

MS International Federation response to the WHO consultation on discussion paper for the Global Action Plan on Epilepsy and Other Neurological Disorders

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1. Do you have any comments on the background and scope?

The MS International Federation is a unique global network of MS organisations with 48 members from around the world, and links to many others. We welcome the opportunity to provide input to the discussion on a Global Action Plan, from the perspective of people affected by MS and MS organisations.

We have provided specific comments relating to different sections of the discussion paper, but there are a few overarching issues that we wish to raise.

The Global Action Plan must be person-centred, and this should be clear throughout the proposed actions. We would like to ensure that people affected by neurological conditions have the opportunity to help shape this Global Action Plan, which ultimately aims to improve their lives, and in doing so, focus action on health and social outcomes that matter most to them.

In particular, we know that the experience of neurological care is unequal, particularly when considering lack of access to diagnosis, treatment and care in low and middle income countries (LMICs). The Global Action plan must aim to reduce inequities globally, and to do so, we hope to see good input into this plan reflecting the diversity of people with lived experience of neurological conditions across the world, and particularly in LMICs. This will not only ensure all challenges are identified, it will help confirm that proposed solutions are feasible and likely to be effective in different contexts.

We believe there should be a stronger focus on effective medicines for neurological conditions. Whilst a range of medicines are not available for all conditions, where there are effective treatments, this should be emphasised. In several places, reference is made to services, care, management and/or interventions, where instead it should be made clear that this includes medicines.

Lack of access to effective medicines results in considerable avoidable disability, and we recommend that this issue receives greater focus in the Global Action Plan. Addressing this challenge requires an integrated and coordinated approach across the WHO, member states, partner NGOs and the private sector. The role of all types of organisations involved in tackling barriers to accessing treatments – including their cost and affordability – should be made clear. As currently written, the actions aimed at the private sector, such as the pharmaceutical industry, are rarely included.

The discussion paper provides an indication of how this initiative links with some of the other WHO resolutions and Global Commitments, but we believe that the connection between this Global

Action Plan and other relevant WHO activity is missing – for example to Essential Medicines, the production of guidelines, or fair pricing.

We have aimed to provide as comprehensive a response as possible within the time available, though we are aware we may have missed issues that are important to people affected by MS across the world. Ideally we would like to engage more widely with our global membership – which we will aim to do for the next round of consultation.

2. Do you have any comments on the vision?

20 i: Prevention is a crucial and cost-effective intervention, but not all neurological conditions can be prevented. The plan should address the realities of those already living with a neurological disorder, and should balance prevention and disease management. Depending on the condition, management may be in the form of effective medicines, or a focus on improving quality of life, such as through rehabilitation.

We suggest amending this to say “neurological disorders are prevented and treated”.

3. Do you have any comments on the goals?

21: The overarching goal is appropriate, but we have concerns about leveraging epilepsy prevention, treatment and care as the entry point. This may not be equally relevant in the wide range of health systems and infrastructure across the world, and it is not clear how this would work in practice, and the situations in which it would be effective.

Whilst we understand there may be benefits to focusing on epilepsy services as a starting point in certain situations, having this focus within the overarching goal of the action plan could minimise action taken by member states/secretariat/partners to address the common needs of other neurological conditions.

4. Do you have any comments on the guiding principles?

26 vii: We support this guiding principle and want to highlight that these issues also affect carers of people with neurological conditions, a burden that is often taken on by women (https://www.oecd.org/dev/development-gender/Unpaid_care_work.pdf).

OBJECTIVE 1: TO RAISE THE PRIORITIZATION AND STRENGTHEN GOVERNANCE FOR NEUROLOGICAL DISORDERS

1.1 ADVOCACY

General comments:

29: While epilepsy can be one of the entry points, it is essential to keep in mind solutions that can be applied across the neurology spectrum, which are relevant in the wide range of health systems and infrastructure across the world.

30: Awareness raising should also include that there are existing effective medicines for many neurological conditions. This emphasis may improve people's perception of neurological diseases, with the result that stigma is reduced and people may be more likely to seek care and be diagnosed early.

1.2 POLICY, PLANS AND LEGISLATIONS

Actions for Member States:

45: There is a specific call to strengthen and/or implement policies, plans and legislation, to reduce discrimination and ensure universal access to financial, social and disability benefits for **carers** – but these actions are not elaborated with the same degree of specificity for people living with neurological conditions. We suggest this is added to point 43.

1.3 FINANCING

Actions for Secretariat:

54-56: In addition to these points, the secretariat should provide guidance on 'fair pricing' of medicines and diagnostics (https://www.who.int/medicines/access/fair_pricing/en/) and consider the importance of price transparency.

Actions for International partners:

57-58: In addition to these points, the pharmaceutical companies should map out access pathways and consider how to ensure fair pricing for existing and new vaccines, medicines and diagnostics in different national settings to ensure a sustainable and affordable supply of health products. As the GAP is planned for the next ten years, this is particularly important to ensure that ground-breaking new health products reach the people that need them without delay.

1.4 INTEGRATED RESPONSE WITHIN HEALTH AND SOCIAL CARE SYSTEMS

General comments:

Neurological conditions require effective management by integrated primary/community care and specialised healthcare. The former can provide a patient-centred, holistic approach to take into account the range of comorbidities that often co-exist with neurological conditions. But specialist

care led by neurologists is essential for diagnosis of some neurological conditions, such as MS, as well as being able to provide effective treatment for the condition. In addition, some neurological conditions are relatively rare, with primary care providers seeing very few cases, therefore the importance of building effective links between primary care and specialist/secondary care should also be emphasised. The role of digital technology in supporting the diagnostic work of primary care practitioners, providing a bridge to specialist care, should also be mentioned.

OBJECTIVE 2: TO PROVIDE EFFECTIVE, TIMELY AND RESPONSIVE DIAGNOSIS, TREATMENT, AND CARE FOR NEUROLOGICAL DISORDERS

2.1 CARE PATHWAYS

General comments:

There is a necessary focus on improving primary care, but there should also be a recognition of the need for improved specialist care in neurology.

71: The focus on this statement is essential medicines, but there should be a recognition that essential medicines for neurological conditions are poorly identified and poorly represented on the WHO Essential Medicine List, e.g. “Expanding medicines for neurologic disorders on the WHO Model List” <https://pubmed.ncbi.nlm.nih.gov/28265046/>

Actions for Member States:

80: The focus of this statement is broad and more emphasis should be placed on ensuring access to timely, appropriate diagnostic infrastructure and effective, affordable treatment options. Specifically, ensuring appropriate diagnostic and treatment guidelines are in place, and effective medicines are made available and reimbursed. Our members also report very complex bureaucratic systems causing severe delays and barriers to accessing diagnosis and treatment, which are often further enhanced by the inequity between urban and rural areas.

2.2 MEDICINES, DIAGNOSTICS AND OTHER HEALTH PRODUCTS

General comments:

98: There should be a recognition that essential medicines for neurological conditions are poorly represented on the WHO Essential Medicine List, e.g. “Expanding medicines for neurologic disorders on the WHO Model List” <https://pubmed.ncbi.nlm.nih.gov/28265046/> and that these need to be assessed and updated.

Actions for Member States:

102: We would like to highlight the need for sustainable supply of medicines. Our members report significant issues in maintaining their medicine supply for their chronic condition due to irregular supply of medicines, affordability and bureaucratic systems to prove eligibility.

103 and 105: It is important that the national regulatory authorities are well-equipped to assess the quality, safety and efficacy of medicines and whether they are interchangeable. We support the statement but would like to highlight the need for transparency of regulatory submissions, assessment and decisions to ensure public trust for all medicinal products manufactured or imported to the country. This transparency will help engender confidence in people using these medicines.

Actions for Secretariat:

107 and 108: Three additional actions should be considered for the secretariat. 'Equitable access' should specifically address affordability for both the health systems and individuals.

(1) Review and assess the WHO Essential Medicine List, WHO medicine formulary, Essential Diagnostics and other relevant documents provided by the WHO to ensure they are up-to-date and appropriate for neurological conditions.

(2) Ensure pathways are in place so that the newest and most effective treatments and diagnostics are considered in a timely manner when they emerge.

(3) Provide technical support and guidance for ensuring up-to-date, evidence-based regional/national/resource-stratified diagnostic and treatment guidelines are in place.

Actions for International partners:

109 and 110: We agree with these statements and would like to add emphasis also on pharmaceutical companies providing vaccines, medicines and diagnostics at a fair price, which ensures sustainable affordability for health systems and individuals.

2.3 HEALTH WORKERS' CAPACITY BUILDING, TRAINING AND SUPPORT

General comments:

We agree with the need for a fully trained, integrated, multidisciplinary workforce to improve diagnosis, management, treatment and care for people affected by neurological conditions. In addition to improving the capacity of primary health care workers with respect to neurological conditions, there needs to be an equal focus on improving neurologist capacity – both in terms of absolute numbers (to include pediatric neurologists too), but also their training and education.

OBJECTIVE 3: TO IMPLEMENT STRATEGIES FOR THE PROMOTION OF BRAIN HEALTH AND PREVENTION OF NEUROLOGICAL DISORDERS

General comments on objective 3:

We support the importance of optimising brain health and having a long term aim to prevent all neurological conditions. Whilst neurological conditions share some risk factors with other NCDs, there is still much to be discovered about the full range of preventable causes of MS and other conditions. Therefore strategies to prevent neurological conditions must run alongside actions taken to manage the effects people experience who are living with these conditions.

OBJECTIVE 4: TO FOSTER RESEARCH AND INNOVATION AND STRENGTHEN INFORMATION SYSTEMS FOR NEUROLOGICAL DISORDERS

General comments on objective 4:

People with neurological conditions should be central within the research and development process. Research institutions should aim to engage the relevant members of the community who are affected by neurological conditions in order to have genuine and meaningful impact on the research output.

201: We support the aim to strengthen research and information systems particularly in LMICs, as we recognise that better data and understanding of the situation relating to neurological conditions in countries is the basis for effective advocacy to promote change.

4.1 INVESTMENT IN RESEARCH

Actions for Secretariat:

212: We agree with these points for guidance and technical support from the secretariat, but believe it is not adequate to focus this responsibility solely on member states. 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.