HEALTH AND SPORT COMMITTEE

WHAT SHOULD PRIMARY CARE LOOK LIKE FOR THE NEXT GENERATION?

SUBMISSION FROM MS SOCIETY SCOTLAND

About MS

Multiple Sclerosis (MS) is a chronic, neurodegenerative condition for which there is currently no cure. In MS, the body’s immune system attacks myelin, the protective cover around nerve fibres. Damage, which can occur anywhere in the central nervous system, interferes with messages travelling from the brain and spinal cord to other parts of the body. Symptoms are many and varied, but unique to each person. They can include problems with balance, vision, the bladder, bowel, speech, memory, fatigue and painful muscle spasms, among many other things. MS affects over 100,000 people in the UK, many of whom experience their first symptoms during the peak of their working lives, in their 20s and 30s.

MS is both a fluctuating and progressive condition. While the progression and symptoms of MS vary from individual to individual, primary progressive MS affects around 10 to 15% of people with MS. This is progressive from the very first symptoms. The remaining 85% of people with MS are initially diagnosed with relapsing forms of MS, where people have distinct attacks of symptoms with the underlying damage building up over time. Many people with MS will go on to develop secondary progressive MS within 15 years of being diagnosed.

At present there are 13 Disease Modifying Therapies (DMTs) licenced for use on the NHS in Scotland. DMTs can help reduce how many relapses you get and how bad they are. They can also slow down the damage caused by MS that builds up over time.

About MS Society

The MS Society is the UK’s largest charity for people living with MS. we're here for everyone living with MS – to provide practical help today, and the hope of a cure tomorrow. We play a leading role in research. We fight for better treatment and care. We let people with MS know they're not alone, and offer advice and support to help them manage their symptoms.

1. Considering the Health and Sport Committee’s report on the public panels, what changes are needed to ensure that the primary care is delivered in a way that focuses on the health and public health priorities of local communities?

At the MS Society we place a huge importance in the co-production not only of our services, our research programme but our campaigning activities too. Our Living Well with MS programme was co-designed from the outset and following established models lead to the redesign of workshops for people newly diagnosed with MS.

We welcome any moves to ensure that primary care is delivered in a way which focuses on the health and public health priorities of local communities. The model of Public Panels
used in the Phase One report for the Health and Sport Committee of the Scottish Parliament is worthy of further consideration.

We believe the third sector has a role to play in increasing community participation. There is a vast wealth of lived-experience which can be tapped into from the people who volunteer in our communities, people who use the services be it community transport, lunch clubs, physical activity sessions or cooking classes to name a few examples.

Many of the priorities of the Panels are reflected in the discussions we have with the MS community. With 30 local MS Groups across the country from Orkney to the Borders and Inverclyde to Fife we regularly seek updates and feedback on local MS services in all their guises. We support local groups to engage with their health board to improve services in their area.

The greatest change that could happen would be to stop addressing issues from the top down and to start to think of them from the point of the user. The general approach to public engagement needs to happen. So for example, in respect of data sharing the question should be: ‘how do we effectively and efficiently share information to reduce the burden on the user rather than to meet the component needs of GPs, acute services and the Scottish Government?’

We regularly hear the frustrations of how people living with MS have to frequently repeat their story to different health professionals and complete numerous forms. Coupled with a feeling that health professionals control what they tell them as patients rather than them owning their records it is not hard to see why people feel disengaged.

2. What are the barriers to delivering a sustainable primary care system in both urban and rural areas?

One barrier to a sustainable primary care system is that services are not future-proofed. MS is both a fluctuating and progressive condition. While the progression and symptoms of MS vary from individual to individual, primary progressive MS affects around 10 to 15% of people with MS. This is progressive from the very first symptoms. The remaining 85% of people with MS are initially diagnosed with relapsing forms of MS, where people have distinct attacks of symptoms with the underlying damage building up over time. Many people with MS will go on to develop secondary progressive MS within 15 years of being diagnosed.

The progression of the condition within individuals is not matched by the provision of health services. In particular the services required as people move from one disease modifying treatment to another as their condition progresses they will need different care plans and services. There is a bigger focus on initial diagnosis, which is of course vitally important, and someone living with MS may not see their MS Nurse and/or consultant from one year to another.

The specific challenges of living in a remote and/or rural area are repeatedly highlighted to us. These ranged from the lack of public transport, the inaccessibility of support services, especially for young carers and the impact of living with MS itself. For example, the fluctuating nature of the condition can make it difficult for people to travel distances for appointments. If primary care played a bigger role in DMT monitoring, taking and reviewing
bloods it would free up specialist nurses to support more complex cases and liaise better with community service provision and reduce some of the aforementioned challenges. We believe that a future primary care service should include a multi-disciplinary model **based within a primary care setting** comprising of a range of professionals and services including:

- Neurologists
- MS specialist nurses
- Physiotherapists
- Occupational therapists
- Speech and language therapists
- Emotional support
- Neuro-rehab

GP's play an important role in the early diagnosis, or lack of, of MS. There has to be a drive to educate GPs about MS and the need for early referral to promote early diagnosis and early treatment. Having a multi-disciplinary team within a primary care setting would improve the patient experience.

Research carried out by the MS Society in 2016 showed that 84% of respondents had not been offered a care plan by their health care professionals. Everyone with MS should be offered an annual review of their care. This does not need to be with a neurologist, but with the most appropriate member of the team according to the individual’s needs. This is an important opportunity to discuss any new treatments that may have become available, for care planning, sign posting and referral to other services for any care and support needs and therapies to manage symptoms.

As the report shows people are willing to embrace technology as we know that the lives of people with MS have changed dramatically due to the influence of technology, which has altered everything from how we shop to how we communicate. But change has been much slower in their health and care. People with MS rightly expect healthcare to catch up and respond to how they live their lives, empowering them to manage their condition and providing the services they need, when they need them.

We commissioned the Nuffield Trust to lead our research to explore the opportunities for better use of technology and data to improve the health and care of people with MS. Our report [Improving care for people with MS: the potential of data and technology](http://example.com) provides a strong evidence base for us to influence health and care across the UK, and we’re seeking to help deliver the best possible treatment and care for people with MS. We want to explore how digital technologies can help people manage their MS, and we want to ensure that NHS data is harnessed so that health professionals have the information they need to provide the best treatment and care.

We know that technology does have the potential to improve the care for people living with MS. In the Western Isles, for example, the NHS Western Isles MS Nurse Service and TEC team have been using *Morse*, a fully integrated mobile platform, to bring together primary and secondary care in a single mobile app. It will eventually include social care too. At the June 2018 meeting of the Cross Party Group on MS in the Scottish Parliament Rachel Morrison, MS specialist nurse, gave a presentation on the impact of technology on patient outcomes and professional practice. The team faced challenges of providing high levels of
care in such a rural location, with connectivity issues and a dependency on travel to utilise
traditional models of care. Utilisation of technology has allowed for an increase in time
spent with patients and a reduction on time spent on administration.
The lack of accurate MS prevalence data to inform workforce planning is another barrier.
The draft action plan provides an estimated prevalence figure of 9,700 people living with MS
based on the 2015 Scottish Burden of Disease data. The MS Society are currently using an
estimated prevalence figure of 11,310 while the latest MS Trust MS specialist nurse in the
UK Mapping Survey uses a figure of 11,794.
Not only does the lack of accurate data impact on the planning of future services there is
already a disparity in the availability of services depending on where in Scotland you live.
One example of this is demonstrated by the differing services offered in NHS Ayrshire and
Arran and NHS. In the Borders there is one part-time MS specialist nurse working with a
neurologist. They have access to a neurology physiotherapy service which is part time and
is predominantly focussed on the Stroke service. Out with this support the local MS Society
Group fund exercise and activity services as well as providing access to Physiotherapy.
There is no Occupational Therapist provision as part of the MS team.
Whereas in NHS Ayrshire and Arran the MS team operates out of the Douglas Grant Rehab
Centre and contains, neurologist support from NHS Greater Glasgow, Rehabilitation
Consultant, MS specialist nurses, Physiotherapists, Occupational Therapists, Speech and
Language Therapists, Dieticians, Orthodontists, Clinical Psychology provision and a
Wheelchair Service. Not all the provision is MS specific but there are clinicians within this
team that are either specialist or have a special interest in MS.
While we understand the need to design individual services to meet the specific needs of
the local population, what these examples highlight is that the service that is available in the
Borders does not have the same resource available as there is in Ayrshire and Arran. This
disparity exists due to local health board priorities and as a result people living with MS will
have access to very different services based upon where they live rather than their
individual needs.
The Draft National Action Plan for Neurological Conditions included a commitment to
increase equitable and timely access through developing rapid access neurology clinics
and the desire to pilot community based teams that will deal with common neurology
issues. We believe this community provision should be extended further with more
community based condition specific provision for the major neurological conditions such as
MS, Epilepsy and Parkinson’s Disease. This would be in line with the policy drive from the
Scottish Government to move from acute to community care.
3. How can the effectiveness of multi-disciplinary teams and GP cluster working be
monitored and evaluated in terms of outcomes, prevention and health
inequalities?
We believe there should be a clear referral pathway into neurological services and therefore
ongoing support to manage patients with a neurological condition like MS. The recently
published General Standards for Neurological Care and Support and the Draft National
Action Plan for Neurological Conditions should be used to develop such a pathway. They
should also be used to monitor and evaluate the effectiveness of multi-disciplinary team
and GP cluster work on the care of people living with MS is measured.
We further believe for this to happen then appropriate level of resourcing must follow both the Standards and the Action Plan otherwise they will be set up to fail from the start.