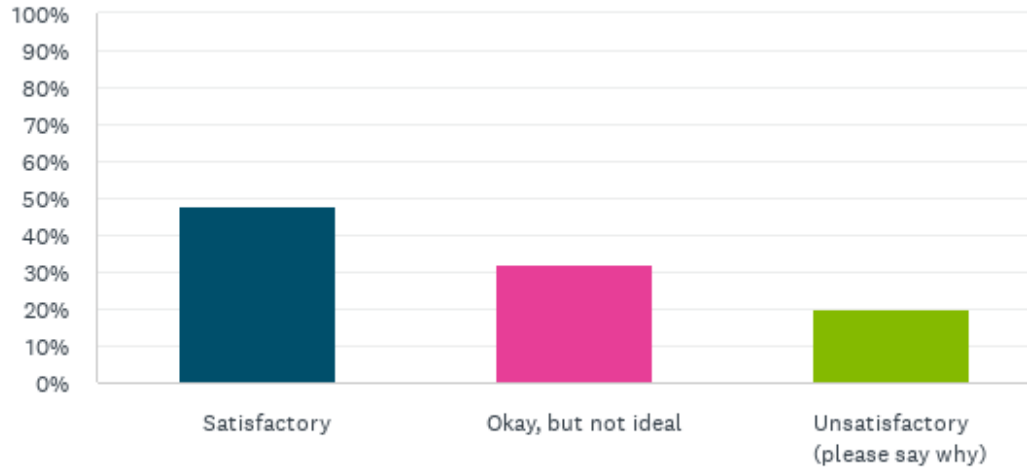


4. Virtual Appointments

If any of your appointments with clinicians have been via video link or over the telephone, how satisfactory for you were these appointments?

- Satisfactory

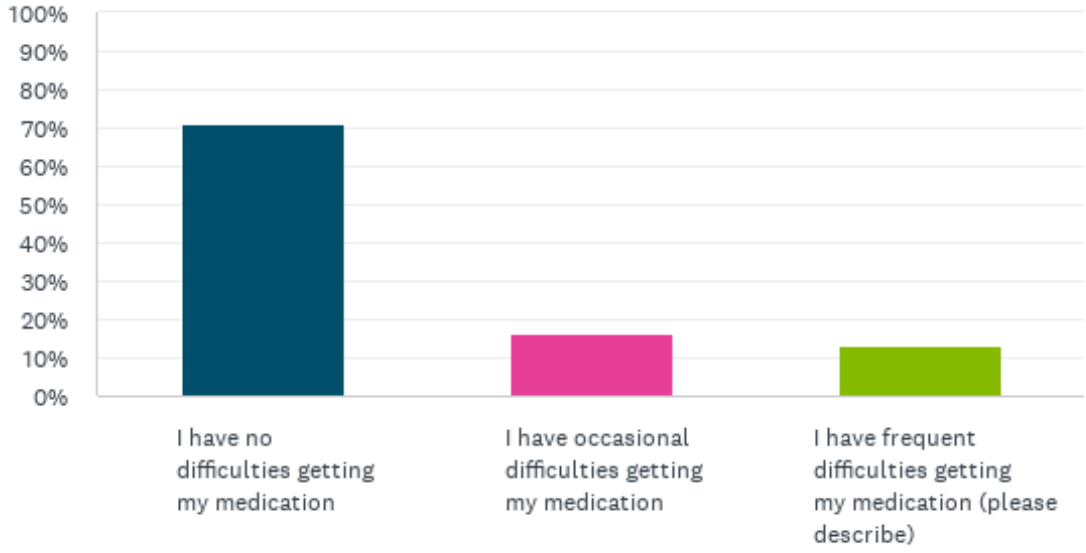
- Okay, but not ideal
- Unsatisfactory (please say why)



5. Access to medications

How easy has it been for you to access medications for your condition, whether through hospital or community pharmacy?

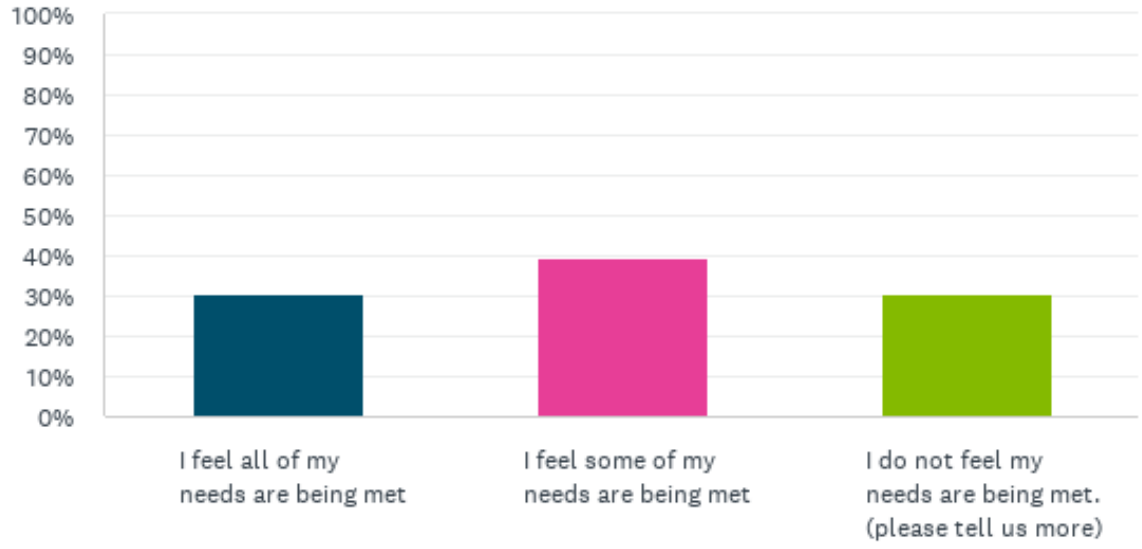
- I have no difficulties getting my medication
- I have occasional difficulties getting my medication
- I have frequent difficulties getting my medication (please describe)



6. Ongoing assessments

It is recommended that individuals have access to and engage with specialists regularly throughout their MS journey. Do you feel your needs are being met by ongoing reviews from clinicians?

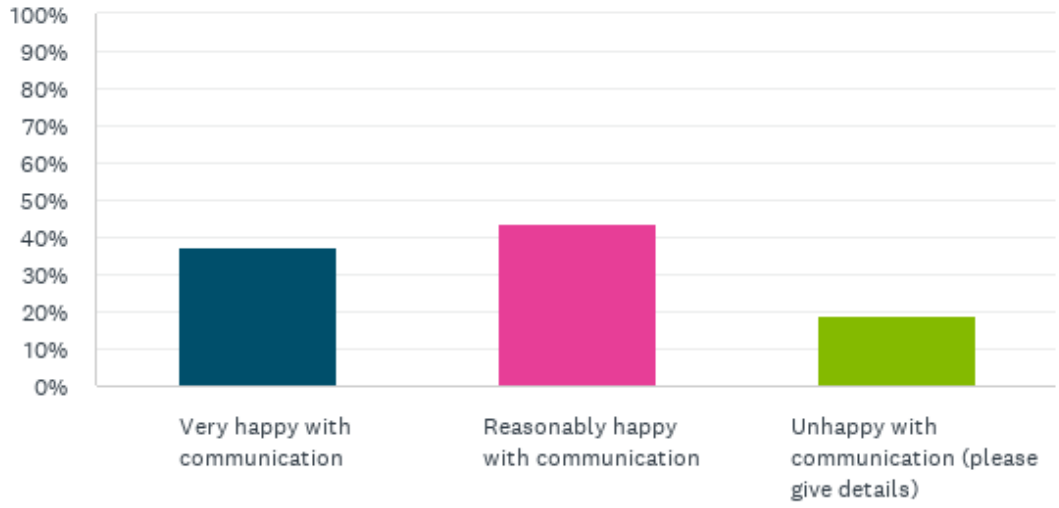
- I feel all of my needs are being met
- I feel some of my needs are being met
- I do not feel my needs are being met. (please tell us more)



7: Communication

Communication from health providers - by letter, phone or email - should ideally be timely and made in a way that is easy for you to access and understand. How happy have you been with the ways that health and care services have communicated with you?

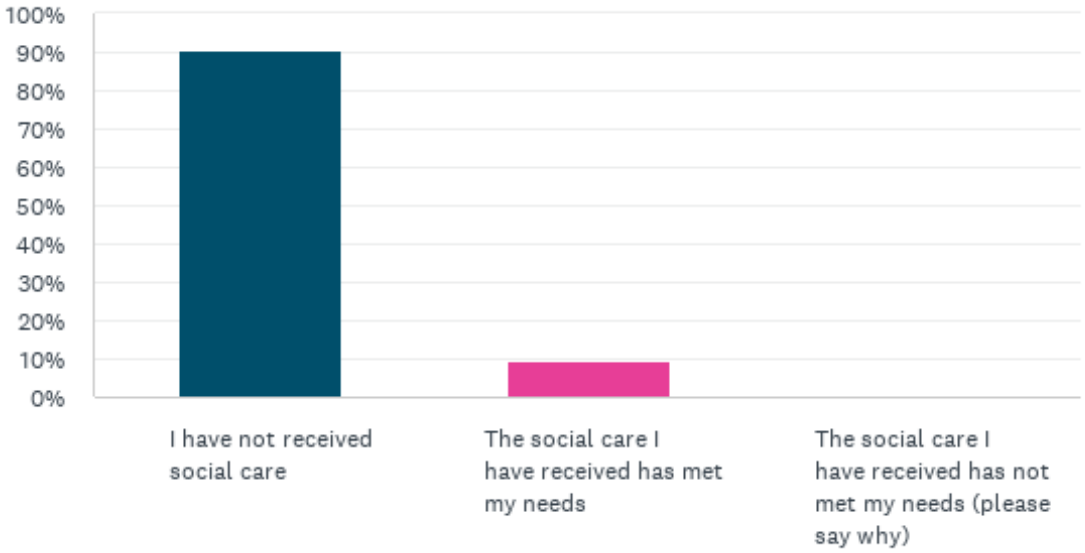
- Very happy with communication
- Reasonably happy with communication
- Unhappy with communication (please give details)



8: Social care

Social Care is practical help with maintaining your independence, e.g personal care, home care, support with daily living tasks. If you have received social care services, has the care provided met your needs?

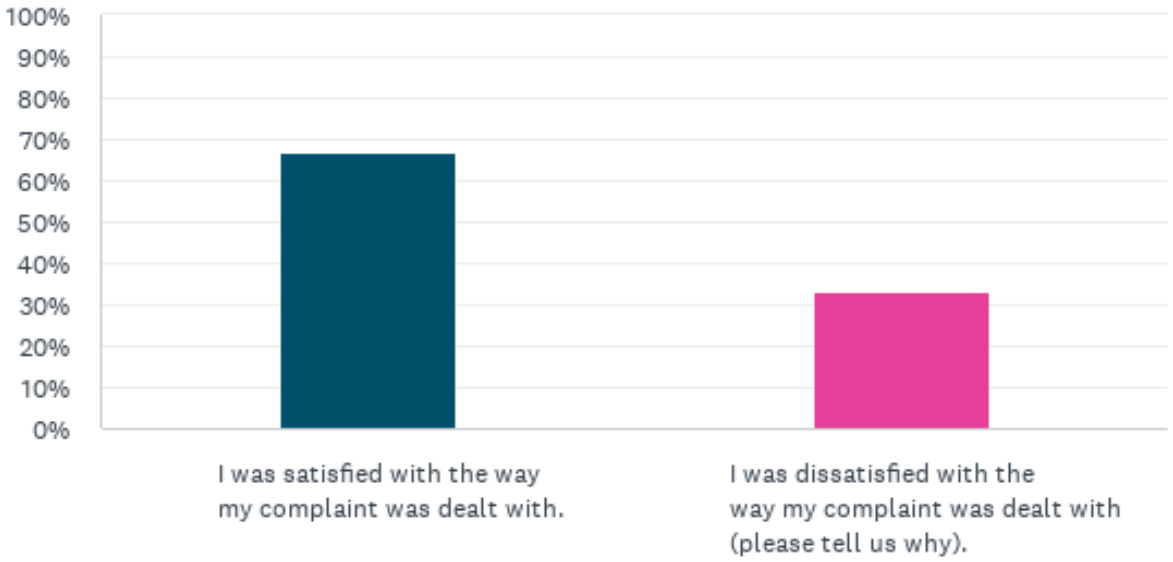
- I have not received social care
- The social care I have received has met my needs
- The social care I have received has not met my needs (please say why)



9. Complaints and appeals

If you have needed to submit a complaint about health or care services, was the complaint dealt with to your satisfaction?

- I was satisfied with the way my complaint was dealt with.
- I was dissatisfied with the way my complaint was dealt with (please tell us why).



10. What have we missed?

Please let us know about any other problems or positive experiences that you encounter living with MS.

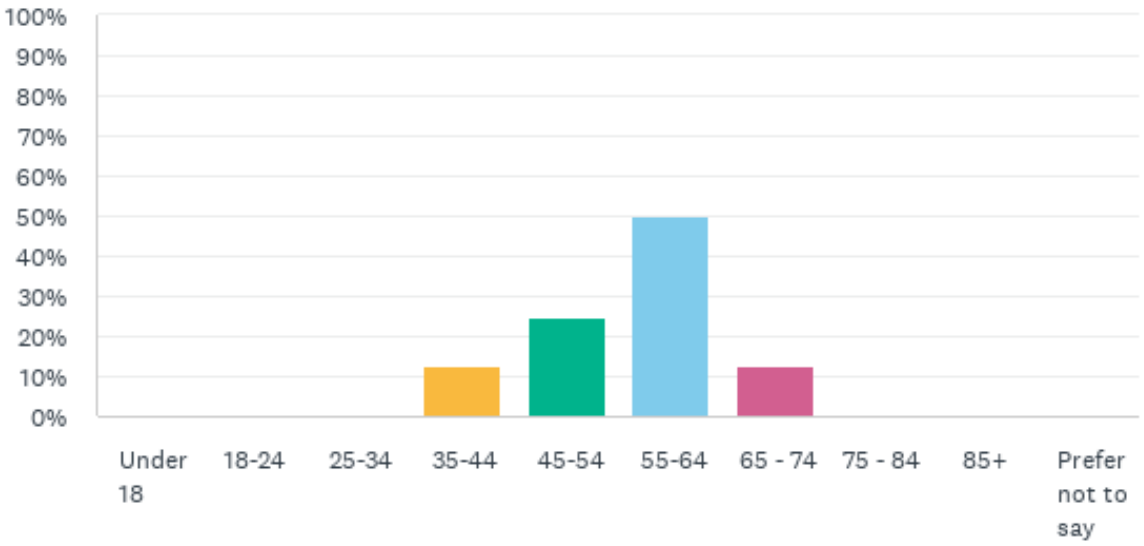
11.

If you would like to be kept updated about our work on MS or are happy for us to contact you about your story, please leave us your contact details (phone or email).

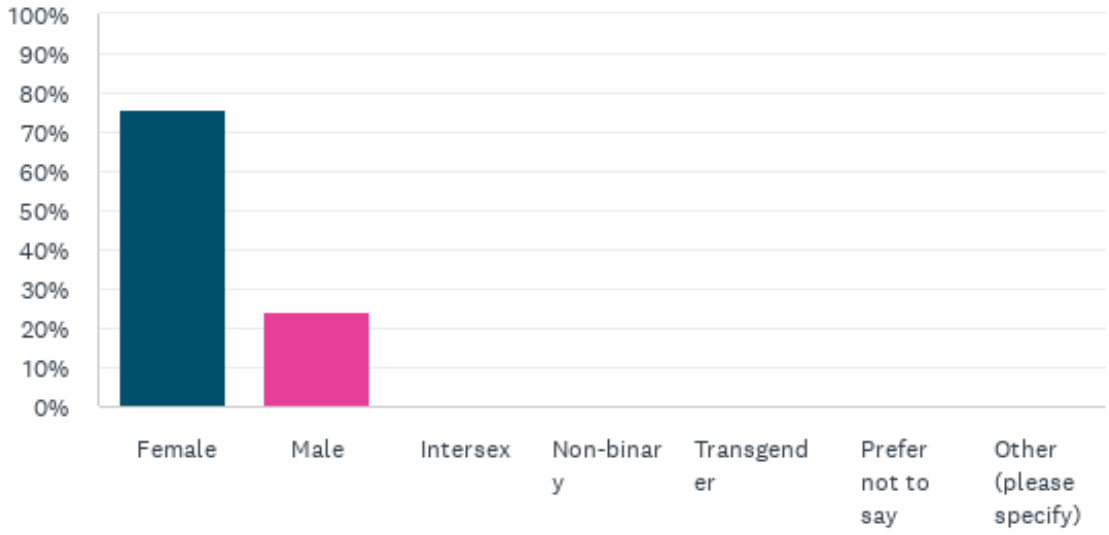
12. What is your postcode?

Devon postcodes	26	78.8%
Plymouth postcodes	1	3
Torbay postcodes	3	9.1

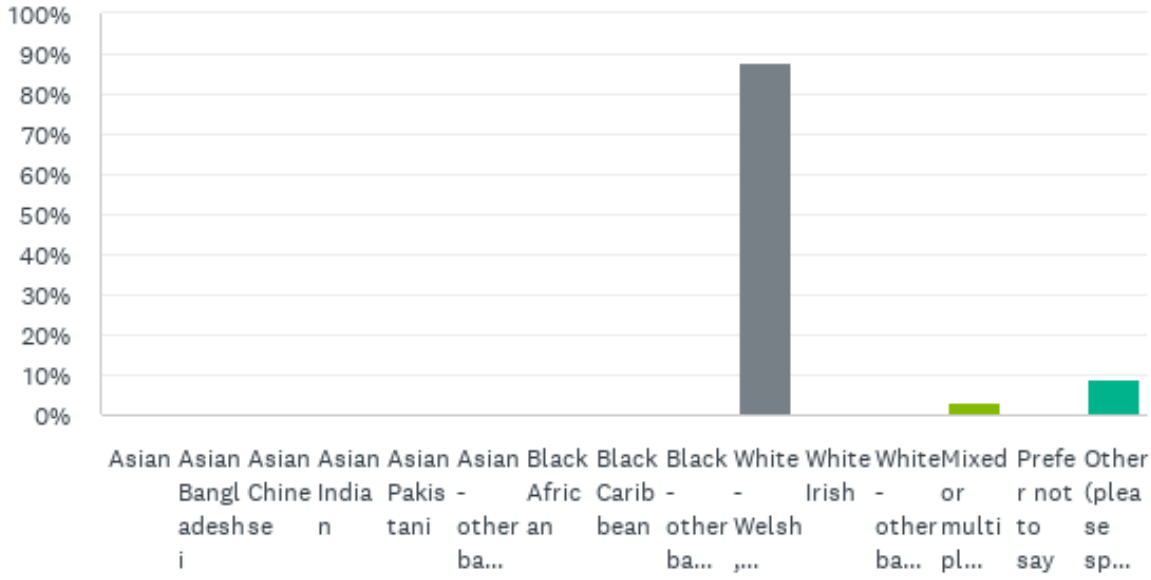
13. What is your age group?



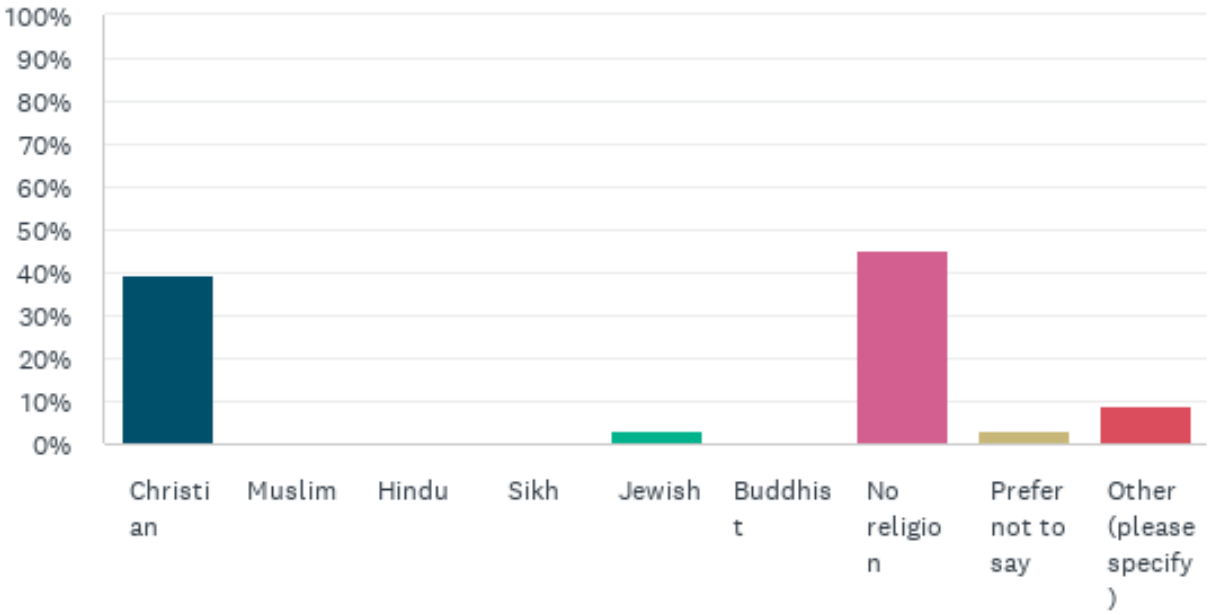
14. How would you describe your gender?



15. How would you describe your ethnicity?



16. Do you have a religion or belief?



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