



# Meeting of the International Medical and Scientific Board of the MS International Federation

Monday 21 September  
Virtual teleconference

Chair: Professor Brenda Banwell

# Welcome

Professor Brenda Banwell



# IMSB Executive Committee

**CHAIR: Professor Brenda Banwell**, Children's Hospital of Philadelphia, Philadelphia, US

**DEPUTY CHAIR: Professor Jorge Correale**, Raul Carrea Institute for Neurological Research (FLENI), Buenos Aires, Argentina

**Professor Kazuo Fujihara**, Fukushima Medical University, Fukushima, Japan – returning member, PACTRIMS President

**Professor Jeffrey Cohen**, Cleveland Clinic, Ohio, US – returning member, ACTRIMS President

**Professor Bernhard Hemmer**, Technical University of Munich, Germany – ECTRIMS President

**Professor Fernando Hamuy Diaz de Bedoya**, Universidad Unida, Asunción, Paraguay - LACTRIMS President

**Professor Bassam Yamout**, American University of Beirut Medical Center, Lebanon – MENACTRIMS President

**Professor Daphne Kos**, KU Leuven, Leuven, Belgium – RIMS President

**Professor Olga Ciccarelli**, UCL Institute of Neurology, London, UK

**Dr Laura Musambayi**, National Spinal Injury Referral Hospital, Nairobi, Kenya

**Professor Frauke Zipp**, University Medical Centre Mainz, Mainz, Germany

**Professor Mohammed Sahraian**, Shiraz University of Medical Sciences, Iran

## Agenda

07:00 EDT	<b>Chair's welcome</b>	Brenda Banwell
07:05 EDT	<b>Atlas of MS – 3<sup>rd</sup> Edition</b>	Clare Walton
07:20 EDT	<b>MSIF's international work on access</b>	Bassem Yamout
07:35 EDT	<b>MSIF Research awards</b>	Michael Thor
07:45 EDT	<b>IMSB Chair's Annual Report</b>	Brenda Banwell
08:00 EDT	<b>Close</b>	

# Atlas of MS – 3<sup>rd</sup> Edition

Epidemiology of MS findings

Clare Walton



# Background to the Atlas of MS 3<sup>rd</sup> edition

A hand holding a blue marker, writing the words "DECISION MAKING" in blue capital letters on a whiteboard. The text is underlined.

First published with the WHO in 2008, updated in 2013

Widely cited in research and used to underpin advocacy work

A hand holding a blue marker, writing the word "IMPROVE" in blue capital letters on a whiteboard. The text is underlined.

## Goals of the 3<sup>rd</sup> edition:

Improve coverage by reaching more countries

Improve quality of data and accuracy of global estimates

Create more user friendly resources and reporting tools

Gather new evidence on availability and access to healthcare

# Atlas 3<sup>rd</sup> edition methodology

- **Recruit experts to act as country coordinators**
- **Neurologists, researchers, epidemiologists, and MS organisations**
- **Encouraged collaboration**

## Recruitment



- **Country coordinators provided data via a survey in English/French/Spanish**
- **115 countries of 138 enrolled (83%) returned the epidemiology survey**

## Data collection



- **Discrepancies resolved with country coordinators**
- **Confidence coding of data sources**
- **Literature search & review of 2013 data to fill gaps**

## Data cleaning and validation

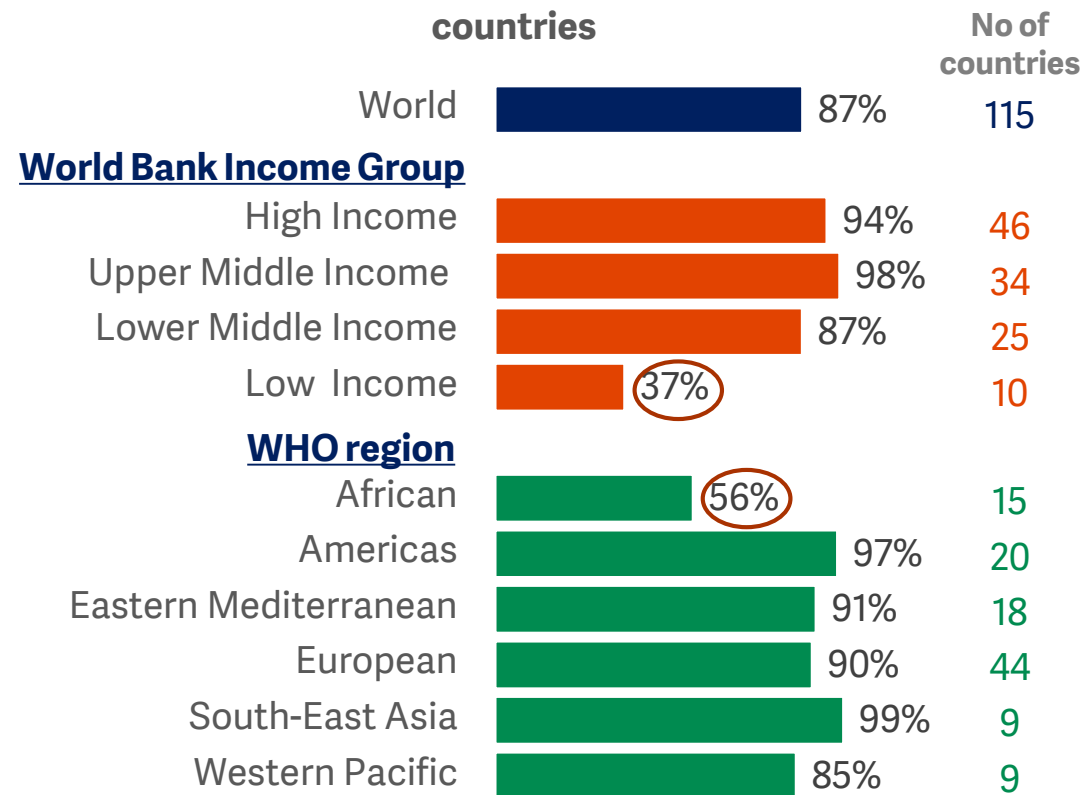




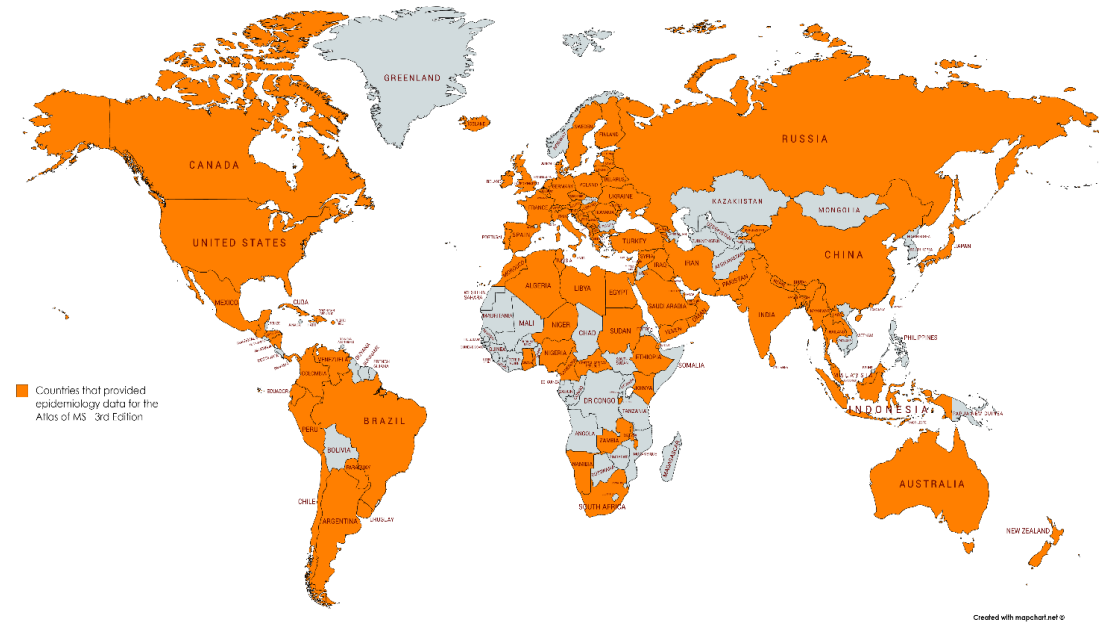
# Epidemiology survey responses

- Responding countries represent 87% of the world's population
- Weakest coverage in the African region and low income countries

## Proportion of population covered by responding countries

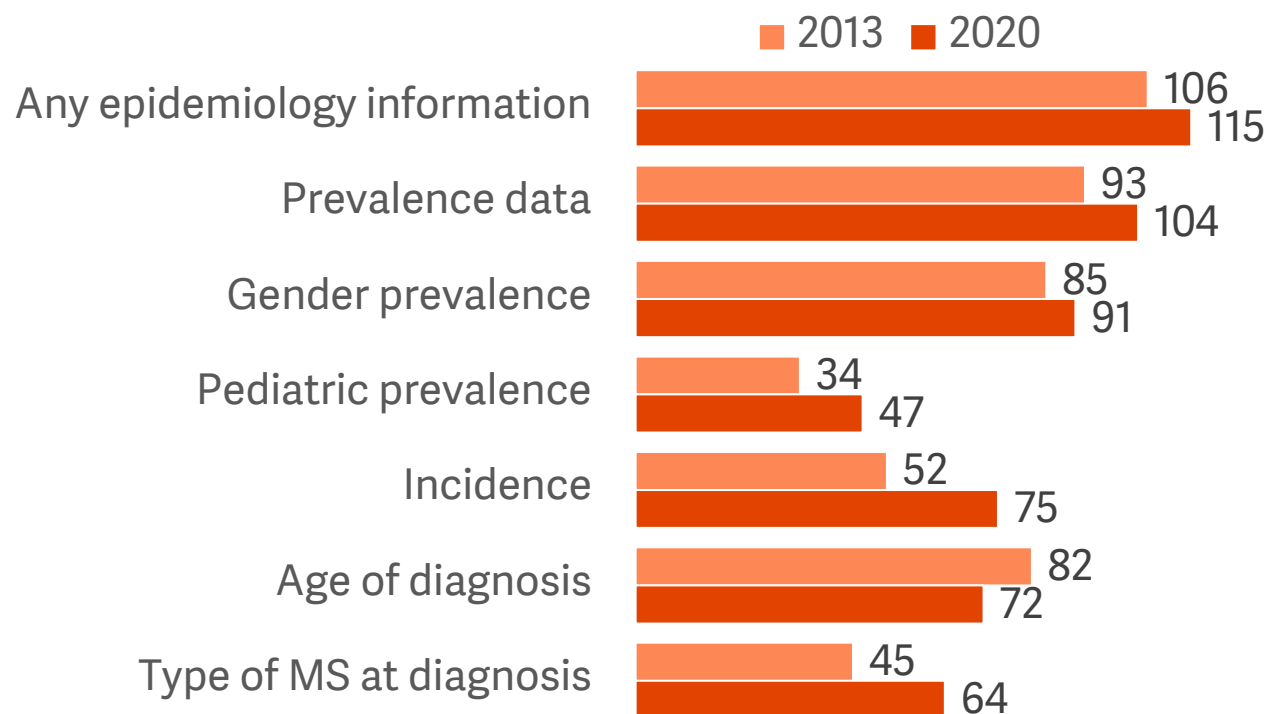


## Countries who responded - epidemiology survey (shown in orange)



# Increase in data reporting in most areas since 2013

Number of countries providing each type of data



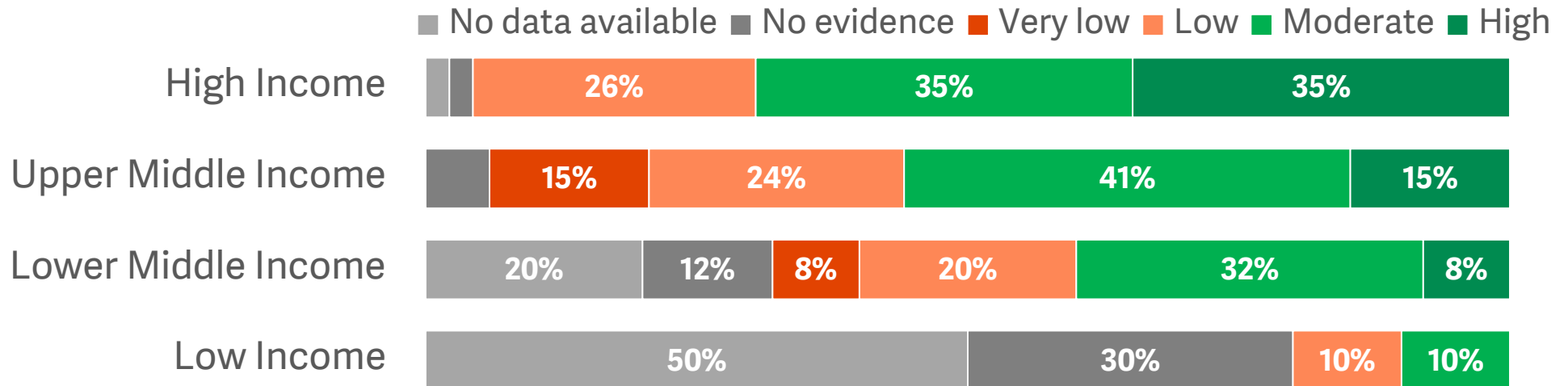
- Prevalence data from 104 countries covering 83% of worlds' population
- Greatest increases in the number of countries able to report incidence and type of MS at diagnosis
- Reduction in number of countries reporting mean age at diagnosis, likely due to 14 countries reporting for the first time

# Prevalence data quality is improved

84% of countries cite a source for prevalence data ( vs 71% in 2013 )

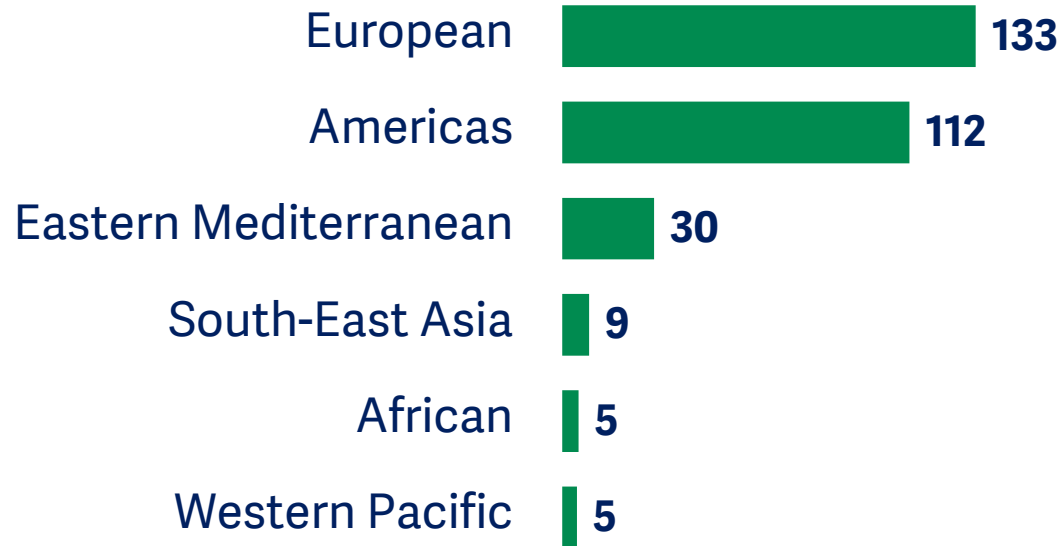
- 57% cite a peer-reviewed academic study (vs 51% in 2013)
- 27% cite electronic medical records or registries (vs 20% in 2013)

## Prevalence evidence confidence coding - World Bank Income



# 2020 MS Prevalence by WHO region

## Number of people with MS (per 100,000)



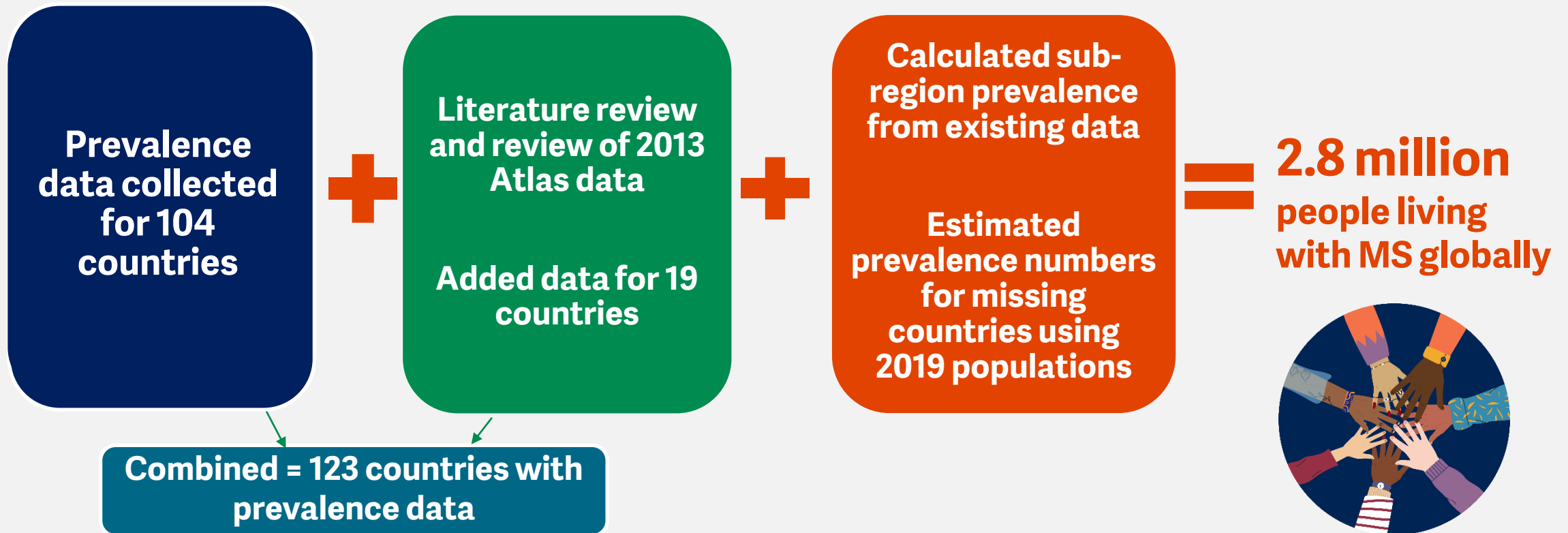
## High geographic variability in prevalence

- Prevalence rates ranged from less than 1 up to 337 per 100,000 people
- Levels are highest in the European and Americas WHO regions

**Most countries that are missing prevalence data are from the lowest prevalence regions**

# Estimating the number of people with MS worldwide

Our new calculation applies sub-region averages to fill the gaps



# Changes in regional prevalence since the 2013 Atlas

**Based on 81 countries who provided prevalence data at both time points, we see increasing prevalence in all 6 WHO regions**

	Number of countries included	2013 prevalence per 100,000 (pooled)	2020 prevalence per 100,000 (pooled)	Absolute change since 2013 (%)
<b>Global</b>	81	29.3	44.0	14.7 (50%)
African	6	5.5	8.8	3.2 (59%)
Americas	15	62.9	117.5	54.6 (87%)
Eastern Mediterranean	14	23.9	33.0	9.1 (38%)
European	35	108.3	142.8	34.6 (32%)
South-East Asia	4	5.4	8.6	3.2 (58%)
Western Pacific	7	3.6	4.8	1.2 (32%)

# Demographic results

- Although the number of people with MS has increased, the global demographic and regional profiles remain similar to 2013
- Increasing recognition of pediatric MS - 30,000 cases compared with 7,000 reported in 2013 – likely due to an increase in reporting countries from 34 in 2013 to 47 in 2020

Average age of diagnosis:

**32** years



At least twice as many females as males have MS

**2x**



MS does not only affect adults  
there are at least

**30,000\***

people living with MS under 18 years



- Based on 47 reporting countries
- NB pediatric age definition varies across countries



Explore all the data at:  
[www.atlasofms.org](http://www.atlasofms.org)

**Clinical management survey data  
will be launched in early 2021**

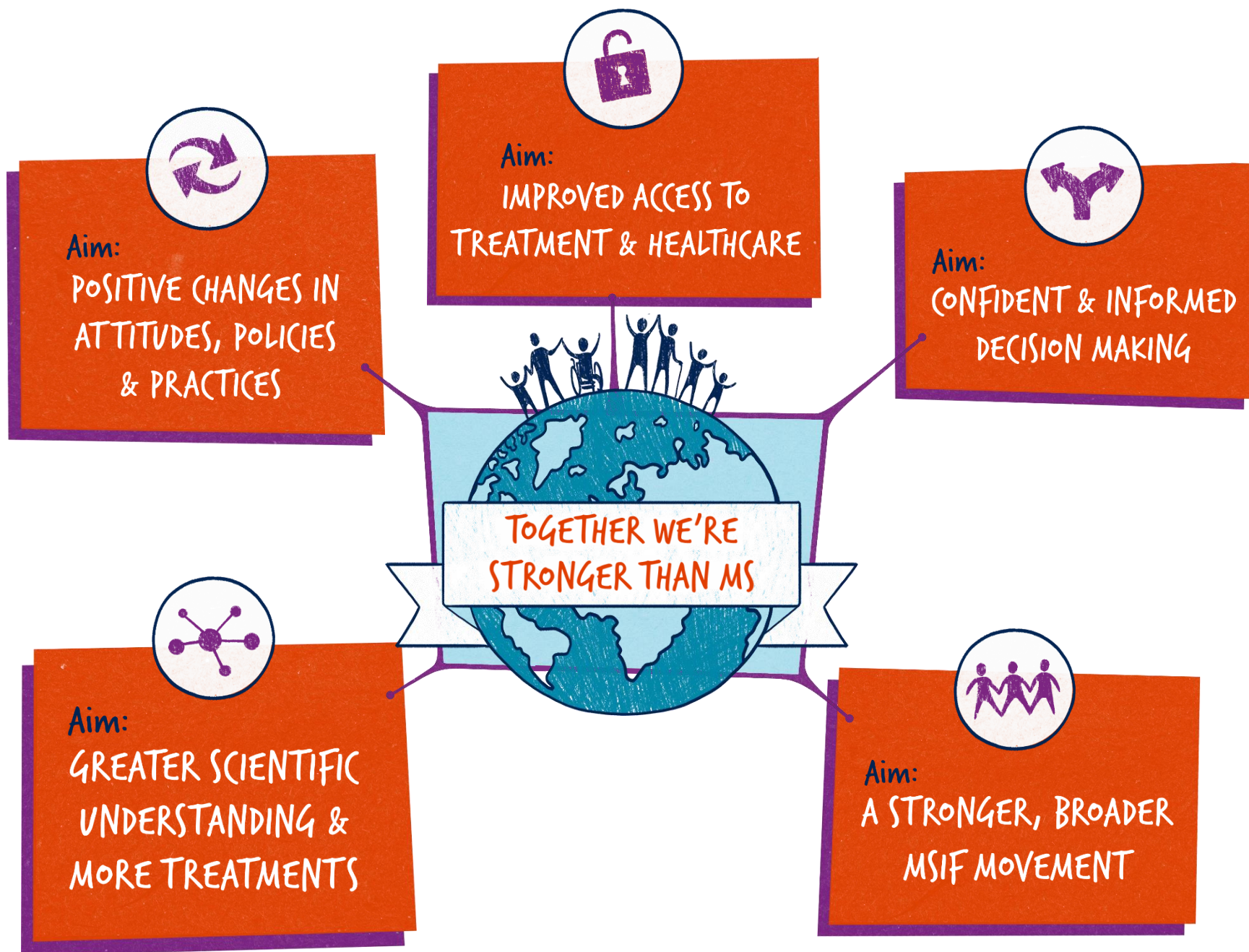
The Atlas of MS is a collaboration between the MS International Federation, its members and the wider MS movement



# Access to Treatment: Off-label Guidance

Prof Bassem Yamout

Co-Chair of MSIF Off-Label Task force (MOLT)





The screenshot shows the WHO website's 'Essential medicines selection' page. The header includes the WHO logo and navigation links: Home, Health Topics, Countries, Newsroom, and Emergencies. The main content area is titled 'Essential medicines selection' and features a sidebar with links to 'Essential medicines selection', 'Essential Medicines List and Formulary', 'Pharmacoeconomics', 'Selection of medicines in emergencies', 'WHO Expert Committees', 'Links', and 'About'. The main text area is titled 'Multiple sclerosis disease modifying therapies - EML and EMLc' and mentions the '22nd Expert Committee on the Selection and Use of Essential Medicines'. It includes sections for 'Drug information' (Section 8.1 Immunomodulating medicines), 'Formulation' (Glatiramer acetate, Fingolimod, Ocrelizumab), and 'Application prepared by' (Multiple Sclerosis International Federation).



The cover of the Multiple Sclerosis Journal (MSJ) features the title 'World Health Organization Essential Medicines List: Multiple sclerosis disease-modifying therapies application' under the heading 'Personal Viewpoint'. The authors listed are Jennifer McDonnell, Kathleen Costello, Joanna Laurson-Doube, Nick Rijke, Gavin Giovannoni, Brenda Banwell, and Peer Baneke.



The cover of The Lancet Neurology features the article 'Health-care disparities for people with multiple sclerosis' under the heading 'CORRESPONDENCE'. The authors listed are Joanna Laurson-Doube, Nick Rijke, Kathleen Costello, Jennifer McDonnell, Gavin Giovannoni, Brenda Banwell, and et al. The article was published in March 2020.



The cover of The Lancet Neurology features the article 'Essential medicines for patients with multiple sclerosis' under the heading 'EDITORIAL'. The article was published in December 2019.

# Global access to treatment

July 2019  
Access meeting  
with IWGA and  
global experts  
identify actions



Time (not to scale)





# Off-label project

## Context:

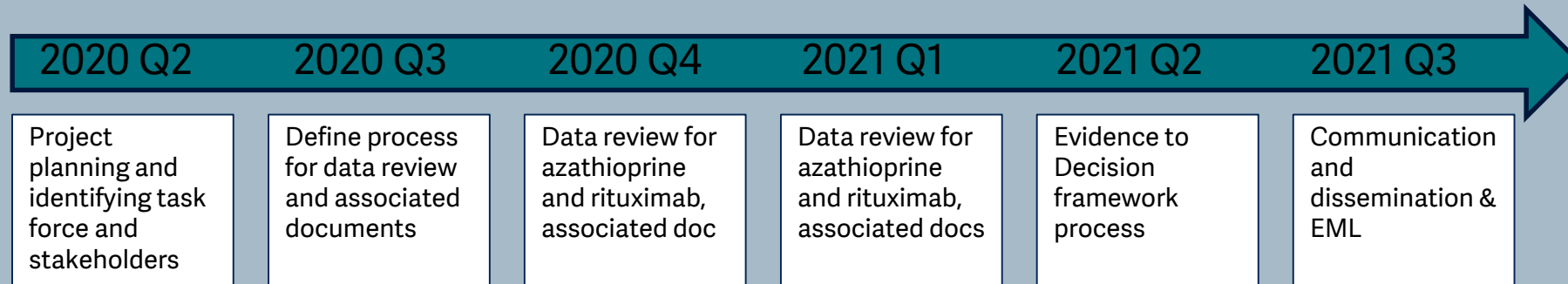
- Review required for WHO EML application
- Off-label DMTs are already widely used, guidance needed
- Where **availability and/or affordability** is stopping people to access a range of DMTs
- Recommendations can be **for** or **against**, consideration on evidence available and the panel discussion and judgements



## Aims:

1. Create a robust and transparent process to review off-label DMTs
2. Review evidence for azathioprine and rituximab to provide guidance on their use

# Off-label project plan and task force (MOLT)



## Co-Chairs:

- Bassem Yamout (MENACTRIMS, Lebanon)
- Bernhard Hemmer (ECTRIMS, Germany)

## Collaborators:

- Cochrane MS and Rare Diseases of the CNS
- McMaster GRADE Centre, WHO Collaborating Centre for Infectious Diseases, Research Methods and Recommendations

## Tier 1 stakeholders:

- IMSB Executive Committee
- International Working Group on Access (IWGA)
- Regional TRIMS
- WFN, AAN, EAN
- WHO Brain Health
- Experts – Sweden, India

## MSIF ▼ Off-label treatments for MS

## Question list 8

- |   |   |
|---|---|
| 1 | Should azathioprine vs. other disease-modifying therapies be used for relapsing forms of multiple sclerosis as first choice treatment?                |
| 2 | Should azathioprine vs. other disease-modifying therapies be used for relapsing forms of multiple sclerosis when switching from another DMT?          |
| 3 | Should azathioprine vs. other disease-modifying therapies be used for active progressive forms of multiple sclerosis as first choice treatment?       |
| 4 | Should azathioprine vs. other disease-modifying therapies be used for active progressive forms of multiple sclerosis when switching from another DMT? |
| 5 | Should rituximab vs. other disease-modifying therapies be used for relapsing forms of multiple sclerosis as first choice treatment?                   |
| 6 | Should rituximab vs. other disease-modifying therapies be used for relapsing forms of multiple sclerosis when switching from another DMT?             |
| 7 | Should rituximab vs. other disease-modifying therapies be used for active progressive forms of multiple sclerosis as first choice treatment?          |
| 8 | Should rituximab vs. other disease-modifying therapies be used for active progressive forms of multiple sclerosis when switching from another DMT?    |

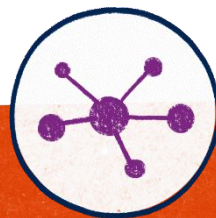
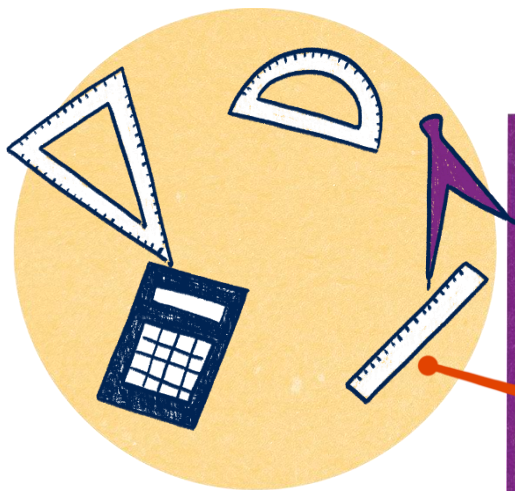
# Questions or Comments?



# MSIF Research Awards

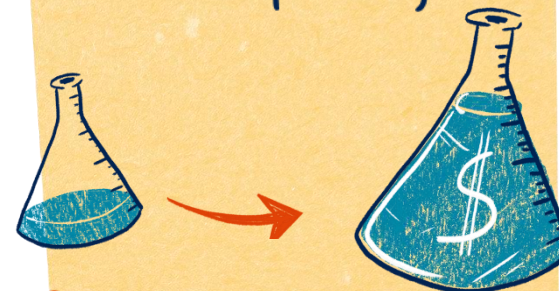
Michael Thor

Measure impact



Aim:  
GREATER SCIENTIFIC  
UNDERSTANDING &  
MORE TREATMENTS

Increase funding



Search for treatments



Improve  
data sharing

Support more researchers



# Changes to the MSIF Awards in 2020

- 1) Extended deadline from June 30 to August 31
- 2) Involved people affected by MS in review process – a pilot project
  - Three people affected by MS per panel, scoring three questions of the application:
    - Continued work in MS related work in low- and middle-income countries (LMICs)
    - Lay summary
    - Involvement with MS organisations
- 3) Broadened eligibility criteria due to COVID-19 travel restrictions

# Broadened eligibility criteria due to COVID-19

Applicants could propose three types of projects:

- A) in a research institute/hospital abroad if travel permits (as in previous years)
- B) in a research institute/hospital in their home country
- C) a virtual project, either in full or in part with host institution mentoring

We will review the situation and outcomes in early 2021 and potentially keep the broader eligibility

# Increased number and diversity of applications in 2020 compared to 2019

30 applications in total – 10 more than last year

Wider geographic representation:

## 2019

- Du Pré: Brazil, India, Iran, Ecuador
- McDonald: Brazil, Colombia, Iran, Mexico

## 2020

- Du Pré: Algeria, Argentina, Brazil, India, Iran, Nigeria, South Africa, Turkey, and Zambia
- McDonald: Algeria, Argentina, Egypt, India, Iran, Nigeria, and Turkey

# Thank you to the 2020 MSIF Award panel members

## McDonald Fellowship panel

- Brenda Banwell (Chair)
- Jeffrey Cohen
- Kazuo Fujihara
- Olga Ciccarelli
- Frauke Zipp
- Fernando Hamuy Diaz De Bedoya
- Bassem Yamout
- Bernhard Hemmer
- Liudmila Gruba (person affected by MS)
- Rosa Juuti (person affected by MS)
- Graham Walker (person affected by MS)

## Du Pré panel

- Jorge Correale (Chair)
- Daphne Kos
- Mohammad Ali Sahraian
- Laura Musambayi
- Hans Lassmann
- Amit Bar-Or
- Christiane Tihon (person affected by MS)
- Peter Nabil Habib (person affected by MS)
- Maureen Wood (person affected by MS)

# Young Investigator Award Panel

- Jaume Sastre-Garriga (Chair)
- Julia Morahan
- Kjell-Morten Myhr
- Tim Coetzee
- Emmanuelle Plassart
- Helen Tremlett
- Jan Meilof
- Liliana Patrucco
- Maria Zuluaga
- Claudia Cárcamo Rodríguez
- Mona M. Alkhawajah

# IMSB Annual Report

Brenda Banwell



# Global COVID-19 and MS activity

## 1. Global COVID-19 advice for people affected by MS

- Consensus advice statement agreed with IMSB Executive committee, TRIMS Presidents and Research staff network in March, and updated twice: [www.msif.org/covid19](http://www.msif.org/covid19)
- Translated into 12 languages and widely shared through members and TRIMS networks

## 2. COVID-19 and MS global data sharing initiative

- Partnership with MS Data Alliance [www.msif.org/covid19data](http://www.msif.org/covid19data)
- To stimulate widespread collection and sharing of a core COVID-19 and MS data set - clinician reported and patient reported information
- Aim: to generate rapid insights on the impact of disease-modifying therapies on COVID-19 outcomes during the pandemic.
- First results will be presented at MSVirtual2020 on 26 September

## International Progressive MS Alliance

- Challenge Awards call for proposals just closed
- Implementation teams meeting – Milan Feb 2020
- Fluid Biomarkers team:
  - New paper on neurofilament light in Neurology
  - Consensus meeting in preparation
  - Seeking letters of support for the biomarker from FDS and EMA



## Patient Reported Outcomes in MS

Four working groups established

1. **Research, development and validation:** of PROs to capture the outcomes that are most important to people living with MS. Chaired by Maria Pia Amato, Giampaolo Brichetto and Bernard Uitdehaag.
2. **Clinical management:** Use of PROs to ensure that the symptoms, abilities and quality of life issues are appropriately addressed in care settings. Chaired by Gilles Edan, Jeremy Hobart, Robert McBurney, Gary Cutter and Iris-Katharina Penner
3. **E-Health:** enabling digital PRO measurement including the passive collection of data. Chaired by Robert Hyde and Letizia Leocani
4. **Healthcare systems:** to increase the uptake of PROs at the level of healthcare systems. Chaired by Gavin Giovannoni and Fabio Pammolli

**Engagement coordination team** is currently being recruited to develop the patient engagement strategy across the whole PROMS initiative. Chaired by Emma Gray (UK MS Society) and a person with MS (TBC)

## Funding our research and access work



# Thank you for joining us

We hope to see you in person next year!