

Irish MS Expert Panel Meeting Report

Overview

Ireland is lagging significantly behind other European countries in the FutureProofing Healthcare MS Index

The MS Index – which was led by an independent panel of experts, in partnership with Roche – gives an in-depth analysis of the state of care for MS in 30 European healthcare systems

The Index measures country performances based on three Vital Signs:



Diagnosis
& Outcomes



Support &
Management



Daily
Living



Specific findings

Out of 30 countries, Ireland ranked:

25th Diagnosis & Outcomes

22nd Overall on the MS Index

21st For Support &
Management

21st For Daily Living

Key issues highlighted:



No rehabilitation centre
for people with MS



Severe lack of
neurologists



Lack of data available at
national or European level,
to give an accurate picture
of the state of care for MS



Chronic shortage of
specialist services and
healthcare specialists

Urgent changes needed:

- Engage neurologists overseas to fill chronic shortage in the Irish system
- Establish a register of MS patients
- Establish written policies for Irish employers to support employees with MS
- Extend neuro-rehabilitation services into non-clinical settings
- Fund 9 peer support worker positions in Budget 2021

What is the FutureProofing Healthcare MS Index?

The FutureProofing Healthcare Multiple Sclerosis Index examines how healthcare systems perform for patients with multiple sclerosis (MS) across 30 European countries.

The MS Index measures a country's performance based on three Vital Signs, which evaluate three main aspects of MS care: Diagnosis & Outcomes, Support & Management, and Daily Living. An independent panel of European MS and health policy experts guided its development.

All the data within the Index comes from accredited publicly available sources.

Ultimately, the Index allows the exploration and comparison of data across different jurisdictions, allowing insights and best practice to be identified and shared.

By analysing the available data, it is hoped to start a collaborative future-focused conversation about how prepared healthcare systems are to meet the needs of people with MS.

The Index is designed to drive change and improve the lives of people with MS in Ireland.

The goal is to deliver meaningful initiatives to improve the healthcare system in Ireland and Roche hopes to co-create pilot projects and initiatives based on recommendations.

Irish MS Index Expert Panel Members

A panel of Irish experts was convened to interrogate and analyse the data within an Irish healthcare context.



Ava Battles
Chief Executive Officer
MS Ireland



Dr. Rebecca Maguire
Lecture/Assistant
Professor in Psychology



Dr. Nina Byrnes
GP and Media Health
Commentator



Mary Harney
Former Tánaiste and Former
Minister for Health, Ireland



Pierre-Alain Delley
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Roche Ireland

Introduction

Ireland was found to rank 22nd out of 30 on the MS Index, placing 25th for Diagnosis & Outcomes, and 21st for both Support & Management, and Daily Living.

The expert panel were not surprised by the findings. As CEO of MS Ireland, Ava Battles is well aware of the service limitations that Irish patients with MS experience, as well as their struggles to remain in active work. Dr Rebecca Maguire spoke of her experience of fearing stigma as a person with MS. GP Dr Nina Byrnes regularly sees the barriers to diagnosis and care within her own practice. Former Minister for Health Mary Harney brought her experience and unique insights of the Irish health system.

Ireland's lack of a defined model for MS care was discussed; while the shortage of consultant neurologists is a major issue, the lack of allied healthcare professionals such as specialist MS nurses who provide invaluable support and services to patients is of serious concern. Patients' inability to access ancillary services such as occupational therapy, physiotherapy and psychosocial supports also makes them more vulnerable and can contribute to them leaving the workplace, the panel noted. Ireland's comparatively low rate of people with MS in active work is an issue the expert panel felt could also be addressed by educating and engaging with employers. Misperceptions of MS and a broad lack of understanding of the condition among the general public can feed into workplace stigma, according to both the panel of experts and the experience of those living with the disease.

This paper includes five calls to action, each practical and achievable, directed at all who have a role in developing a high-quality healthcare system for people with MS:

- 1 The creation of a role with the single responsibility of engaging with neurologists practicing overseas to encourage their participation in recruitment processes**
- 2 The establishment of a body within the Health Service Executive (HSE) that has responsibility for managing registries, including a register of MS patients**
- 3 Increased action by employers and employer bodies to adopt written policies on the accommodation of employees with MS, and in particular to explicitly permit and support flexible work schedules**
- 4 Include the extension of neuro-rehabilitation services into non-clinical settings in the National Strategy & Policy for the Provision of Neuro-Rehabilitation Services in Ireland**
- 5 Funding of nine peer support worker positions (one per Community Healthcare Organisation) in the budget for 2021 to pilot the provision of a peer support service for MS.**



Diagnosis and Outcomes

Inadequate number of neurologists

The data show a severe shortage of neurologists per capita in Ireland, as well as a relatively low number of MRI units. Ireland has just two neurologists per 100,000 people¹ alongside the UK, this is the lowest seen across all 30 countries.

It was noted by the expert panel that this is the number of general neurologists – not all will specialise in MS and/or treat patients with MS.

This shortage was seen by the panel as an historical problem, one that is only compounded by the current consultant manpower.

The panel agree the best approach to MS care is a multidisciplinary team – the consultant neurologist plus the wider team of allied healthcare professionals (HCPs).

The patient's regular touchpoint is the MS nurse, and they may also need ongoing rehabilitation from the physiotherapists and occupational therapists. Both medical representatives and people with MS on the panels felt that psychological support throughout the MS journey is essential.

Properly resourced primary care teams could help to deliver this.

Indeed, a model for MS care would be a very transferable model for any chronic disease, as it incorporates input from a wide range of healthcare professionals across the entire system.

Long waiting times for consultant neurologist appointments, coupled with poor MRI access, means that diagnosis is often delayed by months if not years, agreed the panel members.

Best practice now would suggest that early aggressive treatment is best in order to halt disease progression, but this is not feasible in practice, they noted, adding that a lack of access to MRI is a major roadblock to diagnosis and effective treatment.

As most medications are prescribed by MS specialist neurologists, panel members noted that while there are many new and effective medications, access can be poor due to this lack of consultant appointments.



Call to action:

Ireland only has two-thirds of the number of neurologists needed.²

Recruitment and retention of neurologists faces the same challenges as other specialities - notably the salary gap between new recruits and previously appointed consultants, and specialist remuneration falling behind levels in other countries - and there are a number of long-standing recommendations that seek to address these as well as working conditions.

In regard to increasing the number of neurologists towards 1:70,000 population (from 43 to 64 neurologists), we must both fund these positions and add to the current recruitment efforts.³

The 2017 review noted that among the barriers to recruitment was “lack of Employer knowledge of potentially available Applicants (together with) lack of Applicant knowledge of potentially available Employers and or vacant posts.”⁴

On this basis, our call, in addition to those already under consideration or action, is:

- » To grow the pool of applicants for roles through the creation of a role (either within the HSE National Recruitment Service or with its approval) with the single responsibility of engaging with neurologists practicing overseas to encourage their participation in recruitment processes; and
- » To target these efforts to countries with relatively high numbers of neurologists and where Ireland can provide additional opportunities or accelerated career progression; and
- » To report on addressable barriers to consultants applying and accepting such roles (such as simplifying the application process or ensuring time for academic work) as part of a five-year progress review in 2021

This was echoed by the patient panel, who discussed their own experiences of inability to access prompt diagnosis and treatment.



Ireland needs to improve its access to neurology services. Information is fantastic but it's the services that are badly needed. We need more neurologists, we need neuro-rehabilitation services and we need rapid access to treatments.

Aoife Kirwan, Information, Advocacy and Research Officer, MS Ireland



I spoke to someone recently waiting three years to see a neurologist in the public health system.

Ava Battles

Registry

Ireland's lack of a national MS patient registry was discussed at length.

The panel discussed how internationally, many countries, including the UK, have their own MS registry, and how in Ireland, there are registries for diseases such as cancer and epilepsy. It was noted that these are excellent sources of data.

It was agreed that a national patient registry for MS would be an invaluable resource for advocacy and service planning.

The immediate difficulty in establishing such a registry would largely be ICT-related e.g., different hospital computer systems are incompatible. Despite the relatively small number of patients with MS in Ireland (over 9,000, according to MS Ireland⁵), this would be an enormous project requiring significant funding and manpower.

Call to action:

- » The many actions needed, and stakeholders involved – most notably the introduction of national Electronic Health Records and Individual Health Identifiers⁶ – will only be given sustained attention through the establishment of a body within the Health Service Executive (HSE) that has responsibility for managing registries.
- » This should be accompanied by a national oversight body for the MS patient registry composed of clinicians, patients and other key stakeholders who can work to jointly solve these issues and explore the positive value of a registry for ehealth and telehealth.

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“The whole future of healthcare is centred around data and capturing data to deliver personalised medicine.”

Mary Harney



Employer awareness and education

According to the data obtained for the MS Index, only around 25% of MS patients were estimated as being in active work.⁷

A relatively low score of 2 for the ratio of MS patients in active work was determined by the Index – the panel noted that this was comparable with Croatia.

Alternative statistics due to be published as part of the next MS Barometer survey will likely give a higher estimate for people with MS in active work (approximately 55%), said Battles.

The panel noted that while not captured in statistics, the employment status of informal caregivers for people with MS may also be impacted following diagnosis. For example, family members may have to take time off work or even leave employment to take on care responsibilities.

MS patients may have difficulty in continuing to work for one or more reasons;⁸ while there may be a physical inability to work due to symptoms such as fatigue or more severe disability, the lack of employer support and understanding also plays a major role.

The panel noted that there is a reluctance among patients to share their MS diagnosis with their employer. Panellists agree there is a widespread lack of awareness and understanding about the condition, and this implies a similar lack of understanding among employers.

The panel agreed that people with MS do not wish to place unreasonable demands as per their work terms and conditions with their employer, but often a moderate degree of flexibility will be enough for them to continue to work fulltime. The panel emphasised the importance of this issue by stating that the number of years people will live with MS will often span their entire career. Dr Maguire notes she concealed her own diagnosis within the workplace for years – **“I didn’t want to feel judged”**.

Employment issues such as awareness and flexibility from employers were also highlighted as matters of critical importance by the patient panel, who said this could have a significant impact on how people with MS are included and valued in society.

The panel of people living with MS noted that practical assistance is needed in terms of navigating their rights, such as access to the partial disability allowance.



The biggest thing is to maintain some normality. It’s crucial that we can be employed while also accessing healthcare services and medical cards.

I’m in my 20s, I’m just starting my career and I want to feel I can have the same opportunities as other people my age.

Lauren McCauley, Person living with MS

Call to action:

- » The efforts of patient groups such as MS Ireland to raise awareness of employment issues and rights will require additional support in order to reach larger numbers of employers.
- » Employer organisations such as ISME and IBEC also have a role in educating their membership.
- » Our call to action is for employers to adopt a written policy on the accommodation of employees with MS, and in particular to explicitly permit and support flexible work schedules that accommodate fatigue.
- » Communicating this policy to all employees may also ease disclosure to an employer.

Support and Management

Poor access to ancillary services within the Irish health system was highlighted.

A shortage of HCPs and access to rehabilitation services including physiotherapists, occupational therapists and psychologists is a problem for all users of the Irish health service, noted various members of the panel.

Although specialist rehabilitation centres exist internationally, Ireland does not have such a facility. According to the expert panel, ongoing rehabilitation throughout a person's life is essential but specialist MS rehabilitation centres may not be necessary. Centres could cater for people with all types of neurological conditions. Specific MS rehabilitation programmes could take place in community centres or gyms – they agreed it does not have to be a clinical facility. Again, it was emphasised that people should be linked in with allied HCPs throughout their disease journey and followed up regularly.

This shortage of and patchy access to community services was also discussed at length by the patient panel. Other practical issues were also highlighted in terms of access, such as the timing of daytime community supports i.e. during work hours.

The chronic shortage of MS specialist nurses is of major concern, and the reasons for this, the panel noted, are unevenly distributed throughout the country – there are none at all in the Midwest. The reasons for this are largely funding-related and not due to a lack of training.

Increased funding and a reconfiguration of services is required the panel said. For example, access to occupational therapy is only for priority patient cases; this comes only when a patient has accumulated a significant amount of disability.

Access is needed at the time of diagnosis to ensure and maintain optimum mobility and quality of life.

Call to action:

As the National Strategy & Policy for the Provision of Neuro-Rehabilitation Services in Ireland (2019-21) is reviewed and revised for the period 2021-23, the inclusion of extending neuro-rehabilitation services into non-clinical settings should be considered.

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We need better community access. Like some people with MS, I work full-time and it's important to me. But this can make it difficult for me to get to the community supports I want or need because they are scheduled during the day.

Niamh McCarron, Person living with MS

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These are mobile patients – these are not people who are bedbound in hospitals.

Dr Nina Byrnes

Quality of information at diagnosis

Although Ireland scores high in relation to the quality of information given at diagnosis, the panellists agreed that patients can be overwhelmed with too much information.

In addition, comprehension can vary due to factors such as different levels of health literacy and emotional state.

Assumptions can be made by HCPs as to a patient's understanding of what they have been told.

The panellists agreed that follow-up is essential in order for patients to properly process the information they receive on their illness, management and prognosis.

The patient panel echoed this, saying they had found it difficult to access information on specific topics relevant to their illness.

It was also noted that further/additional information is being accessed by patients from a wide variety of sources, including online sources such as social media support groups. It was agreed that the quality of this advice varies hugely.

Peer support groups could be a low-cost intervention to help patients with self-management.



Research shows that patients want to talk about their prognosis with their neurologist or HCP but only a small number actually have.

Dr Rebecca Maguire



Cognitive issues with MS need to be better understood. I'm 49 now and between the ages of 29 and 49 I can't remember anything. Cognitive services are not available.

Person living with MS



We still want to be independent and do our own thing. It's such an isolating disease.

Karen Hynes, Person living with MS



I haven't seen my district nurse in about two years. They don't do house calls anymore. MS is a lifelong illness and we need help.

Person living with MS

Call to action:

- » The recruitment of peer support workers for mental health by the HSE provides a template for improving peer support among patients with MS.
- » Our call is for the funding of 9 MS peer support positions (1 per Community Healthcare Organisation) in the 2021 budget to pilot the provision of a peer support service for MS.

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I'd like to know about research on the drugs that repair the damage from MS rather than the symptoms.

Person living with MS

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We might be giving patients quality information but we are not evaluating how much of that they truly understand.

Dr Nina Byrnes

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There needs to be better access to information about what you're entitled to. At the moment, this information seems to be very subjective and selective.

Person living with MS

eHealth

Ireland's performance in eHealth is poor, and it was noted that although Ireland has a National eHealth Policy/strategy, there is none for telehealth. The group agreed that eHealth can be an efficient means of empowering patients and offering add-on services.

They added that technology can aid in improving adherence to medication via tools such as apps and reminders. Connected care is in its infancy; the panel agree digital connections to patients would be invaluable but current health service infrastructure in Ireland does not support this.

Daily Living

According to the data, the length of statutory sick pay and level of disability benefits are relatively short/low in Ireland. Some disabled persons can set their own flexible working arrangements, but not all. There was no comparable data available for transport accessibility in Ireland.

The group emphasised that patient needs vary hugely - capturing the individual needs of patients will be critical as we plan future health services for those with MS.

There appeared to be a wide variability among patients in terms of accessing supports and entitlements, with many saying patients should be provided more information on this.

Insights



Access to medicines and access to community rehabilitation services are paramount – these were the main issues identified in the MS Society’s most recent survey of 1,000 people with MS.

Ava Battles



Understanding and addressing the psycho-social consequences of MS is critical, as is reducing fear of stigma within the workplace. It is also vital to support and incentivise research aimed at enhancing the wellbeing and quality of life of people with MS.

Dr Rebecca Maguire



Enhanced access to neurology specialists is necessary in order to speed up time to diagnosis. Community-based access to services will empower patients.

Dr Nina Byrnes



There is a need to engage with employers and employer organisations with a view to them facilitating people with MS in the workplace.

Mary Harney



It is clear that people with MS are not getting all the service and access they need. Addressing issues that affect both their daily living and long-term health such as access to medicines, neurologists and neuro-rehabilitation are key and should be tackled first.

Pierre-Alain Delley

Conclusion

Both people with MS and experts identified significant gaps in the care of people with MS throughout their illness journey, from medical treatment to practical support.

Ireland’s low numbers of consultant neurologists is hampering timely diagnosis and effective treatment, and this was deemed to be an urgent need. Panellists agreed this is exacerbated by the lack of other HCPs, across primary and secondary care, and in the community, such as nurses, physiotherapists and psychologists.

Enhanced community care and support is needed, with better neuro-rehabilitation services. These services should be designed around the patient’s needs.

While many more people with MS are staying in part-time or full-time work, employer understanding and awareness remains low.

Stigma within the workplace is thus a persistent problem and this should be addressed as a matter of priority.

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