



'What Good Looks Like'

Patient engagement on quality MS services
2019/20



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Foreword

This report captures the experiences of the MS community across Scotland prior to the global pandemic. While the context into which we release this report has altered dramatically, the needs of the MS community described here have not disappeared. Indeed, as we gather insight into the impact of the pandemic on the MS community, we have found that some of these needs are more urgent than ever¹.

We want to raise the bar for MS services across Scotland, so that people with MS are able to access the right treatment, care and support, at the right time, no matter who they are, where they live or their circumstance.

The MS Society's recent My MS, My Needs survey² found that whilst access to DMTs for those people eligible has increased to an average of 61% across Scotland, access to community services is much poorer with significant levels of unmet need for emotional support; access to physiotherapy; support to remain physically active; and continence advice.

The publication of the [General Standards for neurological care and support](#) by Healthcare Improvement Scotland in March 2019 is a welcome step in tackling this variation with the commitment that the Standards:

"set out the same high level of care and support for all adults in Scotland regardless of their neurological condition, care setting, geographical location or personal circumstance."

Since beginning this work we have seen the publication in December 2019 of the [Scottish Government's Neurological Care and Support: Framework for action 2020-2025](#); and the subsequent announcement of a funding programme to support collaborative work in achieving the priorities of the framework.

We also now know that there are more people living with MS in Scotland than we had previously estimated – around 15,000 people³. So the number of people not receiving the services they need is similarly higher than we had previously thought.

We ran a series of forums with people with MS around Scotland to talk about their experiences. We asked them to test some working assumptions, and tell us how they would know a service was 'good'.

The views and experiences of people with MS who were kind enough to share them will still be used to affect real change, albeit against a dramatically changed backdrop.

Morna Simpkins,
Scotland Director

About the 'What Good Looks Like' forums

Between November 2019 and January 2020, the MS Society held four face to face events for people with and affected by MS to better understand what aspects of their treatment, care and support matter most to them. We wanted to share our working assumptions, based on lived experience of the MS community, to see if they agreed with the range of services that should be available; the priority given to them; and how they would define the quality of service. That is to say what mattered most to people with MS and what experience or outcome would they feel was 'good'.

These forums took place in Glasgow, Kirkwall, Melrose and Stirling. These areas were chosen for a geographic spread and in the knowledge that local people with MS were keen and willing to share their experiences. This meant that as well as being able to shape our national programme of work supporting innovation and best practice, the forums would also generate specific information on local unmet needs that Health Boards and clinicians could use to improve services.

We recognised that not everyone with or affected by MS would be able or willing to attend a face to face event given the barriers of travel, work commitments and managing their health. We had intended to organise 2 virtual meetings, hosted on Zoom, for people to attend without having to join a group meeting. However the Coronavirus outbreak prevented this work from occurring, with the relevant staff who carried out the engagement events going on furlough leave.

In total 54 people with or affected by MS took part in these discussions, commenting on each aspect of the service pathway. Staff members facilitated discussions and took notes as well as answering any questions participants had. The conversations were structured around the following themes:

- ▶ Diagnosis
- ▶ Access to treatments
- ▶ Support services
- ▶ Comprehensive (annual) reviews
- ▶ Care coordination
- ▶ Self-management

Whilst the discussions were structured, participants were given time to talk about and focus on the issues most relevant and important to them, which meant we collected feedback that mattered to attendees without trying to rush through the list and miss important comments. Participants had handouts that described the pathway under the above headings and the assumptions about what a good service looked like so they could comment directly on these.

Characteristics of attendees:

Fifty percent (**check**) of attendees provided us with information about themselves so that we could check we had a good cross section of different experiences, ages, types of MS etc. The following is a summary of those characteristics

▶ Age

Of those attendees who provided us with their age:

- 12% were 18-34 yrs of age
- 17% were 35-44 yrs of age
- 25% were 45-54 yrs of age
- 25% were 55-64 yrs of age
- 17% were 65-74 yrs of age
- 4% were 75+ yrs of age

▶ Type of MS

Of those attendees who provided this information:

- 54% of attendees had relapsing remitting MS
- 12% had primary progressive MS
- 33% had secondary progressive MS
- 4% identified as a carer
- 0% were partners or parents of someone with MS

▶ Gender

Of those attendees who provided this information, 92% were female

▶ Time since diagnosis

Of those attendees who provided this information:

- 0% had been diagnosed less than a year ago
- 0% had been diagnosed between 1 and 2 years ago
- 13% had been diagnosed between 2 and 5 years ago
- 87% had been diagnosed more than 5 years ago

Executive Summary

Diagnosis

A good MS service is one that...

- You get a diagnosis within 12 weeks of your GP referring you to a specialist MS team
- You are told your diagnosis face to face by an MS specialist health professional
- You are offered information at the time of diagnosis, including written information, to help you understand the condition and the ways in which it can be managed including information about available peer support groups.
- You are asked about any care and support needs you might have and signposted to social care if you might need it.
- You are offered a face to face follow-up appointment with an MS specialist within 6 weeks of diagnosis.
- You are signposted to a course for the newly diagnosed

What do you think?

There was general consensus across the forums that this sounded like a good experience of diagnosis, however the majority felt that this wasn't happening now. The key areas that came up consistently were -

- ▶ Increased awareness amongst GPs of MS to ensure faster referrals

Many people shared their experiences of trying to convince GPs that they needed a referral to a specialist, and some chose to pay privately to speed up the process

- ▶ A face to face diagnosis with a follow up letter

“Face to face human conversations are very important – there needs to be a human touch to diagnosis conversations”

Many saw this as the start of building a relationship with clinicians that would enable them to take more control of their treatment and choices. A letter confirming diagnosis was seen as important for employers or welfare too

- ▶ Broad information needed covering issues such as treatments; finance; emotional support; general health, diet and lifestyle; information for family and carers; useful apps; local support groups and peer support

There was debate as to how much information one could process at the time of diagnosis, but clear agreement that information needed to be wider than just about DMTs (for those eligible). Many people talked about information needs changing and wanting to be given an information pack at diagnosis that they could add to and adapt

- ▶ A follow up face to face meeting with an MS Nurse

Again, seen as crucial to have a face to face meeting with someone with expertise in MS. This meeting to look more at the whole person and their family and discuss treatment, care and lifestyle options.

- ▶ Signposting to peer support and a newly diagnosed course

Attendees didn't always feel that at the point of diagnosis one was fully aware of what support or information they may need. Therefore the idea of a newly diagnosed course or day, and the chance to talk to others with MS, would enable them to better understand what they might need.

- ▶ Emotional support

Access to emotional support was a common theme throughout all the conversations, and that need started right at the point of diagnosis. Coming to terms with the impact of a diagnosis; considering how to tell family and friends; understanding the implications and options – all required emotional support



- ▶ People and clinicians as partners

“Your experience of diagnosis should not depend on your personality or your relationship with professionals”

The point of diagnosis was seen by many as the start of a relationship with clinicians that could enable them to be equal partners in their care, with joint decision making. However for many the experience had felt like a 'tick box' exercise, and lack of 'bedside manner' was mentioned many times

A number of attendees highlighted that whilst this discussion was about initial diagnosis, there were very similar needs as people developed secondary progressive MS – a range of information about how to best maintain health and independence; information on employment or benefits; information for family and carers etc.

And for those who weren't eligible for a DMT at the point of diagnosis, the access to information, support services, emotional support and peer support were all just as, or even more important to them.

Access to Treatments



A good MS service is one that...

- People with a confirmed diagnosis who are eligible and want to start treatment start a DMT within 12 weeks of having had a conversation with an MS specialist in which they made the decision to start.
- The majority of DMTs are available locally
- Travel is not so far that it limits your choice of a DMT
- You are given good quality, accessible information about treatment options and can discuss options with a specialist to reach a shared decision
- You are informed when you start a DMT if and when you might have to stop taking it and why (i.e. under certain clinical conditions) and this is a subject of ongoing discussion at annual review appointments.
- You are told about your legal right to choose where you receive treatment and who from

What do you think?

▶ Shared decision making

Participants were clear that treatment choices were crucial, and required both information and a shared decision between consultant and the individual. For many they felt that health professionals had dominated the choice. In addition we repeatedly heard the views that GPs and hospitals don't work together in the sharing of information which would impact upon decision making.

▶ Availability of treatments

"Quite unfair that because of where you live you can't get access to medicines"

Whilst there was agreement that treatment should be available locally, many participants felt they had experienced a post code lottery and hadn't been offered DMTs because of where they lived or accessed services.

▶ Information

Again, information around treatment options should be holistic, taking into account lifestyle, home and family, working etc. MS Nurses were seen as being crucial to treatment discussions that took these factors into account

▶ Symptom treatment

Treatments aren't just about DMTs – many participants received symptom management treatments and felt that GPs, neurologists and other health professionals could be better at sharing information and coordinating. It was felt that GPs needed a better understanding of how to manage MS symptoms and notes from neurologists shared with GPs would enable them to prescribe more quickly.

▶ Stopping treatment

There were a few comments that conversations about stopping DMTs before one had even started could be off putting, but the majority agreed it was an important part of the decision making process. However there were many conversations about how stopping a DMT should actually be about starting a new regime of care, support and symptom management.

▶ New treatments or trials

Whilst treatments are predominantly available for relapsing forms of MS, participants highlighted how important it was to receive information about new treatments (such as Ocrelizumab) or about new trials. There was a desire for clinicians and the MS Society to be more proactive in providing people with information on new treatments and opportunities to join trials

▶ Continuation of care

Whilst all of the above were seen as a good quality service for accessing treatments, there were many people who had been 'dropped out' of treatment pathways. We heard from one individual who said they hadn't had a review in three years, another told us they had only had one MRI scan in the past ten years.

Other participants reported having to chase referrals, and even feeling they were a nuisance to busy MS Nurses. Better information sharing and coordination of treatments between professionals were important.

"A one stop shop would be good – see physio, OT, MS Nurse etc in one appointment"

Support Services

A good service is one that...

- You can get a timely referral and access to services that help you live well with MS and its symptoms. These services include:

Physiotherapy	Diet management
Pharmacy	Pain management
Vocational rehabilitation	Walking / mobility support services
Occupational therapy	Vision specialist
Speech and language therapy	Fatigue management
Counselling	Vocational rehabilitation
Neuro-psychology	Emotional support
Wheelchair services	Walking / mobility support services
Aids and adaptations	Palliative and end of life care
Social care	
Continence support	

- Has comprehensive and timely access (or referral, in case of non-specialist support not provided within the MS service) to holistic support services

- You can self-refer to many of these services

- You can access these services locally (travel is not a barrier to access)

What do you think?

▶ Timely Referrals

Consensus that having access to all of the above would indeed be a good service, however many people had experienced long waiting times for referrals to see a neuropsychologist and accessing wheelchair services to give two examples. Timely may mean different things – e.g. pain management will require a more urgent response

There was a clear need for a professional to be following up on referrals and sharing relevant information. People with MS reported chasing their own appointments and telling their story over and over to different professionals

▶ Physiotherapy

Physiotherapy and neuro-physio rehab were a common unmet need for people – reporting long waiting lists, limited (6 weeks) intervention, and limited availability close to home. Whilst in some places local MS Society groups were filling a gap it was clear that ongoing exercise and physio to help people maintain mobility and independence was just as important as rehab physio

▶ Self-referral

Many participants were keen to be able to self-refer into support services. However the majority felt that professional input was needed – not everyone

knew what services were available or indeed if they needed them. A Care Coordinator support with information on services and initial referrals, then people would be better able to manage their own referrals and appointments.

▶ Barriers to services

Participants identified barriers to accessing services - travel (and the resulting fatigue); not knowing about services; parking charges; lack of local service; waiting times; poor information sharing

▶ MS Awareness

Support services need a better understanding of the impact of MS and how to provide their services appropriately. Particular amongst these are Occupational Therapy, Emotional Support and Social Care – all of which could be more effective if awareness of MS was improved.

▶ Emotional Support

Again participants talked about the importance of emotional or psychological support services. Acknowledging long waiting times many suggested improved MS awareness amongst GPs could lead to more referrals for counselling services.

▶ Care for Carers

One omission from the list of available support services was seen to be carers' support. As well as access to carers assessments – which didn't appear to be widespread – participants indicated carers may need emotional support / peer support as well as practical training and advice in things like manual handling. Other support some people identified which would be relevant to both themselves and carers / family members included Employment Support, Living Wills, Power of Attorney and Legal Advice

“Unless you support the carer, you don't support the cared for person.”

Comprehensive (annual) reviews

A good MS service is one that...

- Offers you a review of your care and treatment at least once every 12 months, which takes place with a health care professional (or more than one) with expertise in MS.
- That review of your care is a conversation about what matters to you. You are offered the opportunity to talk about how your medications are working for you, any changes in your MS, general health or mental health, whether you are able to do the things that matter to you, and any more care and support you might need.
- Sends you a letter following your annual review recording what was agreed and what will happen next (e.g. any referrals that have been made)
- Refers you onto other services you might need- Shares the outcome of your review with other professionals involved in your care (with your permission)
- Offers you a review in different formats e.g. face to face, by phone or video.
- If you are on a DMT which may have to be stopped under certain clinical conditions, a health care professional with expertise in MS has a discussion with you at your annual review so that you are aware of this possibility in good time.

What do you think?

► Frequency and continuity

There were mixed responses from participants, with many reporting that they did not have an annual review with a neurologist. Length of time living with MS, type of MS and the treatment they were on were frequently cited as reasons for the lack of engagement with a neurologist. For others they had two reviews every 12 months, one with a neurologist and one with an MS Nurse.

“Would get support if had Cancer”

► Relevant and useful

There were lots of comments that the annual review felt like a tick box exercise, with the agenda set by clinicians. Many felt rushed, without the opportunity to explore issues that mattered to them, and that neurologists were meeting requirements around annual reviews whereas patients wanted an opportunity to discuss options and concerns. There were many suggestions as to how to improve the effectiveness of annual reviews –

- A checklist for professionals and patients to prepare in advance
- Conversations about future plans and options for care and managing MS
- Accurate written notes shared with relevant professionals

“This would be perfect – if it happened”

▶ Outcomes

The experience of many people was that reviews weren't as useful as they could be in terms of delivering actually outcomes for people. Too often we heard that the order of appointments were wrong with reviews taking place and then MRI scans and/or blood tests being carried out and a wait to find out results. We also heard how individuals either didn't receive any follow-up or received a note that was "unintelligible medical jargon which you have to 'Google' to make sense of".

Arising from the discussion was a feeling that reviews should be very much part of the care planning process, allowing someone with MS to identify how they wanted to manage their MS in the year ahead; options and support available to them; and referrals to useful services and support (statutory and non-statutory). These plans could include options around new DMTs or clinical trials as well as support for self-management.

These goals and plans should then be written up and shared with the relevant professionals, referrals made, and where necessary followed up on

▶ Face to face or remote reviews?

Participants generally preferred face to face reviews as they helped develop a better relationship with clinicians, and was more suitable for people with any cognitive issues or communication barriers.

A recurring theme in the Orkney session was the challenge of having to travel to Aberdeen, either by ferry or plane for appointments. In comparison to the other sessions they were more experienced in having phone or video based reviews which when well conducted could reduce stress, anxiety, fatigue and expense associated with travel and parking for reviews.

Again the idea of a checklist in advance to help someone identify what they might like to explore during a review could also enable people to choose the most effective way for that review to be held.

▶ Stopping DMTs

Participants acknowledged that having a conversation about stopping DMTs was difficult and they felt they could be better prepared in advance to understand if and when this might be an option. Also that the conversation about stopping a DMT should also be about starting other ways of managing MS, including non-clinical interventions and other sources of support

Overall, whilst participants discussed how annual reviews could be made more effective there was a very clear sense from discussions that a responsive MS team that could be accessed when needed, was far more important.

▶ Care coordination

A good MS service is one that...

- You have a single point of contact for your care and treatment that you can contact if anything changes. This person will coordinate your access to other services and support if needed
-
- Assesses patients and offers them treatment for relapses of MS as early as possible and within 14 days of onset of symptoms.
- You have a written care plan that is shared with you and the professionals involved in your care
- with your permission- and reviewed and updated at least every 12 months as part of a comprehensive review of your care (if you choose to have a review).
- Has practical arrangements to share information about your care with yourself and your health care professionals (with your permission) e.g. the right IT system

What do you think?

▶ Single Point of Contact

There was wide variation as to which professionals people considered to be their single point of contact, obviously based on need. These included GP; MS Nurse; Neurologist; OT; Neuro-Physio. However broad agreement that if that professional sat within a Multi-Disciplinary team the care coordination was easier and more effective.

Many participants suggested that multi-disciplinary team clinics (both real and virtual) would improve the coordination of their care, enabling them to visit the MS Nurse, Physio and OT in one appointment and agree actions

▶ Written care plan

Again there was wide variation as to whether people had a care plan, knew they had a care plan, or who held it. Participants indicated that their care plans were held by their GP; MS Nurse; Physio; or OT. There was consensus that written care plans should be available electronically to both the person and to all relevant professionals – access to the information was essential for speedy referrals and reducing the need to tell one's story over and over again.

This could take the form of an online portal where the care plan, appointment notes and written referrals were all stored and accessed. A few people had this system in place already and were pleased they could access this information themselves.

Some participants suggested care plans should sit jointly across health and social care, and the existence of a written plan and documentation would make it easier to access other support – eg disabled parking; carer's assessments

Self Management

A good MS service is one that...

- Your health care professionals ask if you have the information, support and care you need, regularly (at least every annual review), even if you've declined this in the past.
- You are offered a range of support and tools to manage your condition regularly including online or face to face courses, information resources or offers to participate in research, apps on your phone etc.

What do you think?

▶ Information

"Information is a big thing....you've got to have it at the beginning, and then throughout"

Everyone agreed that access to a range of different, good quality information was essential to enable self-management. This would include information on treatments, support services, lifestyle factors, exercise, diet, employment etc. Participants felt information could and should be available in a range of different ways – information packs; websites signposting to trusted services; online forums; webinars; self-management apps; local groups and organisations. It was clear that participants felt they could better manage their MS with these types of resources

▶ Services and professionals

As well as information, the various discussions made it clear that self-management had to be supported and enabled by various professionals and services. Some made the point that without discussions with a professional it was difficult to know what services or activities would be beneficial. Others suggested that self-management conversations should be part of all annual reviews and appointments.

It was clear that timely access to the right services and support – which themselves promoted self-management was essential. One participant described this as a 'positive circle' that starts with services enabling self-management and ends up with a reduction of the reliance on services to manage your MS.

Social support, peer support and remaining active all came out as priorities for people to enable them to self-manage, although some had concerns that information about their levels of activity and exercise could jeopardise access to PIP and other benefits.

The point was made that self-management required a holistic approach and some services (eg GPs) focussed on MS as the only factor that was relevant.

Miscellaneous

The following issues were raised organically during the discussions within the focus groups:

- ▶ Awareness raising and training for general health and social care staff to better support people with MS. This applies even when the reason for support is not MS related
- ▶ GP awareness raising – to ensure people with MS can access other support not related to their MS e.g. not always referred to a specialist
- ▶ Consistency of support offer across all services and areas e.g. patient transport
- ▶ Lack of access to leisure facilities because of poor or broken equipment, poor disability access, lack of trained support

Next Steps

The publication of the Scottish Government's Neurological Care and Support: Framework for action 2020-2025 offers an opportunity to explore the issues raised with us by participants. Obviously the environment in which MS services are operating has changed dramatically since the work began on this report. Nonetheless as services start to return to normal under the Scottish Government's Re-mobilise, Recover, Re-design: the Framework for NHS Scotland we will push to ensure that the voices of people living with MS are heard.

Over the next three years we intend to:

- ▶ Improve the evidence we can provide on unwarranted variation in MS treatment, care and support
- ▶ Increase our resources to support service innovation and improvement
- ▶ Enhance our programme of work to highlight innovation; influence positive change; and increase professional engagement
- ▶ Better equip people with MS, professionals and commissioners to address gaps in services together, and learn from those who are doing it well
- ▶ Enable our MS Community to mobilise around the issues that matter most to them

¹ Living in Lockdown with MS, MS Society, June 2020

² My MS My Needs Survey 3, MS Society May 2020

³ MS in the UK, MS Society, 2020. <https://www.mssociety.org.uk/what-we-do/our-work/our-evidence/ms-in-the-uk>