

MS International Federation response to the WHO consultation on the first draft of the Intersectoral global action plan on epilepsy and other neurological disorders

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MS International Federation – consultation process with our stakeholders

The MS International Federation is a unique global network of MS organisations, people affected by MS, volunteers, staff, clinicians and researchers from around the world. Our movement is made up of 47 national MS member organisations with links to over 50 organisations in other countries.

We welcome the opportunity to provide input to the draft global action plan, from the perspective of people affected by MS, MS organisations and the MS research and clinical community.

We are pleased to see that in this draft plan there is a greater focus on the central role of people affected by neurological disorders, and that the WHO decided to run a specific consultation for this stakeholder group. In drafting our response, we have tried to reflect the diversity of experiences of people affected by MS.

In making our response to this draft plan, we have consulted with:

- representatives from MS organisations around the world – [members of MSIF](#) and more widely – from all six WHO regions
- 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
- people affected by MS.

As in our previous response to the discussion paper, our feedback includes both overarching issues and some specific points relating to sections of the plan. Some of these were raised previously, but we believe are worth re-emphasising.

Implementation of the Global Action Plan

The organisations we work with, which represent people living with and affected by MS, are engaged with and invested in the development of this global action plan and its outcomes. 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.

The implementation of the actions and recommendations in this plan must be done through co-production with people affected by neurological disorders. Co-production will determine what is most crucial for those actually living with the disease – this will be key to understanding unmet

needs for different groups and in different regions, countries and localities. In *Section 1.1 Advocacy*, 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.

Access to medicines

Improving access to treatment was highlighted repeatedly throughout our consultation with our different stakeholder groups. Lack of access to effective medicines (which should be prescribed as soon as possible after diagnosis of MS) results in considerable avoidable disability. There is potential for the WHO to make a huge difference to the lives of people affected by neurological conditions if focus and resources are given to this issue.

We recognise that not all neurological conditions have effective medicines to treat the disease – and certainly not as many as are available for MS. However, the advances in MS treatment have mainly been seen in the last 20 years, and MS can be seen as 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.

The plan needs more focus on improving global provision of effective medicines for neurological conditions that can be treated. We note some changes have been made to the draft plan since our previous response, but we believe this should go further: specific actions should be identified for making treatments for neurological conditions available and affordable.

In particular, this requires 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.

We suggest two specific actions for the WHO Secretariat:

- (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.

The specific role of all types of organisations involved in tackling barriers to accessing treatments – including their cost and affordability – should be made clear within the plan and included in *Section 2.2 Medicines, diagnostics and other health products*.

Specific actions aimed at the private sector, such as the pharmaceutical industry, should also be included in this section. These actions should include developing and implementing access plans and transparent, sustainable strategies for low and middle-income countries for prioritised medicines for neurological conditions. Consideration should also be given to developing affordable pricing strategies for these medicines.

The WHO's Essential Medicines List (EML) also has a key role in improving access to medicines globally, yet very few medicines for neurological conditions are included in this list. In some countries, medicines are not made available unless they are listed on the EML. Therefore, an urgent and essential priority for the WHO Secretariat, working in collaboration as described above, should

be to expand the number of essential medicines for neurological conditions listed on the EML. The cost of medicine should not be a barrier for inclusion in the EML.

When we polled our stakeholders about which target(s) would have the biggest impact in their region/country, *Global target 2.2 (80% of countries will provide essential medicines and basic technologies required to treat neurological disorders in primary care by 2031)* was chosen by the majority. Despite this, as currently worded, the target will not adequately address the needs for people with MS, whose treatment often requires specialist technologies and delivery of medicines within specialist/secondary care. Therefore, there should be an additional target focusing specifically on specialist/secondary care (including access to medicines, technologies and the specialist workforce), or *Global target 2.2* should also include medicines and technologies (beyond 'basic' technologies) that require treatment delivery in specialist care.

The neurological workforce

Having access to specialist health care professionals, in particular neurologists, is critical for the care of people with MS – for obtaining a diagnosis initially, and then for getting access to the necessary treatments. Whilst the plan notes the need for capacity building of both specialist and general health care workers, our stakeholders reported that greater focus is needed on improving the specialist workforce, including neurologists who have expertise in specific neurological conditions or subsets of the population such as pediatrics. This lack of focus on the specialist/secondary care workforce is highlighted by the way *Global target 2.2* is currently worded, as mentioned above. If target 2.2 is only focused on primary care, this will not meet the needs of the MS community, or those of other neurological conditions whose treatment relies on specialist technologies and expertise for diagnosis and treatment delivery.

Specialist nurses have a proven beneficial impact on the neurology treatment and care pathway, over the long-term course of these conditions, but they are currently lacking from the plan. These nurses may be specialised in a specific neurological condition, in neurology in general, or in specific symptom management such as continence – and they positively influence the quality of life and wellbeing of people living with neurological conditions. Action to build capacity in this form of nursing expertise should be specifically mentioned in the plan in *Section 2.3 Health workers' capacity building, training and support*.

Access to rehabilitation

Rehabilitation therapies are crucial in reducing symptoms and disability experienced by people with neurological conditions, improving their quality of life and wellbeing. Some neurological conditions, such as MS, affect people over many decades, and their needs for rehabilitation change over time, but challenges accessing all types of rehabilitation therapy are frequently reported by our stakeholders. Whilst reference to rehabilitation is made within *Sections 2.2 and 2.3*, we suggest that actions relating to rehabilitative technologies, products, techniques or workforce should be separated into a standalone area that requires action.

Data and information systems

A long-term, evidence-based approach to global neurology requires robust national data and information systems. Our stakeholders repeatedly emphasise the need for good quality data on MS in their countries, and their challenges in collecting and storing this type of data. Improving global data collection on neurology will underpin successful actions addressing the other challenges highlighted in this global action plan. The actions for the WHO secretariat and national/international

partners under *Section 4.2 Data and information systems*, which relate to building capacity for data collection, storing and sharing, are particularly crucial and should be prioritised - and funding for this activity should be included.

Summary

In summary, these are the main changes we recommend are made to the draft global action plan:

- The plan should include a clear, separate, section on how progress towards the global targets will be measured and monitored – both globally and regionally – and when they will be publicly reported on.
- Specific actions to be added:
 - The WHO Secretariat should provide guidance for member states and national/local non-state actors (such as patient organisations) on how to effectively and equitably involve people affected by neurological disorders when implementing actions in the plan.
 - The WHO Secretariat should lead an integrated and coordinated approach across its departments, member states, partner NGOs and the private sector to make treatments for neurological conditions available and affordable.
 - The private sector, including the pharmaceutical industry, should address availability, cost and affordability of medicines to treat neurological conditions.
 - The WHO Secretariat, working in collaboration with relevant organisations, should actively expand the number of essential medicines for neurological conditions listed on the Essential Medicines List.
 - Actions that support building capacity in specialist nursing (e.g. neurology and symptom management).
- Rehabilitation should be separated out as a specific area requiring action.
- The actions for the WHO secretariat and national/international partners under *Section 4.2 Data and information systems*, which relate to building capacity for data collection, storing and sharing, are particularly crucial and should be prioritised - and funding for this activity should be included.
- Global target 2.2 should be split into the separate needs for medicines, technologies and workforce for (a) primary and (b) specialist/secondary care, or this target should be expanded to include specialist care.