Annual Conference EMSP

Prevention in Multiple Sclerosis and Related Disorders:

Uncovering Risk and Protective Factors

PRAGUE | 16-17 MAY 2025

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MULTIPLE SCLEROSIS
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Czech multiple sclerosis society
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16-17 MAY
2025

Results of the Impact of Multiple Sclerosis Symptoms Survey

Tommaso Manacorda &
Patricia Moghames

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Rationale

EMSP MS Barometer in 2020 shows that access to DMTs, **symptomatic treatment and care** was different in countries across Europe

As little information was available on **symptom prevalence, burden and management** quality consultation with EMSP member organisations → Led to IMSS coming to life!

Filling the gaps in knowledge on symptoms from the perspective of patients

Exploring gaps and shortcomings in services needed to improve symptom burden to enable **policy and advocacy actions**

Nationale Belgische Multiple Sclerose Liga vzw
Ligue Nationale Belge de la Sclérose en Plaques asbl

Savez društava multiple skleroze Hrvatske

Czech multiple sclerosis society
MS UNIE ROSKA
Unie ROSKA – česká MS společnost, z. s.

SCLEROSE FORENINGEN

FRANCE SCLÉROSE EN PLAQUES

dmsg
Deutsche Multiple Sklerose Gesellschaft Bundesverband e.V.

Ελληνική Εταιρία για τη Σκλήρυνση Κατά Πλάκας

MS HELLAS
hellenic federation of persons with multiple sclerosis

MSMBA
Magyar Sclerosis Multiplexes Betegekért Alapítvány

Magyar Neuroimmunológiai Társaság
Hungarian Neuroimmunology Society
MANIT

MS FÉLAG ÍSLANDS

MS Ireland
THE MULTIPLE SCLEROSIS SOCIETY OF IRELAND

SCLEROSI MULTIPLA
associazione italiana
un mondo libero dalla SM

LIETUVOS IŠSĖTINĖS SKLEROZĖS SĄJUNGA
LITHUANIAN MULTIPLE SCLEROSIS UNION

MSL
LLSP & FSPL
Multiple Sclérose Lëtzebuerg

VERENIGING MS NEDERLAND
de stem van mensen met MS

MS-forbundet
MULTIPPEL SKLEROSE FORBUNDET

Polskie Towarzystwo Stwardnienia Rozsianego

SPEM
SOCIEDADE PORTUGUESA DE ESCLEROSE MÚLTIPLA

apan
asociația pacienților cu afecțiuni neurodegenerative

združenje multiple skleroze slovenije

MS Platforma Srbije

ms international federation

AEDEM-COCEMFE
Asociación Española de Esclerosis Múltiple

M Esclerosis Múltiple España
www.esclerosismultiple.com

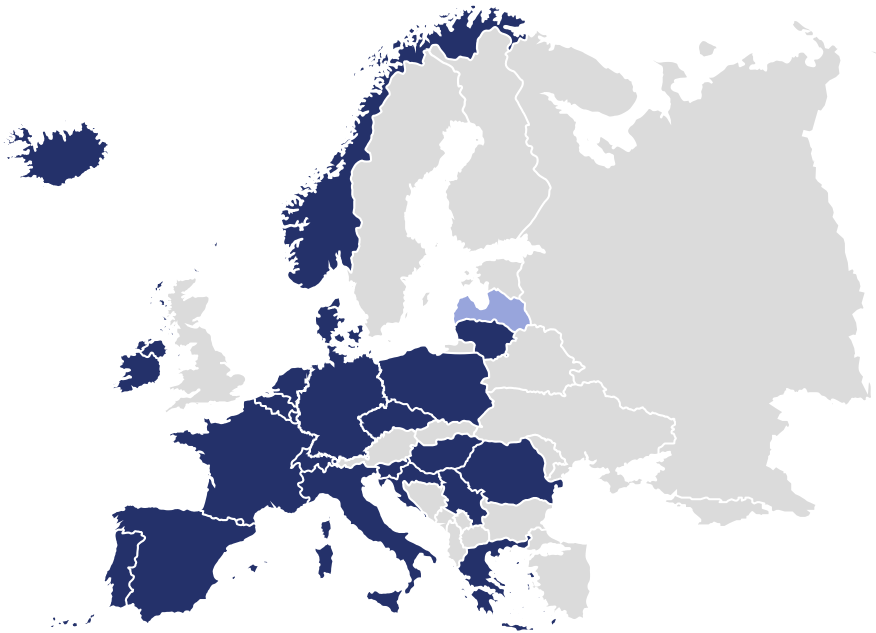
UHASSELT
KNOWLEDGE IN ACTION

KU LEUVEN

Working Group

- Composition of WG: people with MS, neurologists, occupational therapist, rehabilitation specialist, academic, researchers, data managers
- Survey developed and translated with **participating member organisations**

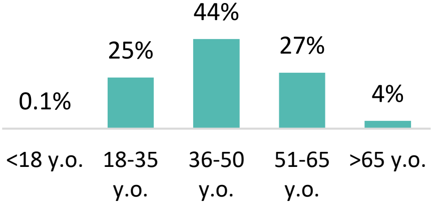
Society or Institution	Member
Belgian MS Society	**Christiane Tihon**
Dutch MS Association	**David Engelhard**
MS Society of Luxembourg	**Isabelle Cames**
MS Center Melsbroek; KU Leuven	**Daphne Kos**
Hasselt University	**Peter Feys**
Portuguese MS Society	**Magda Fonseca**
Croatian MS Society	**Nataša Hlaban**
Swiss MS Society	**Nina Steinemann**
MS International Federation	**Rachel King**
Growth for Knowledge (GfK)	**Sara Anda – Patricia Primo**
Italian MS Society	**Tommaso Manacorda**

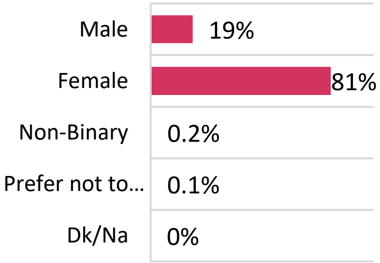


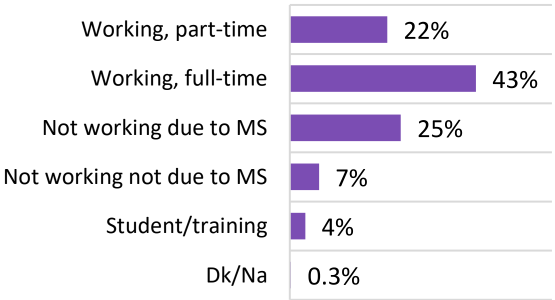
IMSS

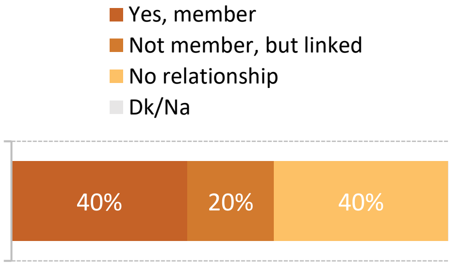
17,151 PwMS

Belgium · Croatia · Czech Republic Denmark · France
· Germany · Greece Hungary · Iceland · Ireland ·
Italy · Lithuania · Luxembourg · Netherlands ·
Norway · Poland · Portugal · Romania · Serbia ·
Slovenia · Spain · Switzerland

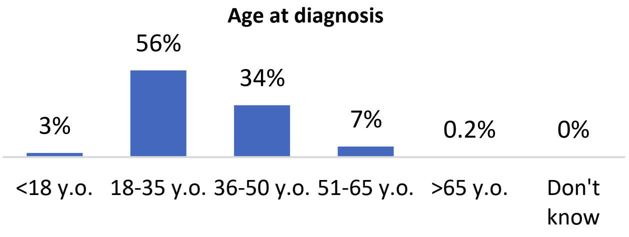




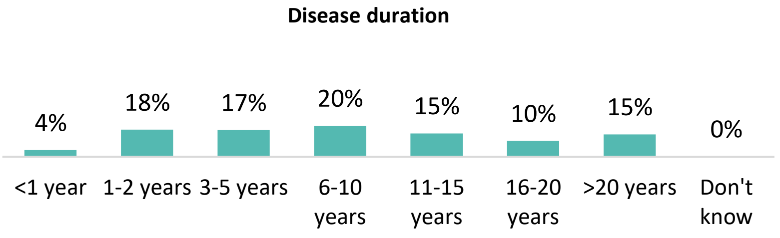



Membership/link to MS Society

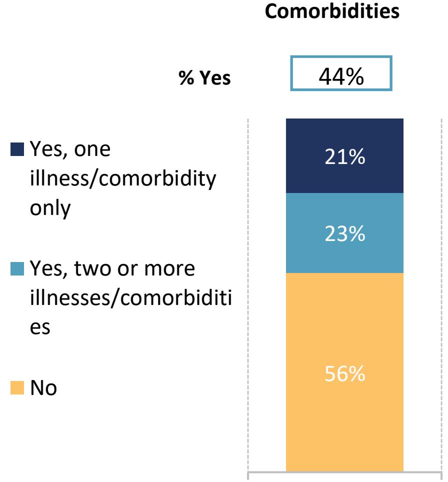
Clinical Situation

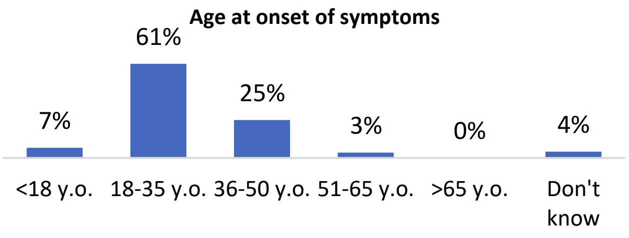


Mean: 34,1 years
Range: 0 to 75 years

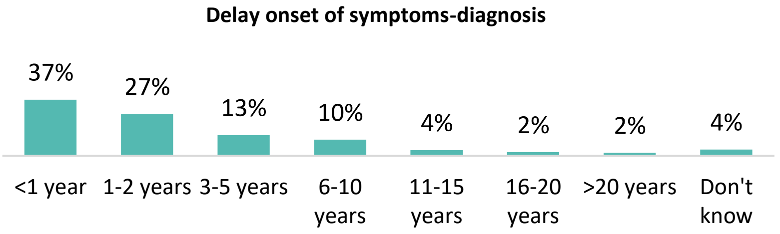


Mean: 10,4 years
Range: 0 to 69 years

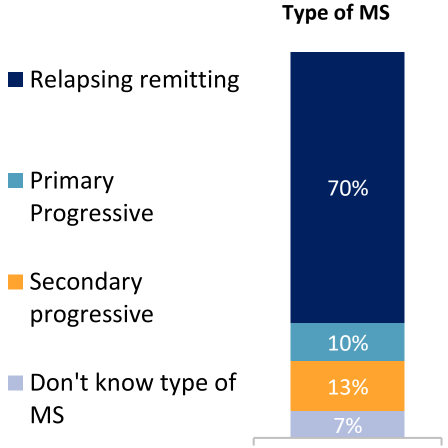




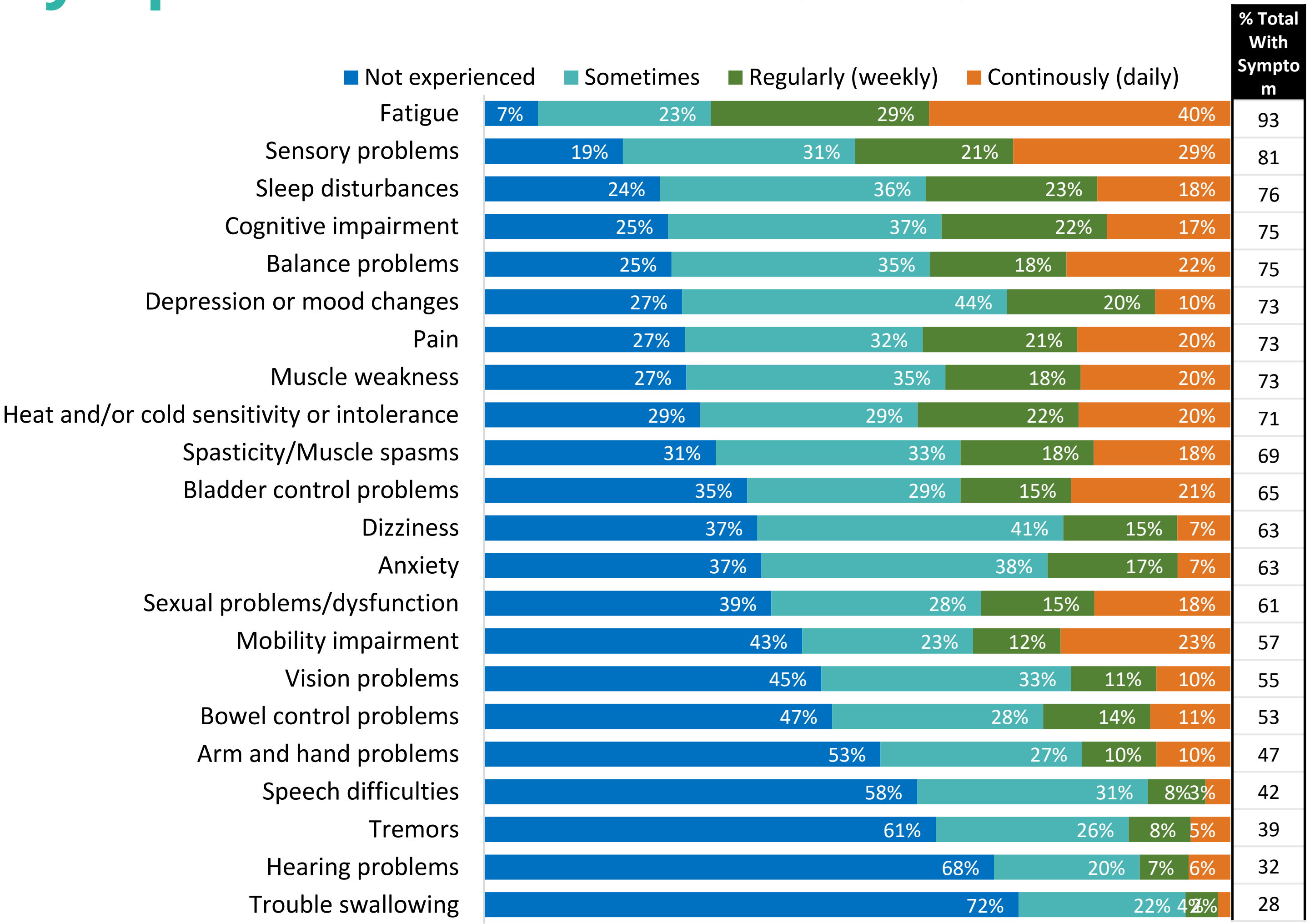
Mean: 30,7 years
Range: 0 to 75 years



Mean: 3,2 years
Range: 0 to 45 years



Symptoms – Prevalence (last 3 months)



DISEASE DURATION

	0-5 YEARS	6-15 YEARS	>15 YEARS
n=	*6210*	*6236*	*4653*
Average number of symptoms	**13,2**	**13,6**	**14,5**

People with at least 1 symptom:

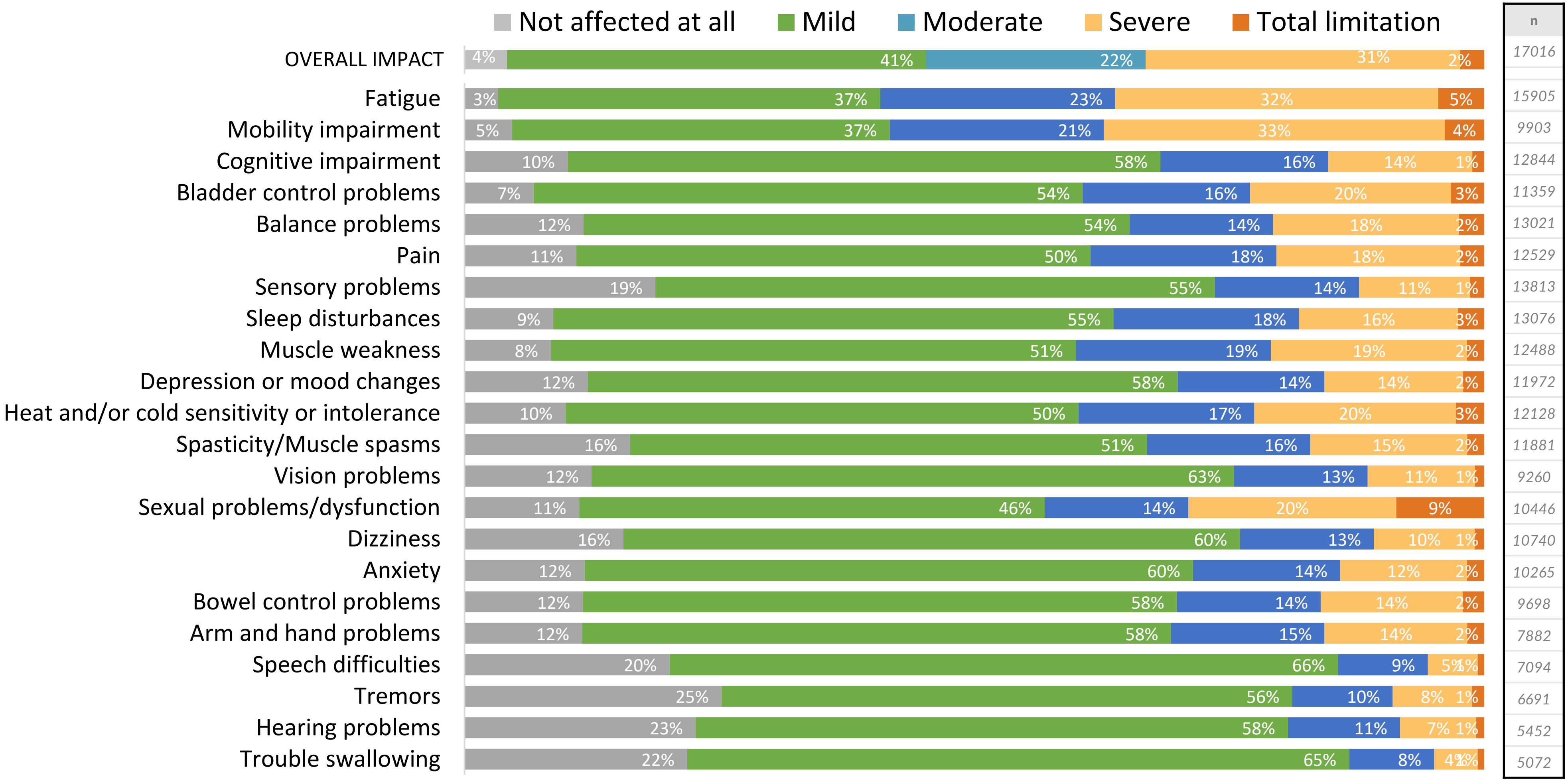
99%

People without any symptom:

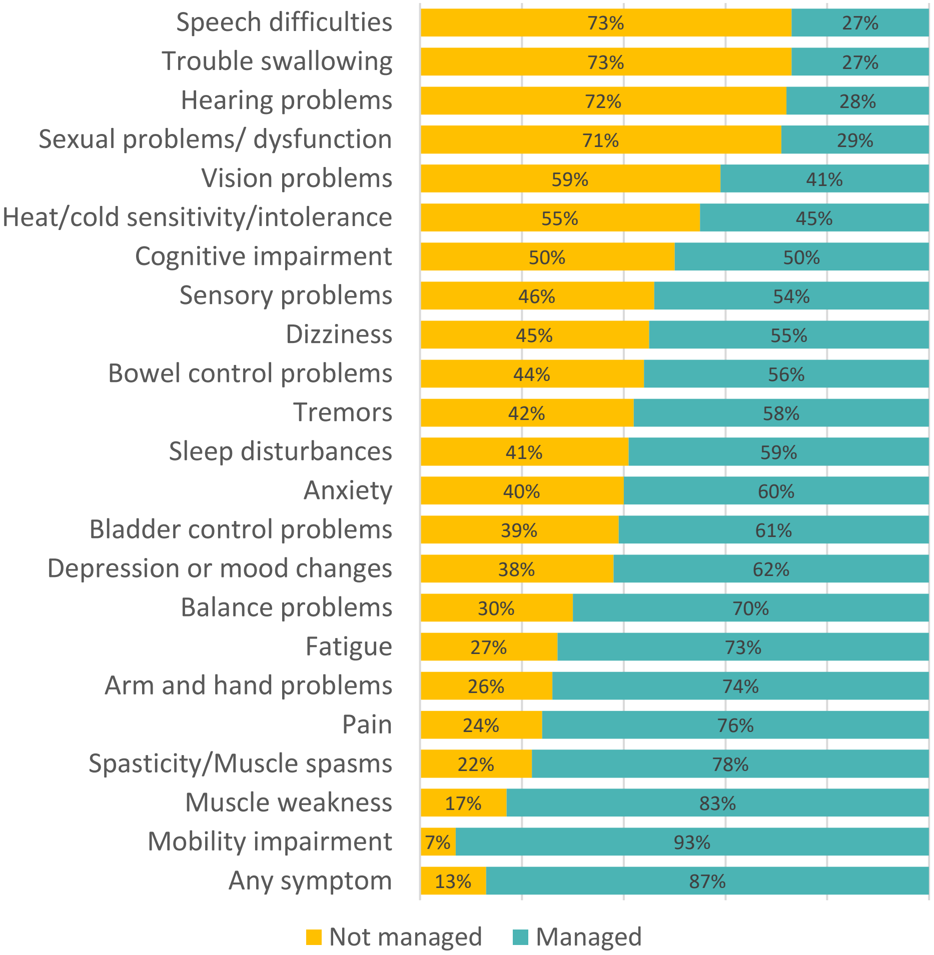
1%

Average 13,7 symptoms

Symptoms - Severity



Management of symptoms



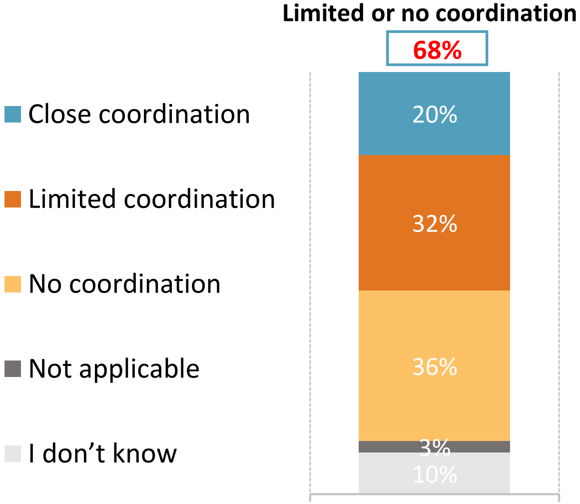
Avg 4,2 healthcare professionals involved

- Neurologist 99%
- GP 78%
- Nurse 38%
- Psychologist/psychiatrist 26%
- …

Avg 5,6 care approaches

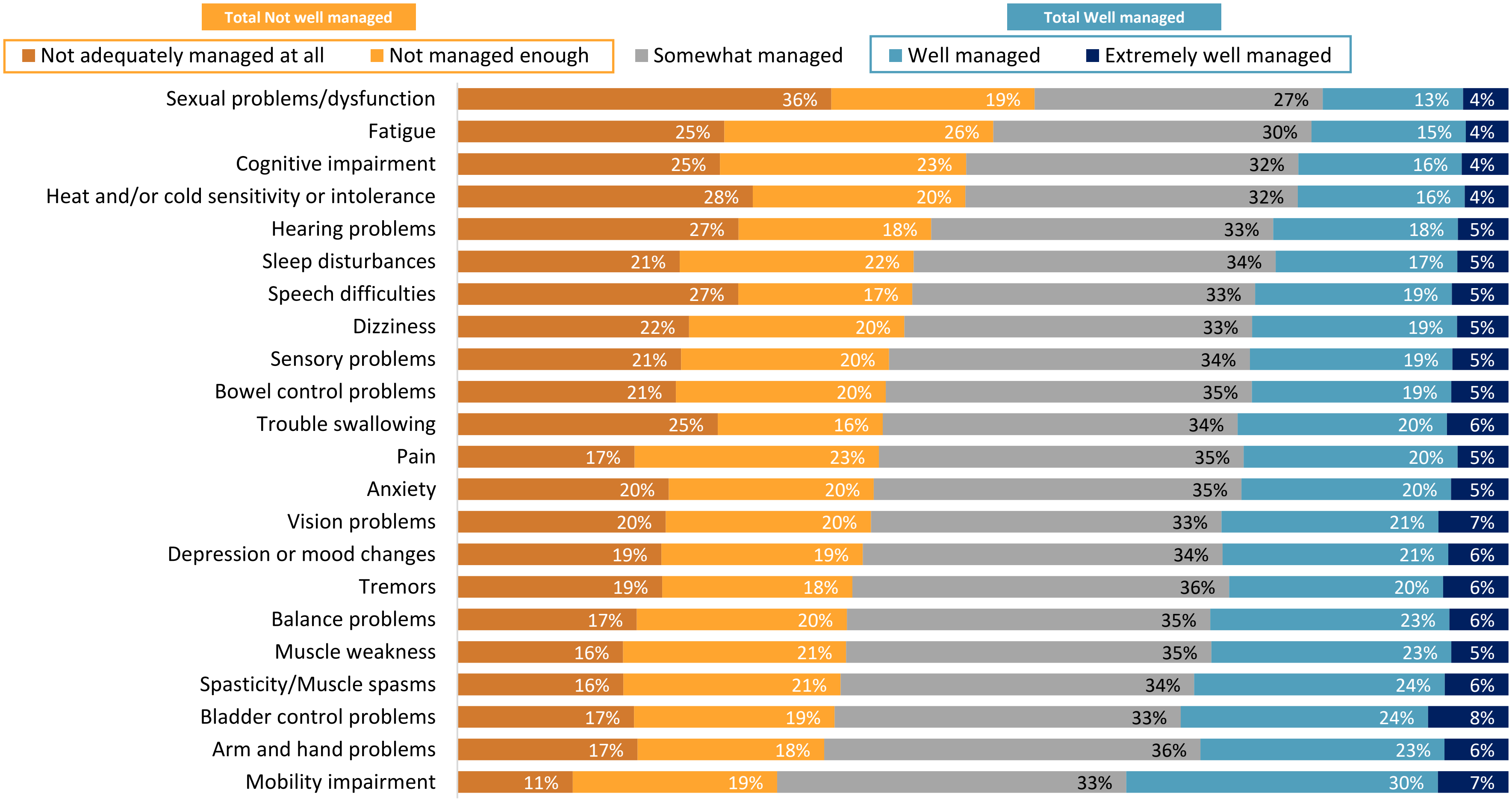
- Medication 71%
- Lifestyle changes 70%
- Therapy /treatments 56%
- …

Coordination between professionals

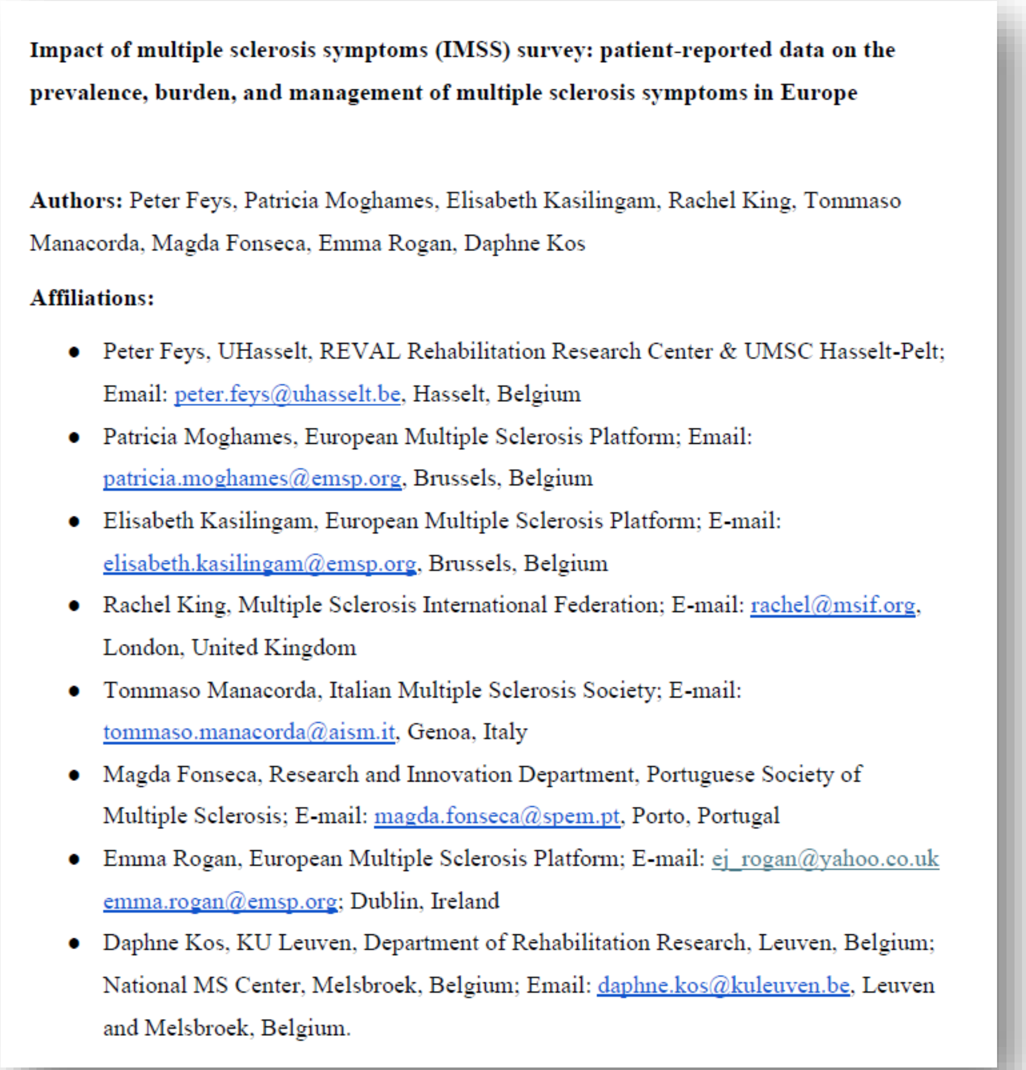


13,7
Symptoms

Satisfaction with management of symptoms



Scientific publication drafted and submitted to Multiple Sclerosis Journal (MSJ)



Impact of multiple sclerosis symptoms (IMSS) survey: patient-reported data on the prevalence, burden, and management of multiple sclerosis symptoms in Europe

Authors: Peter Feys, Patricia Moghames, Elisabeth Kasilingam, Rachel King, Tommaso Manacorda, Magda Fonseca, Emma Rogan, Daphne Kos

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- Daphne Kos, KU Leuven, Department of Rehabilitation Research, Leuven, Belgium; National MS Center, Melsbroek, Belgium; Email: daphne.kos@kuleuven.be, Leuven and Melsbroek, Belgium.

Key results

People with MS live with an overwhelming number of symptoms, many of them are

- Invisible
- Underreported
- Undertreated

A large number of symptoms is already there at diagnosis

Treatments exists, but they are often provided in a non coordinated way

Is the data telling us anything we did not already know?

Join at

slido.com

#2556 133

Are the IMSS results important? Why?

How can these results benefit people with MS?

From stories to evidence: Why this matters

We’ve all heard the personal stories — now we have **evidence**

Evidence shows how widespread and systemic these challenges are — not isolated experiences

Magnitude of problems gives us **priorities**, that enables the shift between awareness and action

IMSS gives us a solid foundation to move towards **evidence-based advocacy**

Data helps us rethink MS symptoms & treatments

Symptoms aren’t secondary: it is how MS leads to function loss and disability

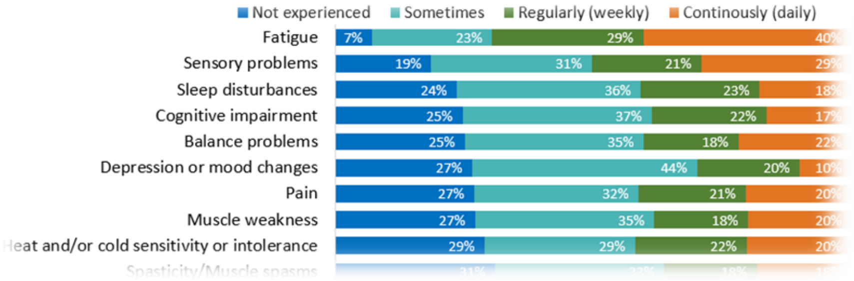
- Treatments protect quality of life so symptom management must be started as soon as possible : that is **secondary prevention!**

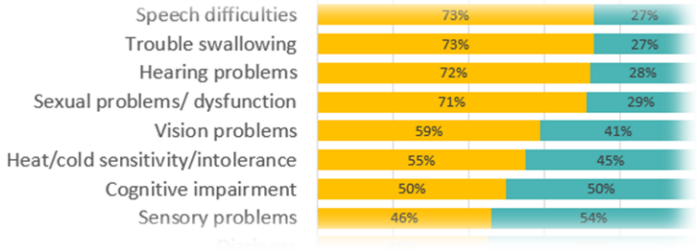
Treatments must be **available when they are needed**: within people’s time, location, financial means, and context

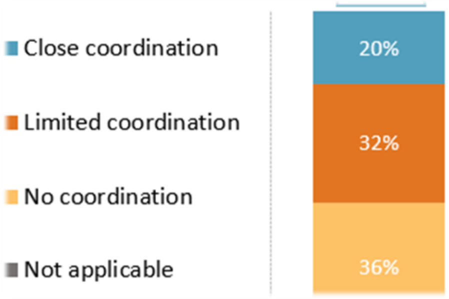
- **13 symptoms** mean that treatments are likely provided by several **professionals**, working in **different organizations**

What needs to be done?

- Raise awareness about symptoms and the risk of under-treatment
- Improve availability of rehabilitation
- Improve access to symptomatic drugs
- Improve access to interdisciplinary care to manage symptoms
- Design a system that supports the person — not one where the person has to manage the system







Who is this data for?

This isn’t just research - this is your tool.

The data is meant to be used by MS societies, healthcare advocates, and policymakers.

The ball is in **our court** — EMSP and its members.
→ If not us, then who? If not now, then when?

How Can MS Societies Use the IMSS Data?

- Support advocacy at national level by using local findings to engage policymakers and health authorities.

- Shape policy narratives backed by data - “We know what’s missing, and here’s the evidence.”

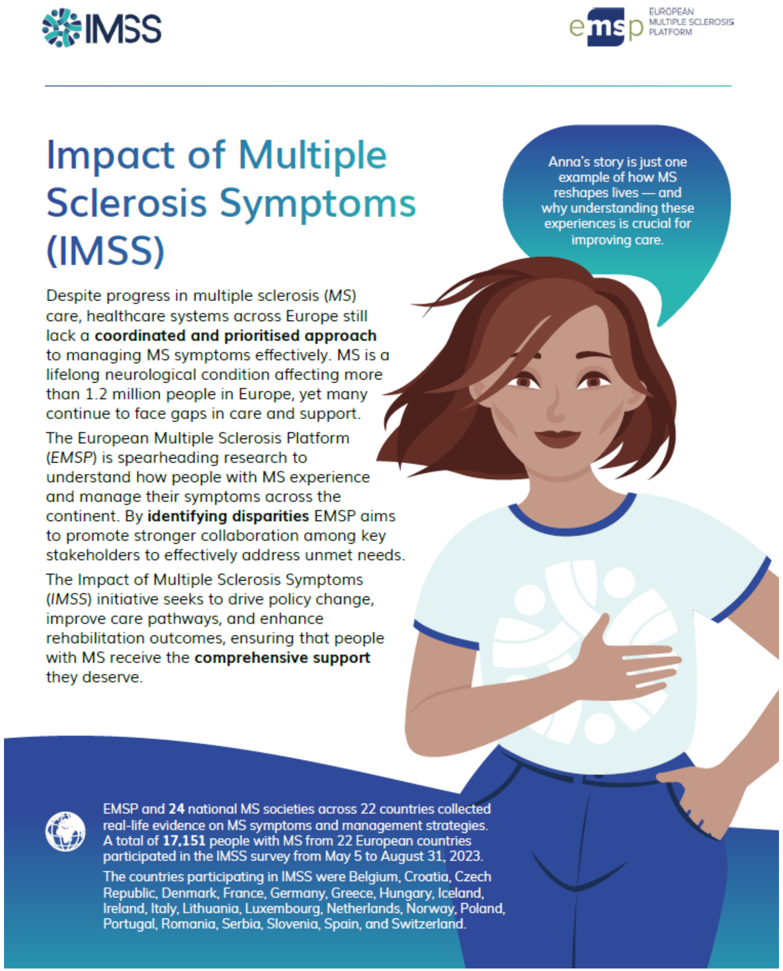
- Push for changes in the actual delivery of services, not just what’s written in policies.

- Highlight policy options: e.g. funding for rehabilitation, MS nurse roles, integrated care pathways, etc.

Next steps

Advocacy Toolkit

- Country sheets (each country)
- European sheet
- Results PowerPoints (each country)
- Social media cards (templates)
- Press release (template)
- Blogpost (template)
- Poster (template)
- Webpage (template)



IMSS

EUROPEAN MULTIPLE SCLEROSIS PLATFORM

Impact of Multiple Sclerosis Symptoms (IMSS)

Despite progress in multiple sclerosis (MS) care, healthcare systems across Europe still lack a **coordinated and prioritised approach** to managing MS symptoms effectively. MS is a lifelong neurological condition affecting more than 1.2 million people in Europe, yet many continue to face gaps in care and support.

The European Multiple Sclerosis Platform (EMSP) is spearheading research to understand how people with MS experience and manage their symptoms across the continent. By **identifying disparities** EMSP aims to promote stronger collaboration among key stakeholders to effectively address unmet needs.

The Impact of Multiple Sclerosis Symptoms (IMSS) initiative seeks to drive policy change, improve care pathways, and enhance rehabilitation outcomes, ensuring that people with MS receive the **comprehensive support** they deserve.

Anna's story is just one example of how MS reshapes lives — and why understanding these experiences is crucial for improving care.

EMSP and **24** national MS societies across 22 countries collected real-life evidence on MS symptoms and management strategies. A total of **17,151** people with MS from 22 European countries participated in the IMSS survey from May 5 to August 31, 2023.

The countries participating in IMSS were Belgium, Croatia, Czech Republic, Denmark, France, Germany, Greece, Hungary, Iceland, Ireland, Italy, Lithuania, Luxembourg, Netherlands, Norway, Poland, Portugal, Romania, Serbia, Slovenia, Spain, and Switzerland.

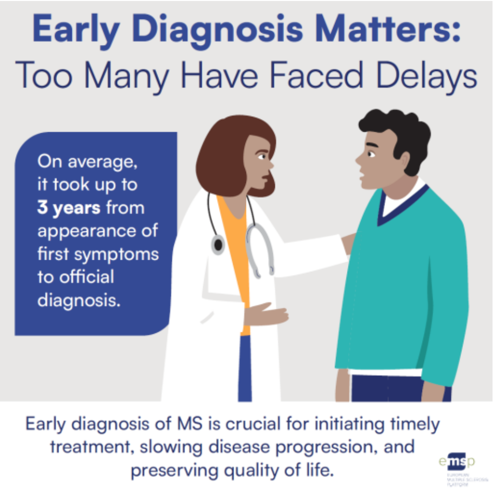
IMSS fact sheets for countries and European findings are now published!

https://emsp.org/projects/impact-of-multiple-sclerosis-symptoms-imss/

Advocacy Toolkit that can be tailored for each country (findings and language) are now available for member organisations.


Symptoms in MS **start early!**

Up to **13 symptoms** are reported by people with MS within the **first 5 years.**


Early Diagnosis Matters: Too Many Have Faced Delays

On average, it took up to **3 years** from appearance of first symptoms to official diagnosis.

Early diagnosis of MS is crucial for initiating timely treatment, slowing disease progression, and preserving quality of life.


Invisible Symptoms in MS: The Struggle You Can't See

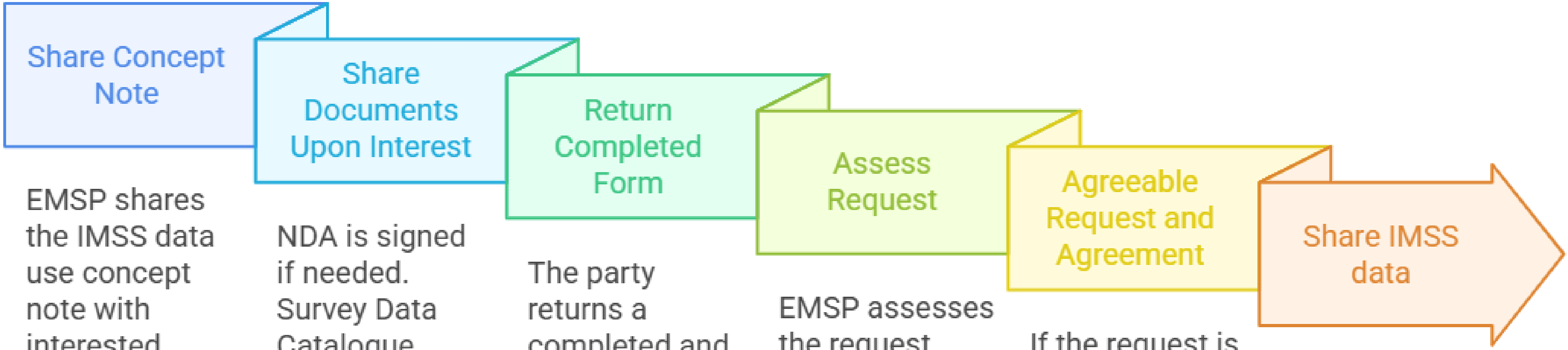
No one should face their symptoms alone.


Progressive MS

1 in 4 with Primary Progressive MS and 1 in 3 with Secondary Progressive MS face severe quality of life challenges.

People with **Progressive MS** need specialised research, treatments, and support.

IMSS Data Sharing Process



EMSP shares the IMSS data use concept note with interested parties.

NDA is signed if needed. Survey Data Catalogue, Request Form, and Fees Scheme are shared.

The party returns a completed and signed Request Form.

EMSP assesses the request internally within a month.

If the request is agreeable, proceed to sign the Terms and Conditions.

EMSP shares the requested IMSS data with interested party, with connection annually on progress.

THANK YOU!

For more information on the IMSS survey, please contact patricia.moghames@emsp.org

almirall

Biogen

Bristol Myers Squibb

Coloplast

MERCK

NOVARTIS

Roche

sanofi