

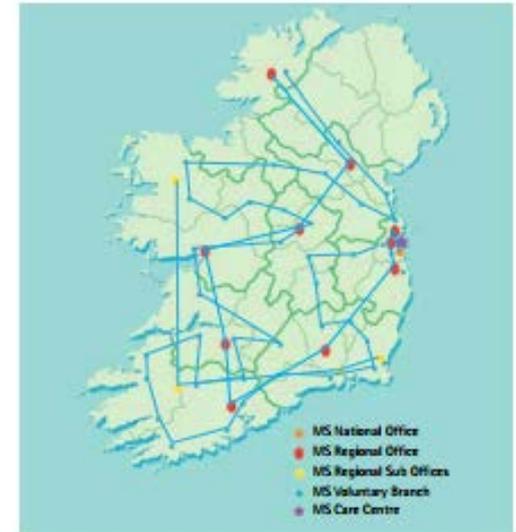
How MS Ireland are letting people with MS set our research priorities
Harriet Doig – Information, Advocacy and Research Officer

Mission:

To enable and empower people affected by Multiple Sclerosis to live the life of their choice to their fullest potential.

The only national organisation providing information, support and advocacy services to the MS community

Structure, Services and Work



About MS Ireland

What MS Ireland does:

- Individual and family support
- Living with MS programmes
- Information Line 1850 233 233
- Information resources – booklets, websites, fact sheets, social media, MS & Me Blog
- MS Care Centre – respite service
- Voluntary Branches
- Research
- Advocacy
- Funding – 50% statutory, 50% fundraised



Multiple Sclerosis in Ireland

Data from 'Societal Costs of Multiple Sclerosis in Ireland 2015' report:



MS is associated with HIGH costs.
Most of these are *OUTSIDE* the healthcare system.

Indirect costs
(e.g. time off work, carers)



Direct cost
(e.g. hospitals, doctors, medication)



Intangible costs
(e.g. quality of life)



MS Ireland and Research

MS Ireland believes that research is the most beneficial way to improve understanding of the disease, leading to better treatments, interventions, management and ultimately a cure for MS. MS Ireland **supports, promotes and funds** scientific and social sciences research.

Translate and disseminate

- Explain and disseminate research to people with MS and other stakeholders – bi-annual research eZine, MS Research Explored events, position papers on specific issues e.g. stem cell research

Collaboration

- Co-fund research projects with the Health Research Board (HRB) and Medical Research Charities Group (MRCG) Academic partnerships include University of Limerick and NUI Galway

Funding

- MS Ireland has had very limited funds for research in recent years (fundraised income decreased by over 50% since 2008). Recent projects funded thanks to generosity of individual donors. Also one Dean Medal Travel Bursary (€2000) every 2 years

Research Priorities Survey - background

MS Ireland Research Strategy – 2015-2019

- MS Ireland published a research strategy in December 2016 to cover the lifetime of our current strategic plan – available here: <http://www.ms-society.ie/pages/what-we-do/about-us/our-strategy>
- In the Strategy we reference the top 10 research priorities developed by James Lind Alliance and the MS Society UK – these were developed following a major piece of research surveying over 650 people with MS
- We decided to conduct an exercise to find out if these priorities are reflective of the views of the MS community in Ireland and if we need to develop our own top 10



James Lind Alliance top 10

- Which treatments are effective to slow, stop or reverse the accumulation of disability associated with MS?
- How can MS be prevented?
- Which treatments are effective for fatigue in people with MS?
- How can people with MS be best supported to self-manage their condition?
- Does early treatment with aggressive disease modifying drugs improve the prognosis for people with MS?
- Is Vitamin D supplementation an effective disease modifying treatment for MS?
- Which treatments are effective to improve mobility for people with MS?
- Which treatments are effective to improve cognition in people with MS?
- Which treatments are effective for pain in people with MS?
- Is physiotherapy effective in reducing disability in people with MS?

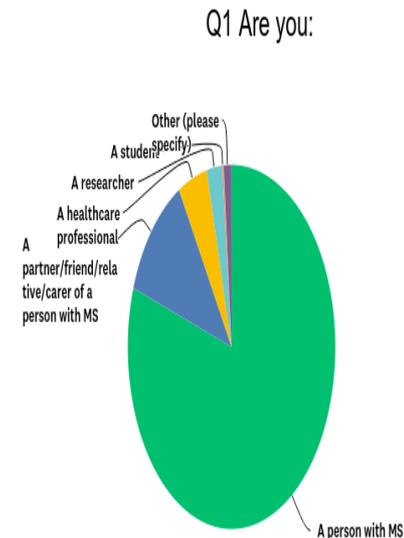
Methodology and sample

The survey was conducted online between June and October 2017. The survey was shared in our Research eZine, monthly eNews, MS News magazine, Facebook, Twitter and MS Ireland website.

Sample

415 people completed the survey. The breakdown of the sample was:

- People with MS – 80.24% – (333)
- Partners/friends/relatives/carers of people with MS – 11.33% –(47)
- Healthcare professionals – 4.58% (19)
- Researchers – 2.41% – (10)
- Students – 0.24% (1)
- Other – 1.20% (5)



Methodology and sample cont...

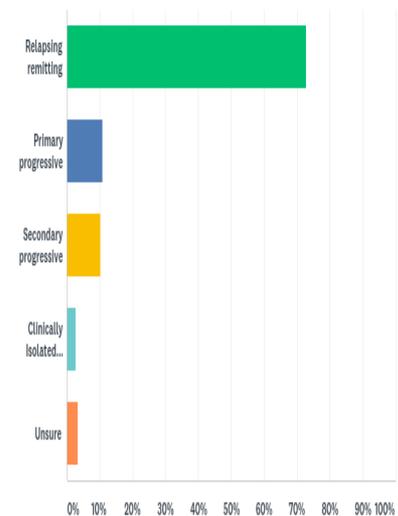
Among the people with MS:

- 72.81% (241) had relapsing remitting MS
- 10.88% (36) had primary progressive MS
- 10.27% (34) had secondary progressive MS
- 2.72% (9) had clinically isolated syndrome
- 3.32% (11) were unsure what type of MS they had

Of the healthcare professionals:

Seven respondents were physiotherapists, five were nurses, two were occupational therapists and there was one each of the following: GP, counsellor, community worker, speech and language therapist, care worker.

Q2 What type of MS do you have?

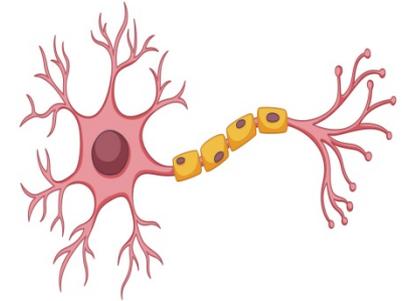


Findings

Open-ended question of “What research questions regarding MS would you like to see addressed and why?” The top 10 most common responses were:

1. Treatments/medications/cures
2. Causes of MS
3. Mobility/exercise/physiotherapy
4. Progressive MS
5. Diet
6. Stem cells
7. Fatigue
8. Genetics of MS
9. Cognition
10. Different types of MS – who gets what type/different symptoms

Other popular responses included researching why medications cause certain side-effects and how these can be prevented, cannabis and how it can be used to treat MS, the psychological effects of MS, Vitamin D and alternative therapies.



Findings

Respondents were then presented with the following list of top 10 research priorities, developed by the MS Society UK and the James Lind Alliance. They were asked “Is there anything that is not on the list above that you think should be included for Irish researchers, and why?”

The majority said that they agreed with the list and had nothing to add. Of those who stated that they felt there were other topics that should be included in the list, the top three most common responses were:

1. Diet

2. Exercise (besides physiotherapy – several commented that they felt this category should be broadened to include exercises such as yoga, Pilates or swimming)

3. Mental health and psychology

Other popular responses included causes of MS, cannabis, genetics, alternative therapies, safety and effectiveness of different medications (including side effects), stem cells, progressive MS, employment, pregnancy and fertility and the process of neurodegeneration and inflammation.

Findings

Respondents were then asked “Is there anything on the list above that you do not think should be a priority for Irish researchers, and why?”

- Again, the majority agreed with the list and did not suggest that anything should be removed
- Some respondents commented that prevention shouldn't be a priority as treatment is more important and prevention would be too costly to research.
- Others stated that they felt some topic areas, such as physiotherapy, were already very well researched
- Others stated that vitamin D should not be a category on its own as this should come under either prevention or treatments



Findings

Respondents were then asked to select three items from the James Lind Alliance list that they felt were the most important areas for researchers to focus on. Based on this, the top three items were as follows:

- Which treatments are effective to slow, stop or reverse the accumulation of disability associated with MS? (74.89%)
- How can MS be prevented? (42.13%)
- Which treatments are effective for fatigue in people with MS? (31.49%)

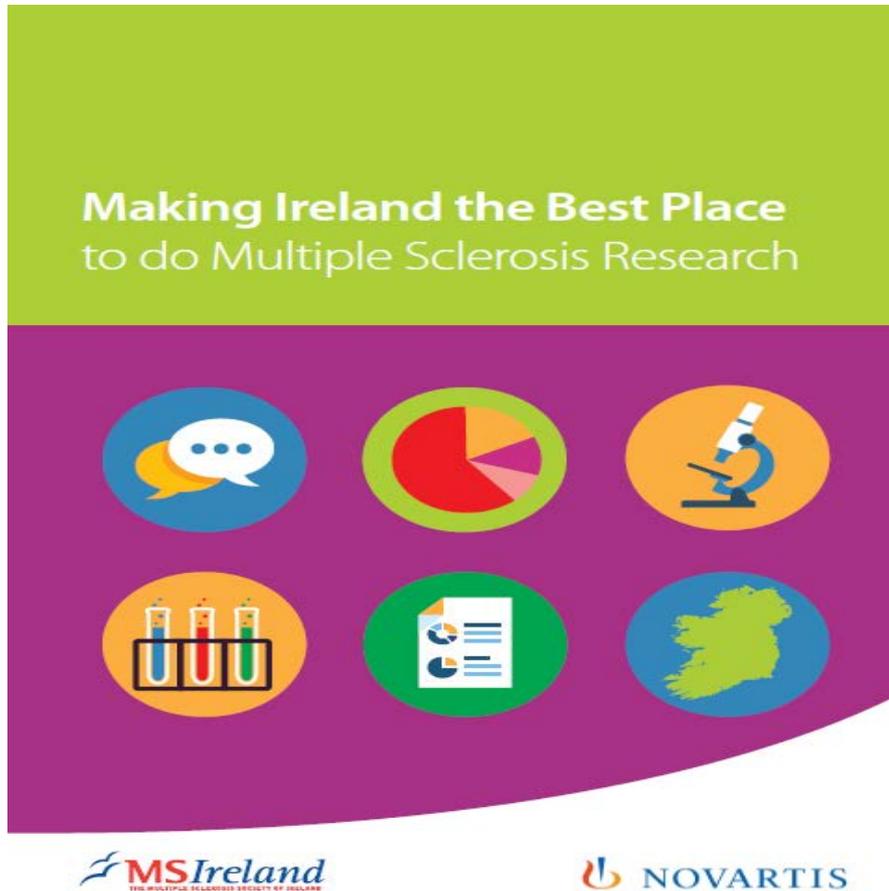


Findings

Finally, respondents were asked to rank the items on the list on order of importance from one to ten, with one being the most important and ten being the least important. The ranking was as follows:

1. Which treatments are effective to slow, stop or reverse the accumulation of disability associated with MS?
2. How can MS be prevented?
3. Which treatments are effective for fatigue in people with MS?
4. Does early treatment with aggressive disease modifying drugs improve the prognosis for people with MS?
5. How can people with MS be best supported to self-manage their condition
6. Which treatments are effective to improve mobility for people with MS?
7. Which treatments are effective to improve cognition in people with MS?
8. Which treatments are effective for pain in people with MS?
9. Is Vitamin D supplementation an effective DMT for MS?
10. Is physiotherapy effective in reducing disability in people with MS?

Report



- Released on World MS Day
- Combines survey results with discussion at a networking event for MS Researchers (people with MS also participated)
- Recommendations for MS Ireland and policy makers

Any questions?

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