MS Ireland
THE MULTIPLE SCLEROSIS SOCIETY OF IRELAND

Time to Act

A consensus on early treatment

Foreword

Introduction by Ava Battles

CEO MS Ireland

I am delighted to present 'Time to Act - A Consensus on Early Treatment in Multiple Sclerosis'. This publication represents an important step forward for MS Ireland in our mission to advocate for access to the best possible treatment and care for people with MS in Ireland.

MS Ireland believes that people with MS should get access to the right treatment at the right time. In 2015, we launched our 'Access to Medicines Campaign Handbook' which provided information and practical advice for people with MS on how to access the right medications for them. With this new publication, we are seeking to engage with clinicians and policy makers in order to raise awareness of what needs to happen to ensure people with MS in Ireland are receiving treatment and care that is in line with current research evidence and meets international standards of best practice.

Current evidence strongly suggests that the earlier MS is diagnosed and treated with an appropriate medication, the better the long term outcomes for the person are. With the kind permission of the MS Society in the United Kingdom, we have taken the research evidence presented in their 2015 consensus paper on early treatment and in consultation with Irish neurologists we have developed a set of clinical recommendations for Irish practice.

Unfortunately, clinical practice is only one factor that impacts on the treatment that a person with MS receives. In Ireland, this is also seriously affected by staffing and resource deficits in the healthcare system. With this in mind, we have also developed a set of policy recommendations which we will be seeking to present to the Department of Health and the HSE in the coming months.

Our recommendations compliment the recommendations in the National Clinical Programme for Neurology Model of Care, which was launched in September 2016, following extensive consultation with a range of stakeholders including MS Ireland and the Neurological Alliance of Ireland (NAI). The Model of Care stipulates a recommended treatment pathway for people with MS, and details what would be required in terms of resources to deliver such a service. MS Ireland and our partner organisations in the NAI will be closely following developments regarding the implementation of the Model of Care, and seeking every opportunity possible to engage with decision makers and stakeholders to ensure that the vision in the Model of Care document becomes reality. We envisage that the Time to Act publication will be a valuable tool in helping us to do this.

MS Ireland would also like to take this opportunity to acknowledge and welcome the considerable work undertaken by the HSE in developing the Model of Care and also the decision to establish a centralised funding mechanism for MS medications that are delivered via hospital-only infusion. The previous system of funding these medications through individual hospital budgets resulted in inequity of access for many, and MS Ireland is delighted that such considerable effort has been put into the development and roll-out of a fairer system.

I would like to thank the MS Society in the UK for allowing us to use their material. I would also like to extend our sincere gratitude to the healthcare professionals who gave their time to assist with the development of this publication, in particular the four Consultant Neurologists who participated in our Advisory Board – Professor Michael Hutchinson, Dr Lisa Costelloe, Professor Tim Lynch and Dr Brian Sweeney.

We look forward to continuing our work to improve access to treatment for people with MS in Ireland, in partnership with people affected by MS and the healthcare professionals who support them.

Ava Battles
CEO MS Ireland

Introduction by Willeke van Eeckhoutte

MS & Me Blogger and MS Advocate

In my view it is critical to give someone who is newly diagnosed with MS access to early treatment, not only to kick-start a possible delay in disease progression, but to give that person the feeling of being in control on an emotional and mental level also.

Because an MS diagnosis is upsetting and life changing, it is important for the person with the illness to feel in control of their life. Take away that safety net and you are left with many questions, i.e. if I don't get my treatment soon, how long will it take for my symptoms to weaken and relapses to subside? Why is my government/ health department delaying treatment people in other countries have easy access to?

With research showing that early treatment after a confirmed diagnosis is beneficial in the long run, I feel that as a person with MS myself, there cannot be any delay in prescribing what is required for someone to thrive in society. If someone decides not to go on DMT treatment, he/she should be able to do so after having an informed discussion with their neurologist.

I am now in my eleventh year post diagnosis. During my treatment I was given a DMT without any explanation of what was available. Because this particular medication was the go-to treatment at that time, I presumed this would indeed be the best choice for me. When 1.5 years later I still had intense flu-like symptoms, I changed to another DMT, which I am still on today.

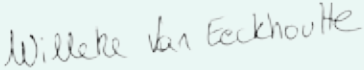
Having an option would have been preferable in both cases. More information was provided however when a nurse from a pharmaceutical company came to visit me at home, as more was explained about how the treatment works and what I could expect. Also, since my diagnosis, I have only had four MRI scans, far from the ideal number when on disease modifying treatment.

In an ideal Ireland, nobody should have to wait five years for a new MRI scan, as in my case, especially when the last scan showed that a large new lesion was found on my brain. Having to press a medical team over and over again because of worries about delays in scanning can lead to unnecessary emotions taking over. It also leads to a further delay in updating or receiving new treatment. Again, in an ideal Ireland where the health authorities actively listen to the patients they should protect, this should not and cannot happen, especially when someone has an illness that is not only chronic, but also neurodegenerative. Limited service funds cannot always be a valid reason for people not receiving proper treatment.

In my view, the following years will show how serious the health department truly is about solidifying neurological services with more neurologists, more treatment centres and widely available DMT prescriptions. Like MS Ireland's 'Societal Cost of Multiple Sclerosis in Ireland 2015' report shows, slowing down disease progression and relapse prevention can lead to reducing public expenditure. While we often talk about cost-effectiveness in regards to medicine distribution, a similar cost-effectiveness can be applied to someone's mental and emotional outlook on life. People with MS are often retired at an early age in comparison to healthy people, which makes one think, "If only I could go back to work, see how cost-effective my new, professional income could be to the Irish state when I can spend more, do more and be more."

For that to happen, though, early treatment is of pivotal importance. I therefore 100% stand behind an Irish consensus like Time to Act.

Willeke van Eeckhoutte
MS & Me Blogger and MS Advocate



Contents

1. Introduction

A number of Disease Modifying Therapies (DMTs) have been licensed for use in Ireland for people with Relapsing Remitting Multiple Sclerosis (RRMS). DMTs have been clearly evidenced to reduce relapses and reduce disability accumulation in MS.

Current clinical evidence now strongly indicates that starting treatment with DMTs as soon as possible after a confirmed diagnosis of RRMS can improve long-term outcomes in terms of slowing disease progression, stabilising disability levels and reducing numbers of relapses. The MS Society in the United Kingdom convened a meeting in November 2014 to examine the body of clinical evidence and review current and emerging practice regarding prescribing of DMTs. The meeting was attended by people with MS and representatives from MS societies as well as neurologists, MS nurses and other medical professionals.

After the meeting, a paper was produced, 'Time to Act – A Consensus on Early Treatment' which outlined the available evidence in favour of early treatment with DMTs, subject to people with MS being able to make informed decisions about the potential benefits and risks involved. This paper draws on 'Time to Act', making detailed recommendations for clinical practice and policy makers relevant to the Irish context. In developing this paper, MS Ireland consulted with a group of Irish neurologists with a specialist interest in MS.

2. Why is the question of early treatment important to people with MS?

Deciding when and if to start treatment with a DMT, and which DMT to take, can be extremely difficult, particularly in the aftermath of a diagnosis of a chronic and potentially life-altering condition. It is therefore vital that people with MS are provided with all the information they need about DMTs, their potential long-term and short-term benefits and also the potential risks and side-effects.

Without clear guidance as to whether there are time-related benefits to starting on DMTs as soon as possible, the decision to start or not start a long-term treatment – with potentially serious side-effects and impacts on day-to-day quality of life – will remain a difficult one. This is particularly true if relapses and symptoms are mild.

3. What are the long-term effects of MS?

MS is a varied and complex condition which has wide ranging physical, social and emotional impacts. Progression and symptoms vary greatly between individuals, however, it is known that 50% of people with MS will need assistance with walking within 15 years of the onset of the disease (Cotterall et al., 1999). Quality of life decreases with disease progression, with those with severe disability levels reporting an average unit value of -0.027 on a self-reported HRQoL instrument, compared with an average score of 0.718 for those with only mild disability levels (MS Ireland, 2015). Levels of depression and anxiety also increase with disability severity, with 47.4% of people with severe disability reporting experiencing anxiety compared with 24.1% for those with mild disability (MS Ireland, 2015).

Furthermore, recent studies have shown that the societal costs of MS increase steeply with disease progression, from €35,000 per person per year for those with a mild form of the disease to €100,000 per person per year for those with more severe forms (MS Ireland, 2015).

4. Why take a DMT?

There are a range of DMTs licensed for use for MS in Ireland. They vary in terms of administration method, efficacy and side effects, with the more effective treatments tending to have more serious potential side effects. Side effects of DMTs can vary from minor, such as mild allergic reactions, to serious and rare effects such as Progressive Multifocal Leukoencephalopathy (PML).

DMTs can decrease the number and severity of relapses (PRISMS, 1998; Kappos et al, 2010). First-line DMTs have been shown to reduce annual relapses by 30% compared with placebo, while newer second-line therapies by up to 60% (Weinstock-Guttman, 2013). DMTs have also been shown to delay the progression of disability and slow the speed at which it happens (Palace et al, 2015; Coles et al, 2012; Polman et al, 2006). This should allow people with MS to improve their quality of life and to maintain independence and control of their lives and their condition.

5. Why aren't more people taking DMTs?

It is estimated that less than half (44%) of people with MS in Ireland are currently taking a DMT (Fogarty et al, 2014). Ireland is ranked 15th out of 27 European countries on the proportion using DMTs, below the European average (Kobelt & Kasteng, 2009). According to the European MS Barometer 2015, a figure of 44% of the population receiving DMTs would place Ireland 14th out of 28 countries with known figures for DMT usage (European Multiple Sclerosis Platform, 2015).

There are various clinical reasons why a neurologist may not prescribe a DMT. Prescribing decisions must consider the efficacy, safety and tolerability of medications and the likelihood of adherence, all of which are unpredictable factors that can be hard to assess, particular early in the disease course (Ford, 2014).

Studies have found many reasons why people with MS might actively decide against taking a DMT, which may or may not be in accordance with the advice of their physicians. Identified reasons why someone might decide against taking a DMT include denial and fear, doubts about effectiveness, not feeling "sick enough", fear of side effects and, in some cases, active discouragement from the physician (Johnson et al, 2006).

Access to DMTs may also be impacted by under-resourcing and underdevelopment of neurology services in Ireland. A recent survey of neurology clinics by the Neurological Alliance of Ireland (NAI), in conjunction with the National Clinical Programme for Neurology, found critical deficits in staffing across all neurology centres and unacceptable waiting times for MRI scanning. Key findings (correct as of January 2015) include:

- No centre has MRI access for routine referrals in under two months and seven of the eleven neurology centres cannot get access within one year of referral
- The ratio recommended by the British Association of Neurologists is for one consultant neurologist per 70,000 population. This ratio is exceeded within every hospital

group in Ireland and in one hospital group (Mid West) the ratio is 1:200,000

- Ireland has less than half of the recommended number of specialist MS Nurses for our population size – MS Nurses play a crucial role in the ongoing monitoring and management of DMT treatment

(NAI, 2016)

These survey findings are supported by the experiences reported to MS Ireland via our MS Information Line and Regional Community Work service, which confirm that people with MS are often facing long waiting times between appointments and long waiting times for first outpatient appointments, which impacts on prompt access to initial diagnosis.

6. Our changing understanding of MS

Advances in the use of MRI scanning over the last 15 years have greatly increased our understanding of the nature of MS and the disease activities which characterize it. Previously, researchers and clinicians were limited to identifying clinical relapses (a sudden manifestation of new and/or increased symptoms that may, for example, affect vision, balance, mobility and sensation) in order to diagnose relapsing-remitting MS and to decide on the best treatment options.

MRI scanning has facilitated a greater understanding of the role of the immune system and inflammatory processes that cause damage to the myelin sheath and contribute to neurodegeneration. It has shown that new MRI lesions are a more sensitive and comprehensive indicator of inflammatory disease activity than clinical relapses, occurring up to ten times more frequently than clinically apparent relapses (Kappos et al, 1988; Isaac et al, 1988). This has greatly improved our understanding of the damage that can be accrued without someone experiencing obvious relapses as well as during a more obvious attack.

This greater understanding has been reflected in the MacDonald criteria which are the now standard diagnostic criteria for MS used in clinical practice. The criteria support diagnosis on the basis of clinical and radiological evidence (spatial and temporal dispersion of MRI lesions), meaning that many people previously considered to have a first clinical episode (known as clinically isolated syndrome or CIS) can now be diagnosed with MS following an MRI. The routine use of McDonald criteria means that many MS patients are diagnosed at a much earlier stage of disease than previously possible.

The modified Rio score has been suggested as a possible way of assessing disease activity over time, incorporating both clinical and radiological parameters. Use of this score and others could inform treatment decisions, both early on and in ongoing management. (Dobson et al, 2014). However, such frequent use of MRI to monitor disease activity and treatment effect is still not standard practice in all centres in Ireland and access to MRI scanning may limit this approach for many neurologists.

7. Does early treatment matter?

These advances in understanding MS and improvements in rates of early diagnosis mean that it is now of crucial importance to examine practices around the prescription of DMTs and ask important questions about when to start treatment. Outlined below is some key evidence that supports early treatment with DMTs, followed by recommendations for policy and practice.

8. Evidence for early treatment

Long-term follow-up of the early pivotal interferon trials present interesting data, with the placebo group being switched to active treatment after three years. The 16 year data showed significantly improved physical and mental outcomes for those receiving the treatment from the outset compared with those in the placebo group (Goodin et al, 2012a).

A further paper was published in 2012, showing an even more stark difference in outcomes between the two groups for the 21 year follow-up. It showed that people who were given beta-interferon in the original treatment group had a 50% reduction in mortality rates compared with people who started on the placebo and switched to interferon three years later (Goodin et al, 2012b).

A six year study of patients taking glatiramer acetate concluded that early use of the treatment has a bearing on efficacy, with those taking treatment (rather than placebo) from the outset being less likely to be using a walking aid at six years (Rovaris et al, 2007).

A seven year follow-up study of people taking alemtuzumab was published in early 2014. This showed that 68% of people on the treatment experienced an overall improvement or stabilisation in disability over seven years (Tuohy et al, 2014). The alemtuzumab trial is especially valuable because people were consciously selected for early treatment. Crucially, the interferon arm also fared better than in previous trials, adding to the evidence around early treatment (Cohen et al, 2012).

Evidence presented at the ECTRIMS conference in 2014 (and published later that year) also suggested that early use of Plegridy led to improved outcomes compared with a later start, though this was over a much shorter timescale than the pivotal 21 year study (Arnold et al, 2014).

The five year results of a ten year observational study into the long-term efficacy and safety of natalizumab in clinical practice showed that patients who started natalizumab treatment when they were therapy naïve, or with lower baseline EDSS scores or relapse rates, or who had used fewer prior DMTs had lower on-therapy annualised relapse rates. This suggested the level of clinical disease activity may be lower when natalizumab treatment is initiated earlier in the disease course (Butzkueven et al, 2014).

In October 2014, a new study was published analysing observational data from 3,060 people with MS on the long-term risk of disability (Cocco et al, 2014). The researchers concluded that DMTs delayed long-term disability in people with MS treated either in the early, or, to a lesser extent, in the later phase of the disease. Thus, the window of therapeutic opportunity is relatively extended, assuming that early is better than late treatment, but late is better than never.

Several trials of DMTs in secondary progressive MS showed a lack of effect of DMTs in treating progressive forms of the disease (Kappos, 2004). Although there are ongoing questions around therapeutic lag and the need for longer follow-up, these studies have helped shape the therapeutic window for current DMTs as being earlier, relapsing forms of MS only.

There have been several studies into the treatment of clinically isolated syndrome with a DMT. The study into the effect of treatment with interferon beta-1b in clinically isolated syndrome showed that early treatment reduced the risk of conversion to clinically definite MS by 37% compared with delayed treatment. However, in this study a delay in treatment by up to two years did not significantly affect disability outcomes at five years (Kappos et al, 2009).

A study looking to assess the efficacy and safety of teriflunomide in people with a first clinical episode suggestive of MS showed that the treatment reduced the likelihood of conversion to clinically definite MS and the number of MRI lesions compared with placebo (Miller et al, 2014).

A study into the effect of DMTs on cognition in patients with clinically isolated syndrome showed that the treatment helped preserve the brain's grey matter and cognitive function (Uher et al, 2014).

9. Evidence questioning the benefits of early treatment

A study looking at the effects of early treatment on various outcomes (including EuroQoL-5D [EQ5D], Patient Health Questionnaire-9 [PHQ9], Multiple Sclerosis Performance Scales [MSPS] and the timed 25 foot walk [T25FW]) showed that early treatment was only beneficial to certain subgroups of the MS population and its effect is modest (Conway et al, 2012).

A follow-up study of people who had presented with clinically isolated syndrome suggestive of MS 20 years earlier showed that 67 of 207 patients went on to develop clinically definite MS. Of those with clinically definite MS, 39% had an EDSS score of 3 or less at 20 years. 82% of those with an abnormal MRI went on to convert to clinically definite MS (Fisniku et al, 2008).

Although our studies show that taking a DMT can reduce the risk of converting to clinically definite MS, DMTs also carry a risk of long-term side effects. Some of these side effects are particularly serious, such as thyroid problems or progressive multifocal leukoencephalopathy. Neurologists can struggle to predict who will go on to develop significant disability and who will not, so it is difficult for people with MS to make long-term decisions about the best treatment option for them. Treating people whose symptoms will remain mild with a DMT that could endanger their long-term wellbeing should be avoided.

Newer DMTs like alemtuzumab, dimethyl fumarate and teriflunomide have only been authorised for use in Ireland relatively recently; the phase 2 and 3 trials happened in the past decade. While follow-up data from the alemtuzumab trials has shown very encouraging results at seven years with the majority of people on the treatment experiencing an overall improvement or stabilisation in disability, the long-term effect of these treatments will not truly be known for another 10 or so years. Further evidence of long-term early treatment effect would provide greater clarity.

10. Use of resources

As well as considering clinical evidence, there are also questions around the best use of public health resources. Limited health service funds need to cover a broad range of treatments and care, so investment in DMTs needs to be considered alongside the relative importance of other interventions including therapies such as physiotherapy and occupational therapy, neurorehabilitation and community care and supports. The cost of the treatment goes beyond the actual cost of the DMT itself. Factored into the overall cost of the treatment include:

- the time spent with specialists to advise, prescribe and monitor patients
- the facilities in which DMT services take place
- monitoring of DMT efficacy and safety e.g. blood tests and/or MRI scans
- referrals or changes to treatments that need to be made as a result of suboptimal response or side effects.

However, these costs should also be weighted against the considerable evidence from MS Ireland's 'Societal Cost of Multiple Sclerosis in Ireland 2015' report that clearly indicates the substantial costs to the Irish taxpayer of MS disease progression and relapses. The report estimates that MS relapses cost Irish society €16.9 million annually. Annual societal costs increase steeply with disease progression and increases in disability severity, from €34,942 per person per year for those with mild disabilities to €100,554 per person per year for those with severe disabilities. These figures combine direct healthcare resource use and indirect costs, including loss of productivity and costs associated with provision of informal care (MS Ireland, 2015).

11. Emerging evidence regarding benefits of Vitamin D supplementation

There has been increasing evidence over the last 10 years that Vitamin D deficiency plays a role in the severity of MS. A number of studies have shown that it plays a role in immunomodulation and reduces the inflammatory response in autoimmune diseases (Laursen et al, 2016; Guzman de la Fuente et al, 2015; Waubant et al, 2015; Alharbi, 2015, Thouvenot et al, 2014).

Two studies currently awaiting publication were presented at ECTRIMS 2016 that demonstrate further evidence of the efficacy of Vitamin D supplementation in people with RRMS. The SOLAR study compared 113 RRMS patients on Rebif and Vitamin D 14,000 IU per day versus a control group of 116 patients on Rebif and placebo. After 48 weeks, the test group showed a

significant reduction in Combined Unique Activity (new gadolinium-enhancing T1 or new or enlarging T2 lesions). (Muris et al, 2016). The second study compared Vitamin D 100,000 IU twice monthly to placebo in a population of RRMS patients on Rebif over two years. In the "completers" population (45 vitamin D / 45 placebo patients), Vitamin D, compared to placebo, reduced the relapse rate by 60% at two years (Camu et al, 2016).

12. Summary and recommendations

An individual who is suspected as having MS should be referred to a neurologist and seen within an audited timeframe. The individual should be seen again after all investigations necessary to confirm or refute the diagnosis have been completed.

The National Institute for Health and Clinical Excellence (NICE 2014) guidelines recommend a timeline of six weeks from referral to neurology consultation and then six weeks to diagnosis of MS, although it may not always be possible to confirm the diagnosis clinically in this time frame and an additional period of follow-up may be required.

In a published audit of clinical practise in one Dublin University Hospital (Kelly et al, 2011), timelines from presentation to diagnosis were calculated. In this study the mean time from assessment to diagnosis was 9.5 weeks (median six weeks, range one day to 80 weeks). The percentage of patients receiving diagnosis within six weeks of their first neurology review was 52%. The remaining 48% had a delay of more than six weeks from presentation to receiving a diagnosis of MS. Patients who had MRI performed prior to neurology review had a much shorter time to diagnosis than patients who did not.

A number of factors adversely affected a timely diagnosis. Patients who experienced a delay were at times patients referred with atypical presentations or where MS had not been considered as a potential diagnosis by the referring clinician. In these instances delays to MRI, access to a review clinic and lumbar puncture occurred. Deficiencies in administrative support as a resource also accounted for delays in some instances. Overall, 78% of patients were seen in an initial clinic by a neurologist within the six week timeframe whereas only 52% received their diagnosis within six weeks of initial presentation. This would suggest that many of the challenges of reaching best practise standards are operational in nature including access to diagnostic services.

The impact of this should not be underestimated when the evidence outlined above indicates strongly that early treatment with a DMT can improve long-term outcomes for people with relapsing remitting MS, compared with a later initiation of treatment.

Conversations regarding treatment should begin at diagnosis and should be followed up during the following six months with a view to developing a treatment plan in this time period that includes a more considered initial treatment decision. The type of DMT, treatment strategy and treatment goal should be decided jointly between patient and neurologist. Clinicians should also be prepared to openly discuss with patients the potential consequences of non-treatment or delaying treatment, including development of severe disability and cognitive decline.

Regular MRI scanning for those on DMT treatment or people with relapsing remitting MS who are not receiving a DMT is advisable. Current guidance from the Consortium of Multiple Sclerosis Centres recommends an MRI every six months to two years for people with relapsing MS (Traboulsee et al, 2015). If new MRI activity is seen then treatment should be escalated, or initiated if not already started. Suboptimal responses to treatment should prompt further discussion about changes in treatment regime.

Whilst clinicians will remain the primary source of advice and information for people with MS as regards the best treatment options for them, the Multiple Sclerosis Society of Ireland should also play a crucial role in disseminating up-to-date information on treatment options and current clinical research to people with MS and healthcare professionals, so as to support informed and shared decision-making.

It should also be acknowledged that DMT treatment is one of many aspects of MS treatment and care, and that for people with progressive forms of MS in particular treatment options are currently very limited. As recognised in the Multiple Sclerosis Pathway in the National Clinical Programme for Neurology Model of Care, people with MS require a continuum of care and support services across a range of disciplines to achieve optimal management of their condition and delay or prevent deterioration. The role of the MS Specialist Nurse is crucial in providing post-diagnosis support, relapse management and symptom management as well as the vital role they play in monitoring and managing DMT usage. The Neurology Model of Care also emphasises the importance of the roles of the Multidisciplinary team - Physiotherapy, Occupational Therapy, Dietitians, Clinical Psychology, Orthoptics and Speech and Language Therapy. In addition, people with MS may require access to specialist neurorehabilitation services, palliative care and a range of community-based supports such as home care packages.

Recommendations for further research

Further research is required to provide greater clarity on: improving understanding of individual prognosis, measuring the effectiveness of intensive monitoring regimes with more frequent MRI scanning, treatment and monitoring for those presenting with clinically or radiologically isolated syndrome, and the risks and benefits associated with early use of aggressive treatments with potentially more serious side-effects and how people with MS consider such risks when presented with all the available evidence and information.

Specific clinical recommendations:

- Patients presenting with symptoms indicative of MS should attend a neurologist, preferably one with a specialist understanding of MS, as soon as possible
- Initiation of disease modifying therapy from diagnosis of CIS or RRMS, subject to people with MS being able to make informed decisions about the potential benefits and risks involved
- At minimum, all patients with RRMS should receive a yearly MRI scan
- Patients with evidence of incomplete suppression of disease activity on the first line of disease modifying therapy should be escalated to second line therapies as soon as possible
- Clinical relapse should prompt timely access to an MRI scan and review of treatment
- Specialist neurological and neurological rehabilitation services should be available to every person with MS.

Irish policy recommendations:

- Formal commitment to support the implementation of the Model of Care of the National Clinical Programme for Neurology, including an outline of specific timescales and budgets outlining how implementation will be achieved.
- Address critical staffing deficits in neurology services, so as to ensure timely and equitable access to diagnosis and treatment and to ensure that appropriate facilities are in place for long-term monitoring of disease activity in people with MS. As well as addressing staffing deficits for consultant neurologist positions, there is also a serious need to increase the numbers of MS specialist nurses, multidisciplinary therapies, neurorehabilitation services and palliative care services
- Timely and equitable access to MRI scans, so that at minimum, people with RRMS can access an MRI scan every year
- Development of an MS patient registry and Individual Health Identifiers, so as to improve monitoring of the long-term effects of MS and the benefits of early treatment, and to allow for the future planning of adequately resourced MS services

- Training and upskilling for General Practitioners on identifying early symptoms of MS and on treating and managing MS, so that GPs can play an increased role in supporting people with MS to make informed treatment decisions

- Improvement and streamlining of the health technology assessment process for new medications, so as to prevent delays in new and innovative MS medications being made available to those who would benefit from them. Neurologists should be invited to make submissions on the potential clinical benefits of new medications as part of the health technology assessment process, as per the process for new cancer medications whereby submissions are sought from oncologists.

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14. Acknowledgements

Adapted from "Time to Act – A Consensus on Early Treatment" by the Multiple Sclerosis Society UK (September 2015), with kind permission.

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The development of this document was supported by an unrestricted grant from Sanofi Genzyme Ireland.

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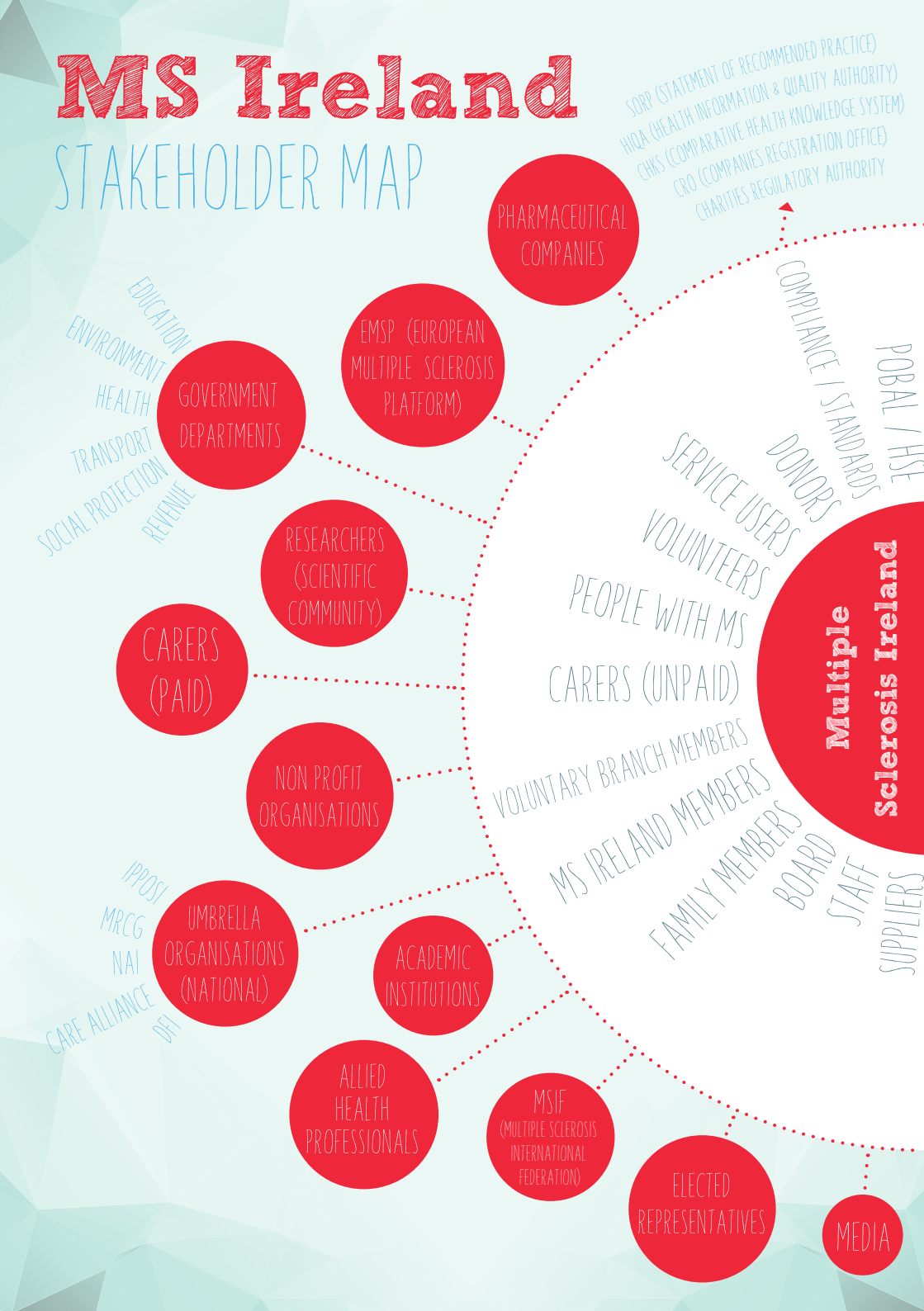
MS Ireland

STAKEHOLDER MAP



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