The WHO intersectoral global action plan on epilepsy and other neurological disorders

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This summary document contains the following sections:

1. What does the World Health Organization (WHO) do?

What is the WHO?

The World Health Organization is the United Nations agency that connects nations, partners and people to promote health, keep the world safe and serve the vulnerable – so everyone, everywhere can attain the highest level of health.

The WHO aims to expand global health coverage, coordinate a global response to health emergencies, and promote healthier lives through setting targets and plans that are based on scientific evidence.

In terms of health coverage and promotion, the main approach the WHO takes is to develop strategies and plans centred on a specific topic (eg ‘cervical cancer elimination’ or ‘rehabilitation 2030’). These plans often have recommendations, targets, and a call to action – some recommendations are for the WHO secretariat, but many are aimed at member states and partner organisations, who carry out much of the activity of the strategy/plan. The WHO then measures progress towards these targets.

There is also some specific activity that the WHO carries out directly, such as:

- Providing training for health care professionals
- Producing and disseminating information resources, including policies and guidelines that can be used at national level, such as the Essential Medicines List

What are the WHO regional offices?

There are six regional WHO offices, covering Africa, the Americas, South-East Asia, Europe, the Eastern Mediterranean and the Western Pacific. These offices translate the global health initiatives set by the WHO into regional health priorities, and help countries collaborate to take action.

2. What is the WHO Intersectoral global action plan on epilepsy and other neurological disorders?

The background to the plan

The development of a global plan to address the challenges of epilepsy and other neurological disorders was proposed at the 73rd World Health Assembly (WHA) in November 2020 by a group of countries (known as 'member states' in WHO terminology). The WHO's Brain Health Unit was tasked with producing this plan – and an initial discussion paper was made available to the public in April 2021. Following the first round of feedback, the draft global action plan was published in mid-June 2021. The second version of the draft global action plan was considered by the WHO Executive Board in January 2022. The final plan was confirmed at the 75th WHA in May 2022.

How has MSIF been involved so far?

MSIF has worked with the WHO for many years – more recently in relation to the Atlas of MS and our application to try to add DMTs to the WHO's Essential Medicines List. We have regular discussions with the staff from the WHO's Brain Health unit.

To compile our feedback, we ran consultation events with:

- representatives from MS organisations around the world – members of MSIF and more widely – from all six WHO regions
- people affected by MS
- our International Medical and Scientific Board, which includes the presidents of the five main regional Committees for Treatment and Research in MS (TRIMS)
- our International Working Group on Access, which includes representation from all six WHO regions.

We have also been talking with other global neurological patient organisations (who are members of the One Neurology Partnership) as well as the World Federation of Neurology, so we can understand better where common challenges exist across neurological conditions, and where there are specific needs of people affected by MS.

To find out more about MSIF's influence on the content of the global action plan, see section 5.

3. What is in the WHO global action plan?

Overview of the global situation
• Rationale for why a global action plan is needed: disorders of the nervous system are the leading cause of disability and the second leading cause of death globally, accounting for 9 million deaths per year. • Needs are not being met and there is considerable inequity.
Scope
• Includes 'neurological disorders' – this is a broad definition and includes MS. • Person-centred approach rather than a disease-specific approach - many neurological conditions share risk factors and/or require a similar health systems-based approach.
Vision
A world in which: • brain health is valued, promoted and protected across the life course;

• neurological disorders are prevented, diagnosed and treated, and premature mortality and morbidity are avoided; and • people affected by neurological disorders and their carers fulfil their potential with equal rights, opportunities, respect and autonomy.	
Goal	
• To reduce the stigma, impact and burden of neurological disorders, including their associated mortality, morbidity and disability, and to improve the quality of life of people with neurological disorders, their carers and families. • In order to achieve the vision and goal, the prevention, treatment and care of epilepsy and other neurological disorders should be strengthened, wherever possible, utilizing entry points and synergies to achieve the best results for all.	
Strategic objectives	
1	To raise policy prioritization and strengthen governance.
2	To provide effective, timely and responsive diagnosis, treatment and care.
3	To implement strategies for promotion and prevention.
4	To foster research and innovation and strengthen information systems.
5	To strengthen the public health approach to epilepsy.
• Each strategic objective contains actions for Member States, WHO Secretariat, and national/international partners. • There are also 10-year targets relating to each strategic objective.	

4. What are the main points of each strategic objective in the plan?

Please note: to keep this summary short, we have pulled out some of the points we feel are most relevant to multiple sclerosis. Targets listed are for 10 years i.e. to be evaluated in 2031.

Objective 1: To raise the prioritization and strengthen governance for neurological disorders.

1. Raise awareness of the social and economic impact of neurological disorders.
2. Involve people with neurological disorders in decision-making.
3. Develop national plans/policies for neurological disorders.
4. Fund policies/programmes to ensure access to prevention, diagnosis, treatment and care for people with neurological disorders and their carers, and to reduce the financial impact of out-of-pocket health and social care costs.
5. Collect/use up-to-date epidemiological data to make informed decisions on healthcare budgets for neurology.

Targets:

- 75% of countries will have adapted or updated existing national policies, strategies, plans or frameworks to include neurological disorders
- 100% of countries will have at least one functioning awareness campaign or advocacy programme for neurological disorders

Objective 2: To provide effective, timely and responsive diagnosis, treatment and care for neurological disorders.

1. Care pathways should be inclusive of all people and consider the whole life course, as well as from early intervention to palliative care.
2. Integrate neurological care across health and social systems – eg primary and secondary care, community-based care, formal and informal.

3. Strengthen health and social care workforce capacity to rapidly identify and address neurological disorders - specialist as well as primary healthcare workers.
4. Enable people with neurological disorders to make informed choices and decisions about care that meets their needs, by providing evidence-based, accessible information.
5. Support health and social care workers to use technologies such as telemedicine, internet/mobile phone technologies to expand the neurological care to remote and low-resource settings and to support home-based services.
6. Ensure that essential, safe, affordable, effective and quality medicines and health products for neurological disorders on the WHO Essential Medicine List are available.
7. Ensure availability, access and use of appropriate relevant diagnostics.
8. Establish transparent regulatory frameworks, resources, and capacity to ensure quality, safety and ethical standards are met for medical products.

Targets:

- 75% of countries will have included neurological disorders in the universal health coverage benefits package
- 80% of countries will provide the essential medicines and basic technologies required to manage neurological disorders in primary care

Objective 3: To implement strategies to promote brain health and development and prevent neurological disorders.

1. Support development and implementation of policies and programmes for healthy behaviours across the life course, addressing nutrition, substance use (such as alcohol and smoking), physical activity etc.

Targets:

- 80% of countries will have at least one functioning multisectoral programme for brain health promotion and the prevention of neurological disorders across the life course
- The global targets relevant for prevention of neurological disorders are achieved, as defined in the:
    - Global action plan for prevention and control of noncommunicable diseases 2013-2020,
    - Defeating meningitis by 2030: a global road map,
    - Every newborn: an action plan to end preventable deaths.

Objective 4: To foster research and innovation and strengthen information systems for neurological disorders.

1. Support research collaborations – including public and private partnerships - for neurological disorders to generate new knowledge and enhance sharing of research data.
2. Strengthen capacity for research including institutional capacity building and the creation of research fellowships and scholarships, particularly in LMICs.
3. Support the implementation and scaling up of proven treatment and prevention strategies for neurological disorders including in LMICs.
4. Encourage involvement and engagement of people with neurological disorders, their families and carers in research and development.
5. Support the building of new data-sharing programmes and initiatives that drive better disease understanding and evaluation of neurological services in low-resource settings.

Targets:

- 80% of countries routinely collect and report on a core set of indicators for neurological disorders through their national health data and information systems at least every three years
- The output of global research on neurological disorders doubles

Objective 5: To strengthen the public health approach to epilepsy and promote synergies with other neurological disorders.

1. A well-functioning epilepsy care service can present a good opportunity to strengthen the management of other neurological disorders – by incorporating care for other neurological conditions in routine epilepsy services.

Targets:

- Countries will have increased service coverage for epilepsy by 50% from their current coverage in 2021
- 80% of countries will have developed or updated their legislation with a view to promoting and protecting the human rights of people with epilepsy

5. What points in the global action plan did MSIF influence?

MSIF responded to the WHO with comments on the draft global action plan during the first and second rounds of feedback.

The comments we made that were incorporated into the final version of the plan are described below (numbers in brackets refer to the relevant points within the plan).

- **We made the case for a stronger focus on treatment and effective medicines for neurological conditions.** 'Treatment' was added to the vision, along with a greater emphasis of the crucial role of essential medicines throughout the global action plan (eg 59, 63b).
- **We stated that the plan should include a clear, separate, section on how progress towards the targets will be measured and monitored – both globally and regionally – and when this information will be made publicly available.** There is now more detail about indicators that show the targets are met. But no information about intermediate targets to be achieved over the next 10 years, and monitoring progress is specified as the role of member states – there is no mention of the WHO's role in monitoring and reporting on progress.
- **We recommended that the implementation of the actions and recommendations in this plan must be done through co-production with people affected by neurological disorders, and that an additional action for the WHO Secretariat should be to provide guidance for member states and national/local non-state actors (such as patient organisations) to support this specific type of advocacy to happen effectively.** Throughout the plan there are actions for developing advocacy plans (eg 29), policies, research agenda (eg 129) etc in collaboration with people affected by neurological disorders, and the action for the WHO Secretariat was included (31c).
- **We noted the importance of building effective links between primary care and specialist/secondary care, particularly as some conditions like MS are relatively rare with primary care providers seeing very few cases. We suggested that the role of digital technology in providing a bridge to specialist care, should be mentioned.** This was included

in the plan, noting that continuity of care can be optimized using digital health solutions that foster greater information-sharing between providers (54).

- **We made the case for MS being a model for where other neurological conditions will be in the next decade – as is suggested by current advances in neurological research. If the challenges around access to treatment (for those neurological conditions that have treatments available) can be addressed through specific actions in this plan, this will have benefits for other neurological conditions as treatments become more readily available for them.** This was included in the plan (62).
- **We recommended that the WHO Secretariat, working in collaboration, should aim to expand the number of essential medicines for neurological conditions listed on the EML, and that the cost of medicine should not be a barrier for inclusion in the EML.** The plan noted that the EML should be updated to ensure it is appropriate for neurological conditions (64b). This is not a commitment to expanding the number of neurological treatments listed, but may be a step in the right direction.
- **We highlighted the need for transparency of regulatory submissions, assessment and decisions to ensure public trust for all medicinal products manufactured or imported to the country, to help engender confidence in people using these medicines. We also recommended that the WHO provides guidance for ensuring the necessary regulatory guidelines are in place.** Actions related to transparent regulatory frameworks and guidance for these were included (63d, 64a).

6. What is missing from the plan that we believe is important for MS?

Some of our recommendations have not been included in the global action plan, as described below. These are areas that MSIF could continue to advocate for alongside the actions contained within the global action plan.

- **We advocated for specific actions for making treatments for neurological conditions available and affordable, which would require an integrated and coordinated approach led by the WHO, across its departments (i.e. not restricted to the brain health unit), member states, partner NGOs including patient organisations, and the private sector. These actions were:**
  (1) To focus on areas highlighted by the WHO's Fair Pricing Forum that will lead to improvements in access to health technologies and essential medicines for neurological conditions.
  (2) To work with the WHO pre-qualification programme to improve access to safe, effective, and affordable medicines for neurological conditions, especially in LMICs.
  Specific actions for member states, the WHO Secretariat and other non-state actors were included, but the role of the private sector/pharmaceutical industry was not included, nor were the two specific actions we recommended.
- **We highlighted the need for sustainable supply of medicines, as we know there are significant issues in some countries in maintaining a sustainable supply of DMTs.** This was not referenced in the plan.
- **We recommended re-wording Global target 2.2 (80% of countries will provide essential medicines and basic technologies required to treat neurological disorders in primary care by 2031) to include medicines and technologies (beyond 'basic'**

technologies) that require treatment delivery in specialist care. This would help to meet the needs of people with MS whose diagnosis and treatment often requires specialist technologies and delivery of medicines within specialist/secondary care. This greater focus on building capacity in secondary/specialist care was not included.

- **We recommended a specific action to build capacity of specialist nurses, who can positively influence the quality of life and wellbeing of people living with neurological conditions.** This was not included.
- **We suggested that access to rehabilitation therapies should be given greater focus, as they are crucial in reducing symptoms and disability experienced by people with neurological conditions, improving their quality of life and wellbeing.** Whilst reference to rehabilitation is made within the plan, there are no separate actions focusing on access to rehabilitative technologies, products, techniques or workforce.
- **We recommended that funding is needed in order to build capacity globally for neurological data collection, storing and sharing.** Whilst several actions are listed for improving national data and information systems, which we are strongly supportive of, a reference to the crucial need for funding this activity was not included.

7. What is in the plan that already aligns with the work of MSIF?

There are many points within the plan that are relevant to the MS Community (see section 4 for a summary). There are some targets and actions for international and national partners that are particularly relevant and already align with the work of the MSIF secretariat and membership.

Global Target 1.2: 100% of countries will have at least one functioning awareness campaign or advocacy programme for neurological disorders

- We contribute to this target through World MS Day, which in 2021 was celebrated in 117 countries.

32 c) Provide a platform for dialogue between associations and organizations of people with neurological disorders and their carers, health and social workers, government sectors and other relevant actors at international, regional and national levels, while including young people and older people and ensuring gender-balanced representation.

- This is one of the main aims within MSIF's strategy, in terms of strengthening the MSIF movement.

39 b) Support the creation and strengthening of associations and organizations of people with neurological disorders, their families and carers, and foster their collaboration with other organizations as partners in the implementation of policies for neurological disorders.

- This is one of the main aims within MSIF's strategy, in terms of strengthening the MSIF movement.

Global target 2.2: 80% of countries will provide the essential medicines and basic technologies required to manage neurological disorders in primary care

- This links to MSIF's work to apply for medicines for MS to be added to the WHO's Essential Medicines List. However, the target notes that these medicines are for managing neurological disorders in *primary care*, which may not be the case for medicines needed to treat MS.

65 a) Encourage all relevant stakeholders to engage in activities to promote efforts for improving access to affordable, safe, effective and quality medicines.

- This is one of the main aims within MSIF's strategy.

70 b) Support the implementation of capacity-building programmes, including training and education, for general and specialized health care workers to identify neurological disorders and provide evidence-based interventions to promote diagnosis, treatment and care for neurological disorders.

- Some of MSIF's members provide support for clinical training of neurologists and other health professionals. Many members are also involved in the production of diagnostic and treatment guidelines for MS. The MSIF secretariat is currently engaged in producing guidelines for the off-label use of certain DMTs in low resource settings, as well as recommendations for essential medicines.

132 a) Promote and mobilize financial support for research in neurological disorders, participate in priority-setting exercises and contribute to the dissemination of research findings in user-friendly language to policymakers, the public, people with neurological disorders, their carers and families.

- This is a key activity undertaken by many members of MSIF – raising funds for research, developing research strategies, and research communications.

132 b) Engage the research community, health professionals, policymakers and the private sector in promoting the innovation and development of new tools and treatments for neurological disorders, while ensuring equitable and affordable access of these products in low- and middle-income countries.

- An example of this is the work of the collaborative International Progressive MS Alliance. Note that we also commented that the industry producing these products should take responsibility in planning and developing methodologies to ensure suitable products for low-resource settings and equitable and affordable access.

132 c) Support national efforts to strengthen capacity for research, development and innovation and knowledge exchange, including institutional capacity-building, research collaborations and the creation of fellowships and scholarships for the prevention, diagnosis, treatment and care of neurological disorders.

- An example of this is MSIF's fellowships for researchers from low and middle income countries.

Global target 4.1: 80% of countries routinely collect and report on a core set of indicators for neurological disorders through their national health data and information systems at least every three years

- Some of these core indicators will align with the data in the Atlas of MS. Through the Atlas, MSIF collates and provides country/regional comparisons of data that can be used for research and advocacy purposes.

8. What are MSIF's next steps in relation to the WHO global action plan?

The final version of the global action plan was discussed at the WHO Executive Board in January 2022. There was widespread support from member states for the plan, and it was adopted at the World Health Assembly in May 2022.

MSIF will use actions and targets within this plan to add emphasis and leverage to our current work at the global, regional and national levels, particularly in terms of advocacy.