

# Making Ireland the Best Place to do Multiple Sclerosis Research



## Executive Summary

The aim of this report is to help create a multiple sclerosis (MS) research landscape that would put Ireland at the forefront of MS research, innovation and therapeutic application.

Research is of key importance in the area of MS, as shown in the results of, The Societal Cost of MS in Ireland, conducted in 2015, which showed that 92 per cent of people with MS experience fatigue and 33 per cent are diagnosed with depression and overall, people with MS have a 32 per cent reduced quality of life compared to those without the condition. MS patients also account for approximately 21,000 neurology appointments each year. In addition, up to €10 million per year could be saved by reducing relapses in MS and €19 million per year could be saved by delaying disability.

In November 2017 MS Ireland, in association with Novartis Ireland Ltd., facilitated a meeting, in order to gain input from a diverse mix of stakeholders to inform those interested on the current state of MS research in Ireland. The meeting aimed to help to shape the approach to Irish multiple sclerosis (MS) research into the future, as well as outlining the challenges and opportunities in the field.

This reports outlines the consensus from the meeting on, MS Ireland's research priorities, the current research landscape, the clinical challenges faced when doing research, data and information sharing, the involvement of people with MS and the key policy asks to make Ireland the best place to do MS research in Europe.



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## MS Ireland's Research Strategy

MS Ireland's complete research strategy document is available for download from their website. The document was comprised using data from the MS Ireland Research Priorities Survey.

### Research Priorities Survey

The survey was conducted with a variety of participants, the vast majority of whom were people living with MS, as well as partners, relatives and carers of people with MS, and a small number of healthcare professionals, researchers and others. In total, 415 people responded to the survey.

When asked the question,  
**What research questions regarding MS would you like to see addressed and why?**

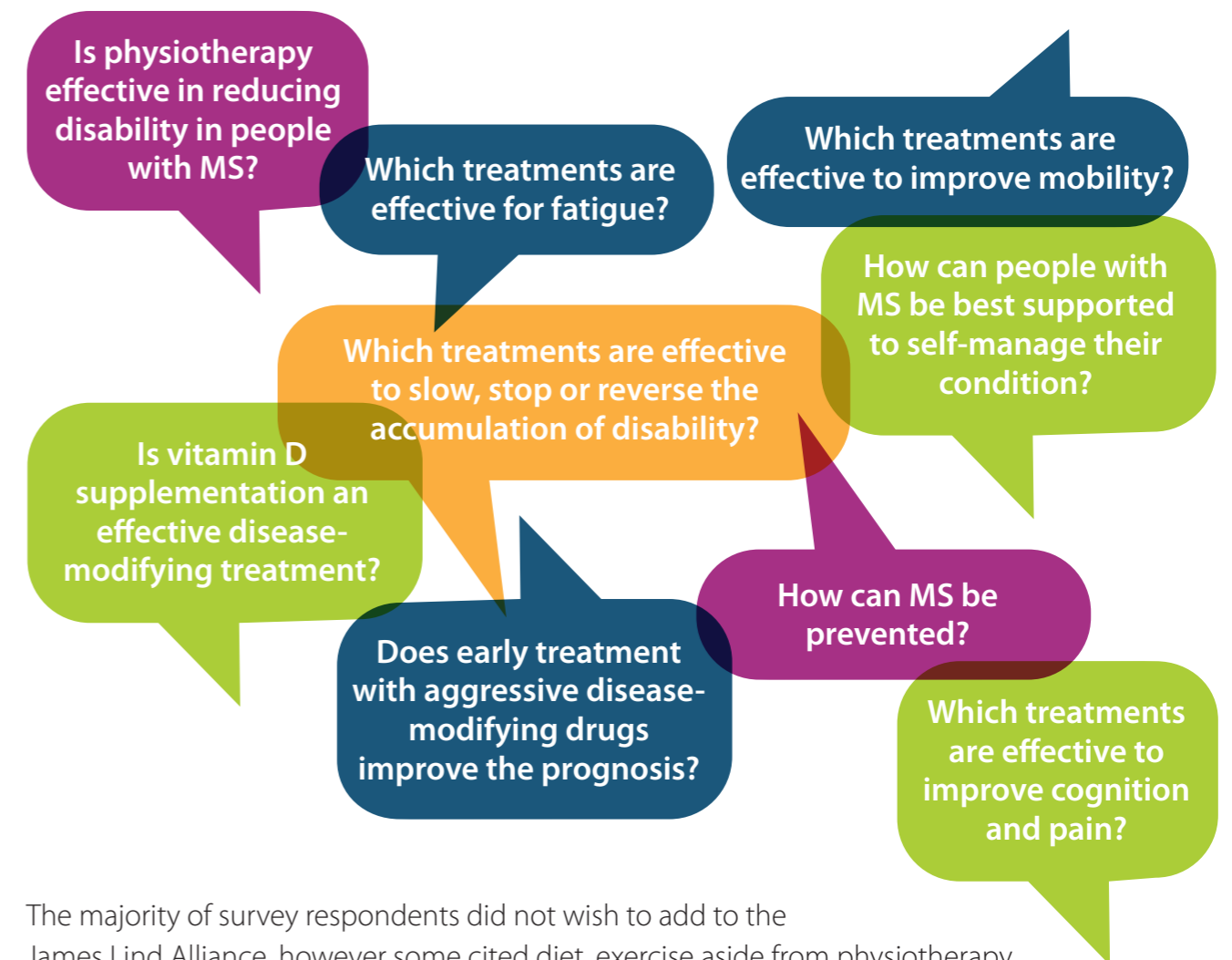
The responses in order of priority were:

1. **Treatments, medications and cures**
2. **Causes of MS**
3. **Mobility, exercise and physiotherapy**
4. **Progressive MS**
5. **Diet**
6. **Stem cells**
7. **Fatigue**
8. **Genetics of MS**
9. **Cognition**
10. **Different types of MS and why certain people contract them, and why different people with MS get certain symptoms**

Additional responses related to side-effects of medication, cannabis, psychological effects of MS, vitamin D and alternative therapies.

### James Lind Alliance Research Priorities

MS Ireland's research strategy currently references the top 10 research priorities, as developed by the James Lind Alliance and the MS Society in the UK, resulting from a survey of 650 people with MS. These included:



The majority of survey respondents did not wish to add to the James Lind Alliance, however some cited diet, exercise aside from physiotherapy, mental health and psychology as other factors for consideration.

The below items were identified as the key priorities by the survey respondents:



The most overwhelming survey response related to the need for treatments and cures.

## The Current Research Landscape

Dr Claire McCoy from the Royal College of Surgeons and Dr Kate O'Brien from Genomics Medicine Ireland gave presentations on their perspectives on the current benefits and challenges of Ireland as a place to do MS research. Key points from their presentations include:



Given the incidence of MS in Ireland, we should be “leading the way in MS research” and this should be pursued, not least because of the economic burden caused by MS in Ireland.

To achieve this, key areas must be built upon, including the need to act as a collective MS community, while another is to identify research strengths and to use that to leverage international funding.

### MS Research Community



The MS community, can be defined as, people with MS, care-givers, clinicians and allied healthcare professionals, researchers and nurses, as well as MS Ireland itself. This community also includes industry and funders.

However, as a research group we have no clear visibility. When comparing Ireland with international experience there should be more communication and better cohesiveness among the Irish MS community.

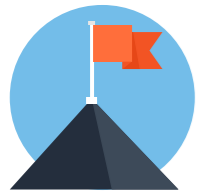
### Reasons to do Research in Ireland



In terms of research, Ireland’s educational system is in the top-10 in the world and there is a good infrastructure here to conduct translational research, as well as a strong presence among the pharmaceutical industry here.

Ireland’s capacity to conduct clinical research has expanded by 37 per cent since 2014 and more clinical research ultimately leads to better outcomes for patients and as such, Ireland is a good place to conduct MS research. The relatively small number of neurologists in Ireland should also theoretically provide better access to patients. However there is limited resources and therefore limited time to allow engagement in research.

### Clinical Challenges



The clinical challenges in MS research include resources, time and funding, as well as a lack of research nurses in hospitals, while neurologists are often over-burdened with clinical duties that make them unable to conduct research, even though they would like to do so. Lack of an electronic health record and variance in care pathways present further challenges and finalising contracts also presents a major stumbling block to research.

There is also a lack of a centralised ethics committee for clinical studies and geographical location of patients can also provide complications, and there can also be a bias towards relapsing-remitting patients in centres of care.

Currently Genomics Ireland are undertaking genomics research in people with MS in Ireland, which is aimed at getting two-thirds of the MS population in Ireland studied and will have a follow-up period of five years. This will create an environment to facilitate the next generation of medical research and discover novel gene and drug targets for Irish patients with MS. Genetic diversity is a positive aspect on a global scale but can confound research results and mask discovery of rare variants and requires the study of very large populations.

However, Ireland’s relatively isolated population and large patient numbers provide an advantage in this regard and this means greater discovery potential for rare variants in MS. Ireland’s large diaspora – some 80 million people – also means that any research conducted here can be translated to a much wider population.

People with MS and neurologists alike want to be helpful in conducting research but there are practical difficulties in obtaining saliva and blood samples initially, particularly in terms of taking blood samples and gaining access to medical records and this is a source of frustration. Research nurses also tend to be overworked, which compounds this problem.

While research infrastructure has improved in recent years, it is still not to the standard of many other countries. This makes research slow and costly.

### Funding Options



As the discussion moved on to funding, it was determined that those present may need to look beyond what they are “comfortable with” to a wider variety of funding sources e.g. Enterprise Ireland.

The role of MS Ireland was outlined by Harriet Doig, Information, Advocacy and Research Officer, which included updates on research activities and samples of collaboration on other research and charity groups and academia.

It was explained that up until 2008, MS Ireland had ring-fenced funding specifically for research but unfortunately, that is no longer the case. Available funding is divided on a case by case basis and total funding for research projects has declined by approximately 50 per cent.

Funding is available from a number of agencies but there is potential for this to be increased.

While research infrastructure has improved in recent years, it is still not to the standard of many other countries. This makes research slow and costly.



## Next Steps

### Establishing a MS Research Community

Difficulty in gathering samples was the main reason for forming an MS research network in Northern Ireland forming the initial link between scientists and neurologists. There was very little funding available for the network in the first year but this is beginning to improve and there is now greater involvement from all stakeholders. In terms of gathering samples, it was said that organising a steering group to agree protocols is very important, because “how we sample is just as important as what we sample”.

An MS network would also need to be inclusive, in order to share knowledge and ideas to make the MS community as robust as possible. The high quality of Irish research into MS is a great strength. This is helped by our island status, a “stable population” and high level of inter-connectivity and the dedication of researchers and clinicians.

While the top priorities in MS research are currently being addressed, this could be done better if the MS community addressed them as a collective, and Ireland’s current research strengths should be leveraged in order to obtain more funding and improve research visibility.

The NHS and National Institute for Health Research in the UK provide a good model for connectivity that could be emulated in Ireland. This ultimately helps to support researchers and also allows patients to gain earlier access to treatments and advances novel therapeutics.

The Epilepsy Lighthouse Project in Ireland also provides a good example of a genomic pipeline that is linked to an electronic patient record and it “would be fantastic” to establish something similar for the MS community.

It was added that there is a burden on a person with MS when it comes to providing a blood sample in terms of travel and it was questioned why this could not be done locally. However, people with MS are generally happy to accommodate when it comes to providing samples. Creating a network, may help to alleviate this problem, and sharing of samples may avoid duplication of such processes.



### Data and Information Sharing

Beginning a dialogue to establish what samples researchers currently have would be a good initial step towards a collaborative approach to research and serve as a stop-gap until a biobank is established.

Datasets exist on paper in written notes and in the US, for example, even when paper files are converted to an electronic health record, this data is still not grouped and structured.

Another problem can be the challenge of keeping the database up to date, it was added, as well as issues around long-term sustainability. As such there is a need for standardisation of data for all research.

There is a need for a conversation on information-sharing and establishing who holds what type of research information and to establish a patient register. However, there are templates in existence from other diseases that could be useful in this regard. It was suggested that a meeting with the Lighthouse Project may be helpful.

It was also suggested that a common ethical procedure for researchers would significantly simplify the process, because applying to every hospital for ethical approval is too cumbersome. An all-island clinical trials network, as exists for cancer, may be a viable solution.

### Involvement of People with MS

Patient involvement is almost always required in applying for research grants but recruitment and ethics are stumbling blocks. This may be solved by the new collaborative approach, providing patients with greater involvement in research. MS Ireland can be helpful in finding people with MS to input into ethics proposals and invited queries in this regard.

There is now a “huge emphasis” on Patient Public Involvement (PPI), and applications to some funding bodies requires the involvement of patients in the development of proposals and conducting trials.

There is also need for patient education in terms of what questions to ask when they are considering participating in clinical trials. Wellcome Ireland, now has a PPI ‘enrichment award’ and this is something that MS Ireland may be interested in.

Sometimes in research, in terms of PPI, “improvement in quality of life for the person with MS is a bonus but does not always seem to be the goal of the research”. Therefore at the commencement of research, the work should be informed by the relevant community of patients.



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Alternatively approaching patients in clinics to offer them involvement was suggested as a good mechanism to gather their opinions and overall data, as they would be in a clinic for some hours with spare time on their hands to consider such things.

### Potential Forms of Funding

In terms of funding, this has the potential to be increased in Ireland and referenced the European Marie Curie ITN as a model for a training network that could be successfully emulated in Ireland, as well as the MS Society in the US and the International Progressive Alliance. A variety of potential funding bodies were listed.

Philanthropy was also mentioned as a funding source and it was pointed out that large donations from donors and international organisations are often made to universities. Organisations representing people with other diseases sometimes gain access to some of these funds and it was suggested that this is something MS Ireland may like to look at as a possible fund-raising mechanism.

Obtaining EU funding is often dependent on networks and multi-sectoral care, said one delegate, and it was suggested that a website should be established to highlight Irish research and the Irish researchers involved in order to increase visibility.

A major source of patient contacts for trials is still through local media, such as newspapers, or perhaps a text from a clinic or research centre. Corporate involvement featuring the MS Ireland logo on letterheads, for example, could be another way to raise awareness, it was suggested, and crowd-funding should also be considered as a fundraising mechanism.

### Disseminating Research Findings

It is also necessary for research findings in MS to be made more visible and comprehensible to lay people, as such it has been suggested that the MS Research eZine could be opened out to a wider audience.

An MS Ireland outreach event is to be organised next year at a Neuroscience Ireland meeting. As people MS prefer to develop long-term relationships with researchers and want to feel that their opinions are valued over a longer time-span.

It is important to disseminate research to people with MS. MS Ireland to organise an event to facilitate the dissemination of ongoing research in the area.

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## Key Policy Asks

### Recommendations for MS Ireland:

- Creation of a Facebook Workplace platform where researchers can contact each other, share information and seek opportunities for collaboration
- Establishment of a Public Patient Involvement (PPI) Network of people with MS, who researchers can contact for assistance with designing studies and grant applications
- Raising awareness with researchers that MS Ireland is available to be a partner/collaborator on funding applications (where no financial contribution is required from MS Ireland)
- Seek opportunities to collaborate with academia and industry on the establishment of an MS registry
- Organise at least one networking event for MS researchers per year, to build on the work and the discussions initiated at this event

### Recommendations for Policy Makers:

Recommendations for policy makers draw on those previously developed by the Medical Research Charities Group (MRCG) and the Irish Health Research Forum (IHRF) regarding improvements to the general medical research landscape in Ireland:

- Increasing state investment in medical research, including increasing funding for the Medical Research Charities Group and the Health Research Board Joint Funding Scheme for medical research charities
- Establishment of an MS patient registry and the development of a national policy framework and infrastructure for the development and maintenance of patient registries
- Prioritising implementation of The Health Information & Patient Safety Bill and The Human Tissue Bill

Formalising of structures and policies around public patient involvement in research – for example, requiring evidence of PPI to be a requirement of funding applications.





## Meeting Photos



Claire McCoy,  
RCSI



Kate O'Brien,  
Genomics Medicine Ireland



Prof Susan Coote,  
University Limerick



Harriet Doig,  
MS Ireland





## Notes

## About MS Ireland

Multiple Sclerosis Ireland is the only national organisation providing information, support and advocacy services to the MS community. We work with people with MS, their families and carers and a range of key stakeholders including health professionals, students and other interested in or concerned about MS to ensure that we meet our goals. MS Ireland is chiefly a services driven organisation, focused on providing timely, person-centered services that create independence and choice for person with MS and their family.

**[www.ms-society.ie](http://www.ms-society.ie)**

With special thanks to MS Ireland and Novartis Ireland Ltd. for facilitating the meeting on November 30th 2017 and to all the below for their valued input.

**Presenters:** Ms Harriet Doig, Information, Advocacy and Research Officer at MS Ireland, Dr. Claire McCoy, Principal Investigator in Inflammation and Biochemistry Lecturer at the Royal College of Surgeons in Ireland (RCSI) and Dr. Kate O'Brien of Genomics Medicine Ireland (GMI)

**Chair:** Prof Susan Coote, Physiotherapist, University Limerick

**Attendees:** Kam de Leeuw, Denise Fitzgerald, David Kavanagh, Kate O'Brien, Marie Fitzgibbon, Eric Downer, Joan Jordan, Pat Kelly, Claire McCoy, Alexis Donnelly, Amy Sweringen, Conor Duffy, Lajos Csincsik, Sinead Hynes, Ruth MacIver, Emma Kinnane, Niamh Murphy, Michelle Naughton, Jill McMahon, Aidan Larkin, Elaine Ross and Bridget Doyle

**Report Writer:** Pat Kelly





