



MS Brain Health

Time Matters



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MS Brain Health global impact Survey results and case studies

A review of the impact of MS Brain Health –
5 years after publication of our report

Overview of contents

- MS Brain Health endorsing organizations
- MS Brain Health global impact: quantitative survey results
 - Impact reported by healthcare professionals
 - Impact reported by people with MS or their carers
- MS Brain Health global impact: qualitative case studies

MS Brain Health recommendations are endorsed by 50+ professional and patient organizations



450+ MS Brain Health champions from >65 countries



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MS Brain Health global impact: quantitative survey results

Survey completed October–
December 2020



Thanks to MS Brain Health, 16 of the countries surveyed have changed their MS practice

	Australia		Czech Republic		Greece		Portugal
	Belgium		Egypt		Mexico		Romania
	Brazil		France		New Zealand		Serbia
	Canada		Germany		Norway		United Kingdom

MS Brain Health has had a global impact: here's what some of the survey respondents said ...

"More availability of disease-modifying treatments for all MS patients equally"

"Helped with establishing rapid pathways for newly diagnosed to be seen and commenced on treatment"

"MS Brain Health has certainly changed the way that leading MS neurologists view best practices in MS care"

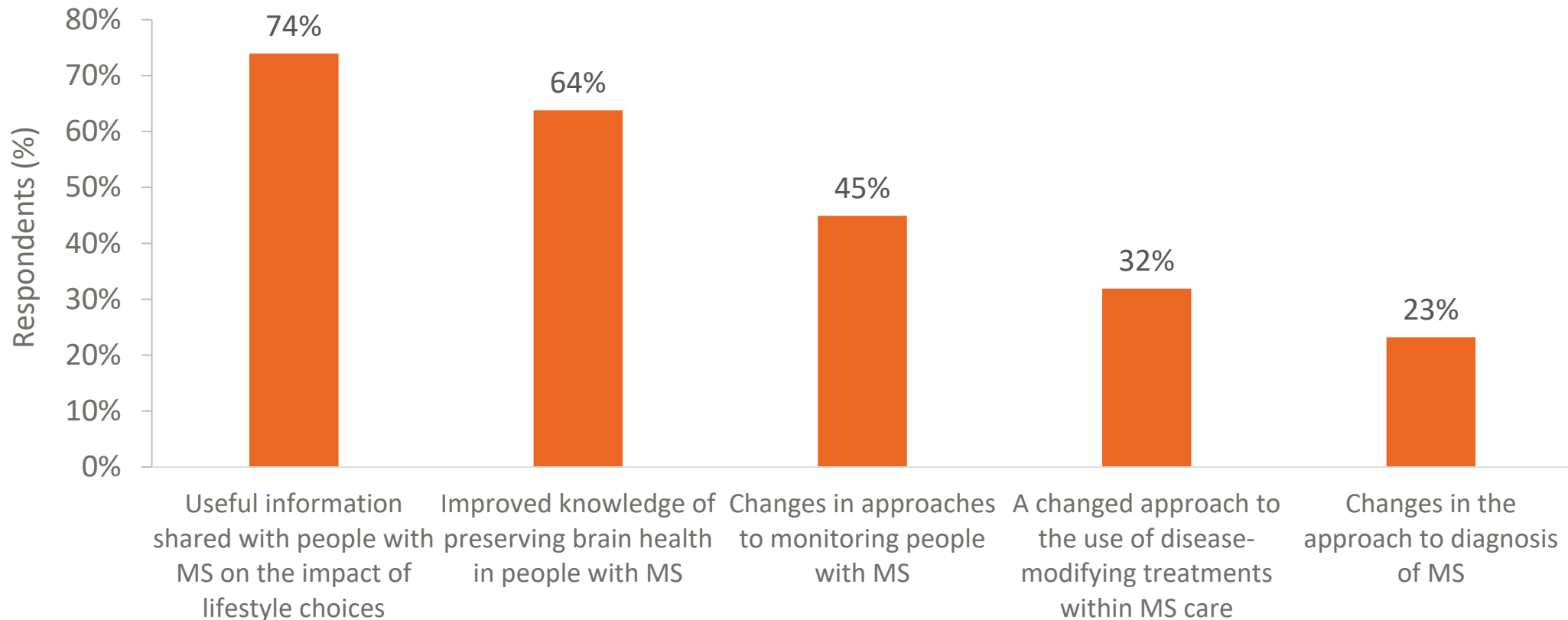
"Directed the focus of our organization's advocacy work"

"We have made sure politicians and health planners have copies of brain health. We are also participating in three centres in using the MS Brain Health auditing tool and look forward to the results"

"We have used MS Brain Health to ensure all of our staff and people with MS understand the importance of advocating for better care"

Changes to clinical practice include patient education and new approaches to diagnosis and management

Areas where MS Brain Health has supported changes in practice within the healthcare organization of the respondents



Reported changes are far-reaching, including treatment access and changes in national policy

“Have seen an increased use of higher efficacy therapies in our area”

“Initiatives to speed up diagnosis and treatment”

“MS Research Australia policy adoption/endorsement”

“Preservation of upper limb function”

“Updated criteria for reimbursement of MS DMTs”

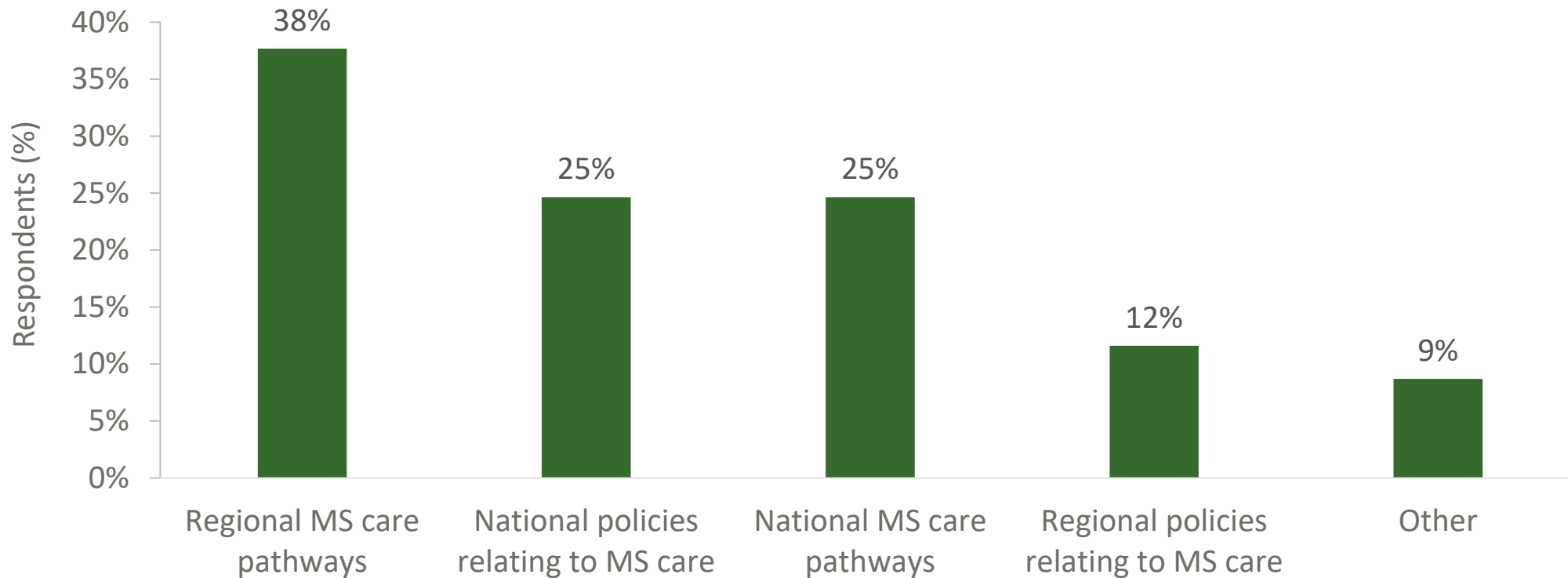
“...the Brazilian Academy of Neurology cites the MS Brain Health report in the documents that argue for a change in the standard national MS protocol”

“The lifestyle recommendations are part of newly updated standards for diagnostics and treatment of MS and NMO in Czech Republic”

“Greater acceptance of positive impact of early interventions, monitoring and the changes individuals can make”

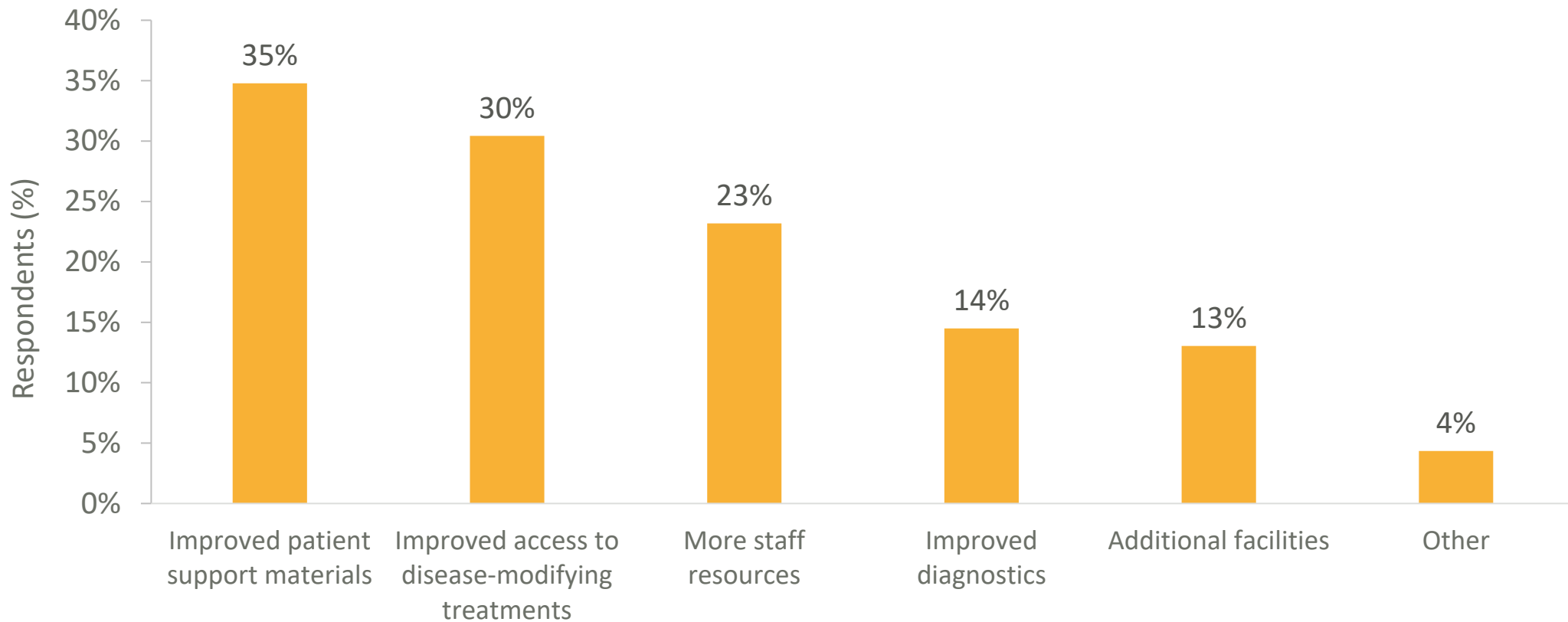
MS Brain Health has influenced established regional and national MS care pathways

Areas where respondents have noted changes in MS care pathways or policies that have been supported by the MS Brain Health initiative



Investment in MS care has increased in some centres

Reported areas where MS Brain Health has supported increased investment in MS services



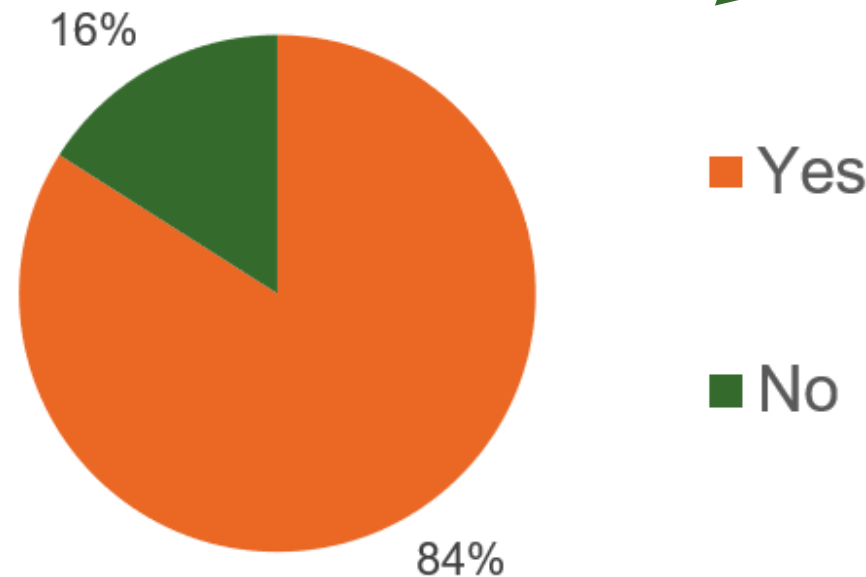
MS Brain Health has helped equip people with MS and their carers to manage the disease

The survey asked people with MS and their carers about the impact of MS Brain Health on:

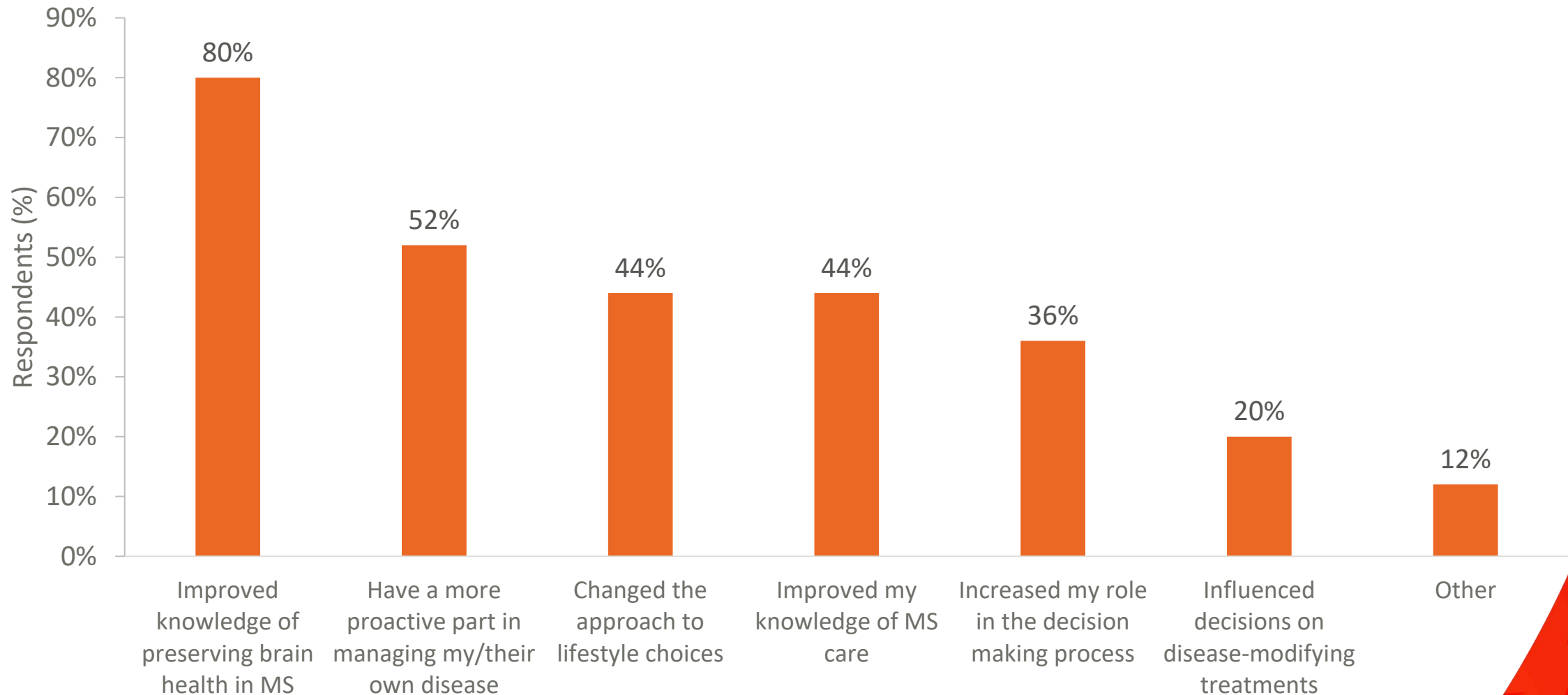
- management of their MS (or that of the person they care for)
- the MS services they use

In this group, 25 people from eight countries completed the survey

“Have the MS Brain Health recommendations and consensus standards influenced how you manage your MS or the MS of the person you care for?”



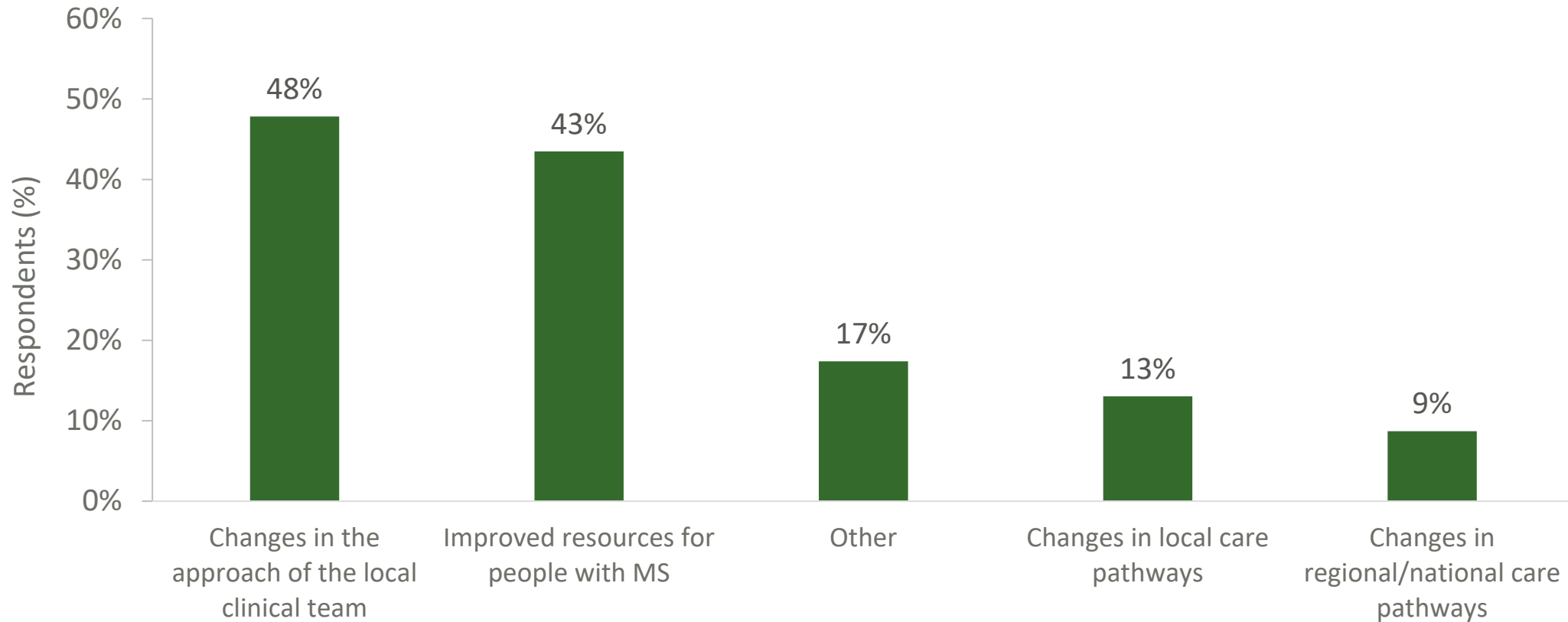
Changes in MS knowledge and self-management among survey respondents with MS



n = 25 people with MS or carers who responded

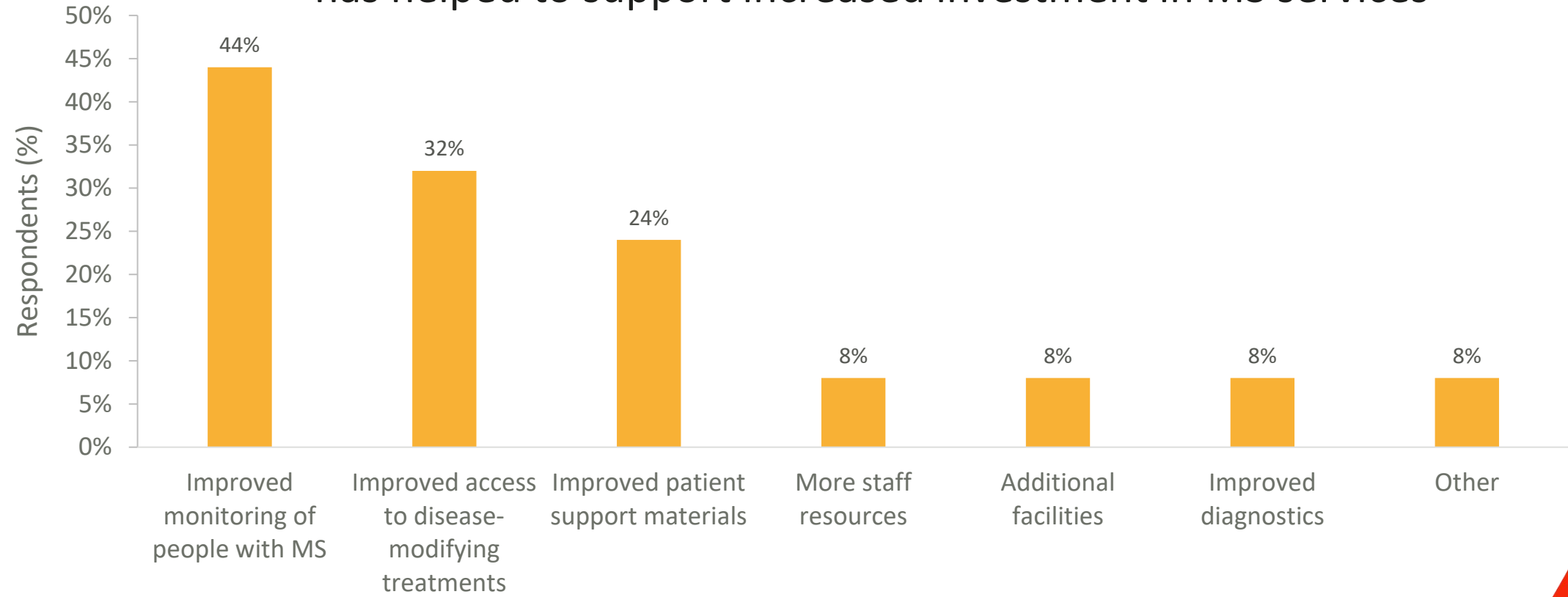
Areas of change in clinical care reported by people with MS

If you have noted changes in MS clinical care due to MS Brain Health, what have you seen?



Areas of increased investment include improved monitoring and access to DMTs

Areas where people with MS reported that MS Brain Health has helped to support increased investment in MS services



DMT, disease-modifying treatment
n = 25 people with MS or carers who responded



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MS Brain Health global impact: qualitative case studies

Some activities by national groups
that have impacted local health
policy and practice



'Impact' case studies: by country or region

- [Australia](#)
- [Europe](#)
- [New Zealand](#)
- [Norway](#)
- [Serbia](#)
- [Spain](#)
- [UK](#)



Influencing policy: MS Australia election commitments



MS Australia has played an active role in promoting MS Brain Health recommendations, by:

- asking the major political parties at the 2016 general election to **commit to funding the implementation of the recommendations**
- making a pre-budget submission to the 2017 federal budget to fund a project to help implement the recommendations

Outcome: Australian Parliament formally recognized World MS Day 2018 and acknowledged the importance of timely MS care, a brain-healthy lifestyle, and the need to increase investment in MS research

Election Commitments



MSA seeks an election commitment from all sides of politics for:

1. Full funding and timely roll out of the Medical Research Future Fund and assistance with prioritising an allocation from the Fund of \$25 million to Multiple Sclerosis Research Australia for the purpose of funding a number of promising, signature areas of research that will boost the chances of finding a cure for MS.
2. A specific contribution of \$15 million for the Brain Health Project; a therapeutic strategy with the potential to minimise disease activity and maximise lifelong brain health for those with MS.
3. Immediately establishing a MS Stem Cell Research Working Group for discussing with key decision-makers how to alleviate

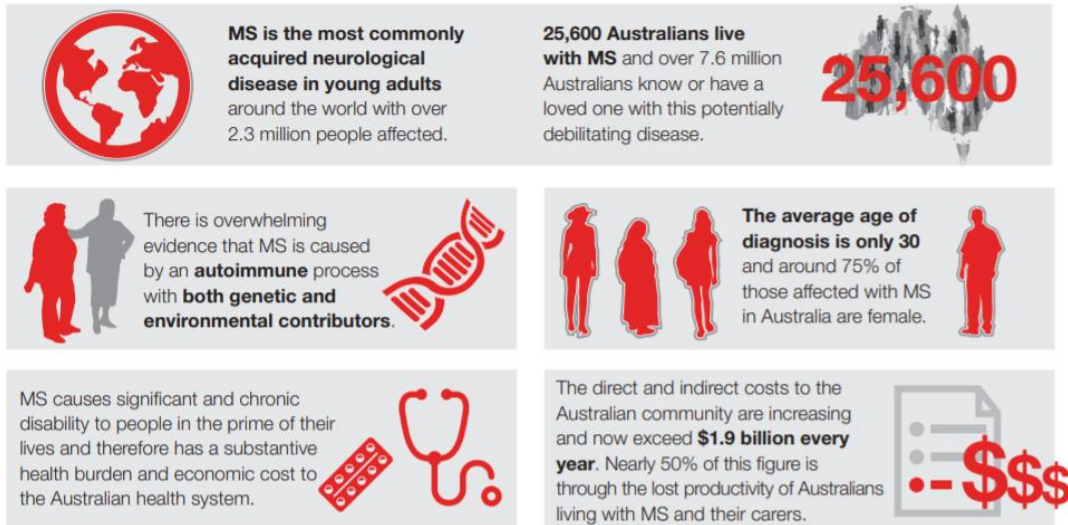
'Election commitments' roadmaps in Australia: to mirror government ministerial portfolios



A Roadmap to Defeat **Multiple Sclerosis** in Australia



Why is this important?



MAY 2018

Improved management of MS

What needs to be done?

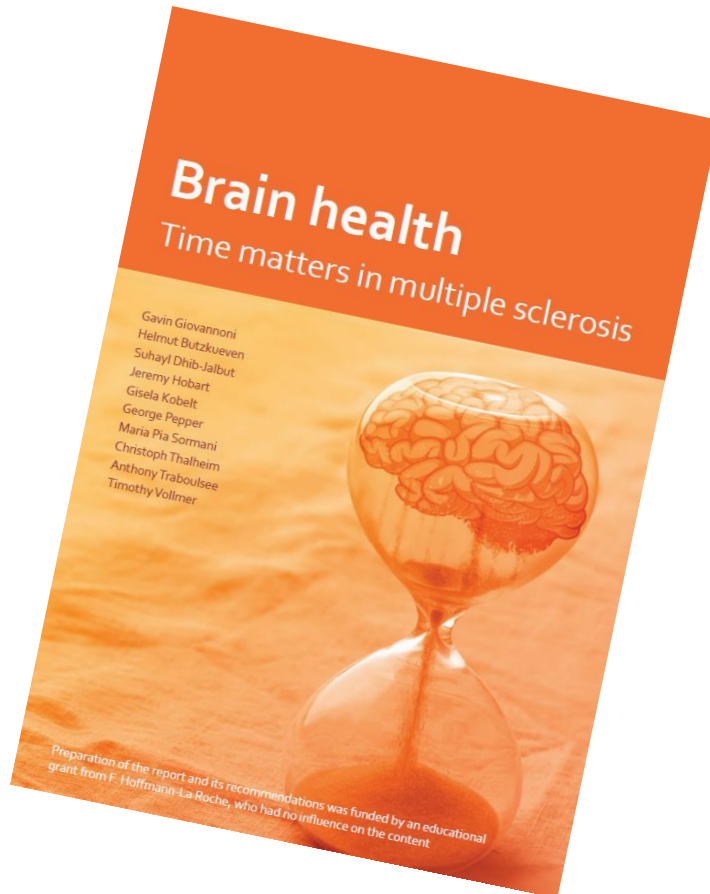
"Recognising the critical importance of early diagnosis and early treatment in minimising the impact of MS, increase understanding of MS within Primary Health and across the wider community to expedite diagnosis and referral to an expert in MS, as per the recommendations of the international consensus initiative, *Brain health: time matters in multiple sclerosis*"

DESTINATION: Access to early interventions and the most effective treatment therapy is well established

National advocacy: MS service improvements, Australia



- 2017: formation of first local MS Brain Health group



Australian MS Brain Health Community Aims and scope



- Promote the implementation of MS Brain Health recommendations
- Identify challenges and barriers to the implementation of these recommendations in Australia
- Deliver projects to target these barriers
- Actively identify and recruit MS Brain Health champions (advocates of the strategy to maximize lifelong 'brain health')

Advocacy for policy change: Europe-level advocacy by MS Brain Health leads

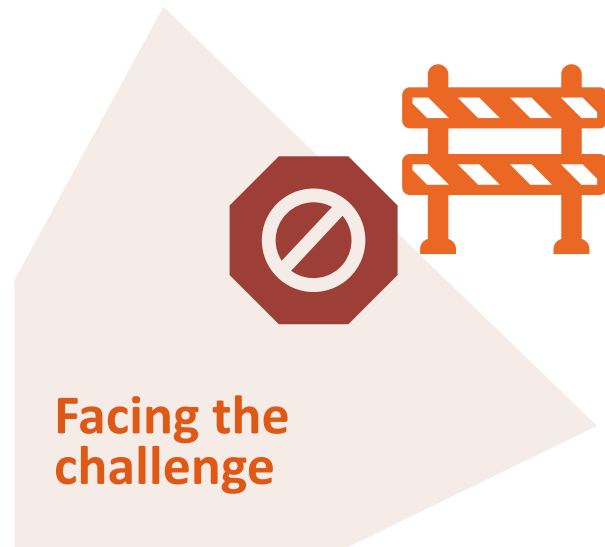


Promoted the importance of timely intervention in MS to policy makers in European Parliament

- Gavin Giovannoni made the case that time is critical to:
 - preserve brain reserve
 - slow the course of MS
 - improve quality of lives of people with MS
- Gisela Kobelt set out the economic case for early intervention
 - A cost-of-illness study across 16 countries involved almost 17,000 patients¹
 - Costs of illness increased, on average, fivefold between mild and severe MS¹



National policy: challenging access and MS drug funding, New Zealand



Facing the challenge

- Difficulty for more than 20 years in getting timely and appropriate access to new MS drugs
- Implications for patients; precludes timely treatment initiation
- Requirement to stop treating if MS deteriorates by two EDSS points



Influencing decisions

- Submission to New Zealand Government drug-buying agency PHARMAC for extended access to DMTs
- Favourable recommendation from PHARMAC



Impact

- From March 2021, people with MS and EDSS score ≤ 6 have access to DMTs
- Two-point progression limit has been removed

National advocacy and patient impact: reduced time to diagnosis and start of therapy, Norway



Norwegian Multiple Sclerosis Competence Centre followed guidance from ***Time Matters in MS*** and ***Six ways to lead a brain-healthy lifestyle***

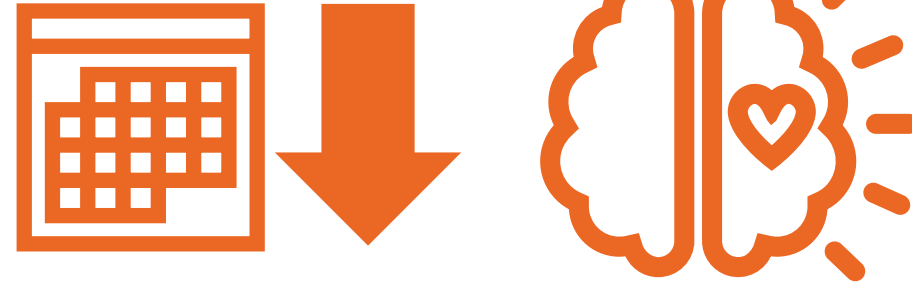
Impact

- Using ***Time Matters in MS*** has gradually reduced time to diagnosis in Norway

Education


- ***Six ways to lead a brain-healthy lifestyle*** is routinely given to people with newly diagnosed MS

Time to diagnosis









“The MS Brain Health report and guides have influenced policy, practice and behaviour in Norway.”

MS Neurologist

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Six ways to lead a brain-healthy lifestyle

Having a healthy brain that functions well is important for people with multiple sclerosis. Here are six positive steps you can take to keep your brain as healthy as possible, whatever your MS diagnosis.

 Keep as active as you can	 Keep your weight under control	 Keep your mind active
 Avoid smoking	 Watch how much you drink	 Continue taking other medicines your doctor has prescribed

1. Keep as active as you can
Higher levels of aerobic fitness are associated with faster information processing and preserved brain tissue volume.^{1,2} This suggests that being as active as possible may help to preserve brain health in people with MS.

2. Keep your weight under control
Obesity is associated with higher numbers of MS lesions (areas of intensive damage) than maintaining a healthy weight.²

3. Keep your mind active
Education, reading, hobbies and artistic or creative pastimes help to protect against cognitive problems in MS when pursued over a lifetime.³⁻⁷

Advocacy and policy impact: MS Society of Serbia



Identifying barriers

- 9000 people with MS in Serbia
- Limited access to therapy owing to financial constraints
- Poor understanding of need for new treatments



Using MS Brain Health resources

- *Brain health: time matters in MS* report translated into Serbian
- Supports argument for timely diagnosis and treatment initiation
- Gavin Giovannoni working with MS Society of Serbia medical board



Reaching the right audience

- *Brain health: time matters in MS* report submitted to government, including President, Prime Minister and Minister of Health and Finance
- Also shared with Director of Serbian Health Insurance Fund
- Ongoing communications with relevant parties



Gaining a voice

- MS Society of Serbia now has representation in the Serbian Health Insurance fund
- Collaboration established with MS Working Group of the Serbian Society for Neurology
- 30 local associations meeting with healthcare professionals and patients

Clinical and patient impact: access to MS treatments, Serbia



Advocacy to key stakeholders leads to direct, positive clinical impact and increased access to MS treatment options

- MS Society of Serbia worked with Gavin Giovannoni
- *Brain health: time matters in multiple sclerosis* recommendations supported MS Society of Serbia mission



Funding for existing and novel MS treatments

~2500 Patients with MS with access to treatment



Number of MS patients treated more than doubled

Patient impact and education: healthy living for people with MS, Spain



Inspiration

- In 2020, *Esclerosis Multiple España* launched their patient web site <http://emforma.esclerosismultiple.com/>
- Focused on physical activity and healthy living

Communication

- Several new items based on MS Brain Health included on www.esclerosismultiple.com

Networking

- MS Brain Health report distributed to over 100 professionals working in MS in Spain



>100

people received the MS Brain Health report in 2017, including professionals in MS care and rehabilitation working in MS associations and foundations

MS Brain Health leaflet prompted MS Society UK's quit smoking campaign



The *Six ways to lead a brain-healthy lifestyle* leaflet, led the **MS Society UK** to run a **quit smoking campaign**

- The campaign was part of the annual, national, public health *Stoptober* campaign

It secured more than 100 regional and local pieces of media coverage, as well as 13 items of national coverage

More than 4000 people viewed a news story about the link between smoking and MS on the MS Society UK website

