

MEETING INFORMATION

This meeting took place via zoom on Tuesday, June 29th. There were two sessions – attracting approx. 60 advocates in total. The majority were from Europe, but there were participants from Australia, USA, Cuba, Malawi and India. The event kicked off with presentations on the global burden of neurological disorders and the importance of brain health, before we introduced the OneNeurology Initiative. Dr. Neerja Chowdhary of the WHO Brain Health Unit then presented an overview of the Global Action Plan before a group discussion and polling on its content – with a focus on the suggested action for each actor. Representatives from WHO EURO and AFRO also attended the meeting, with pre-meeting calls taking place with PAHO. The report that follows captures the key points raised and makes suggestions for next steps for OneNeurology.

SETTING THE SCENE

- Almost 60% of participants felt that policy makers in their country did not fully understand the burden of neurological disorders and the need to act now.
- In only one country represented at the meeting (Scotland) is there a standalone policy framework for neurology. In most countries, there were some disease specific plans/strategies but no overarching framework. In many countries, neurology is not on the public health agenda at all.
- Participants felt that the GAP was an opportunity to call for these disease-specific plans/strategies to come together under one national framework.
- Participants were asked what type of policy framework they would like to see for neurology, spinning out of the GAP, within 10 years:
 - o Most participants felt a wider strategy on brain health was the optimal outcome, although this was closely followed by standalone strategies on neurology. Disease specific plans as entry points and integration in the area of NCDs ranked lower, and very few felt neurology should be integrated in efforts on mental health.
 - o In terms of what was realistic within 10 years, most felt a brain health plan was achievable. However, many also thought disease specific entry point and/or integration in NCD plans was more likely in their regions. Less thought standalone neurology policies were likely in 10 years.
- Examples of current national frameworks for neurological disorders or brain health plans should be collected, reviewed and shared e.g. Scotland:
<https://www.gov.scot/publications/neurological-care-support-scotland-framework-action-2020-2025/>

INITIAL COMMENTS ON THE GLOBAL ACTION PLAN

- Participants were asked to read the plan and to provide feedback to OneNeurology so that we can craft a consensus based, consolidated response to the consultation.
- In the main, the plan was well received – although it was felt that regional/national prioritisation would be needed to ensure it addressed the specific needs in different parts of the world.
- There were calls for more emphasis to be given to specific population groups e.g. carers, young people, refugees and asylum seekers.
- The role of nurses in the text is not sufficiently addressed.
- Palliative care and neuro-rehabilitation are mentioned in the GAP – but it was felt they were not given sufficient attention as approaches to care required across the spectrum of neurological disorders.
- A stronger link to rare diseases could be included, particularly in relation to universal health coverage.
- It was felt that the focus on raising awareness of brain health could be better linked to raising awareness of neurological disorders. There is a need to ensure those living with neurological disorders and their needs are also communicated.
- Ensuring access to early, accurate diagnosis needs to be better emphasised – as well as adherence to treatment.
- Important to enshrine the added value of the meaningful involvement of those living with neurological disorders in shaping, implementing and monitoring the plan – but also ensuring they are resourced to do so, particularly in LMIC settings where such advocates/groups are not in contact with policy makers.
- Targets needs to be strengthened, with intermediate steps and monitoring, to ensure accountability.
- Role of the secretariat could be strengthened and the role of the regional offices included (see most important actions below).
- Finance was raised – how will this be resourced?
- Covid and Long-Covid discussed are areas to be leveraged by neurology.
- The scope of the disorders to be covered was questions: What about the peripheral nervous system? What about functional disorders?
- Epilepsy as an entry point was not well understood or obvious to all, and some context might be needed in this section.

MOST IMPORTANT ACTIONS FOR KEY ACTORS

A poll took place to rank the most important of key actors. The below are the synopsis results:

MOST IMPORTANT ACTION FOR WHO INTERNATIONAL

- Set and monitor targets: *Those listed in the GAP need to be strengthened, there should also be intermediate targets and indicators must be developed to map progress*
- Conduct global research, facilitate global data sharing and coordinate global access initiatives: *The roles for the secretariat in these areas are not well enough defined in the GAP*

MOST IMPORTANT ACTIONS FOR WHO REGIONAL OFFICES:

- Monitor and guide implementation by member states
- Map the burden of neurological disorders regionally (and prioritise actions)

MOST IMPORTANT ACTIONS FOR MEMBER STATES:

- Ensuring equitable access to diagnosis, treatment and care
- Collecting national data
- Supporting research

ACTIONS FOR CIVIL SOCIETY:

- Advocate for involvement
- Raise awareness of neurological disorders

SUPPORT NEEDED BY CIVIL SOCIETY:

- Advocacy and policy training – clear priority
 - Awareness campaigns
 - Support to build alliances
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- *Note: Providing a platform for exchange, sharing/disseminating best practice was the lowest ranking priority for WHO International and Regional Offices, although this is seen as a key action for the secretariat in the current draft. How do we address this?*
 - *Internal integration of neurology into other policy priorities: Do we need to better communicate the need for neurology to be integrated into other policy areas e.g. NCDs? Is it a priority for OneNeurology?*
 - *A dedicated staff/budget at regional level was also not deemed a priority. But how the implementation of GAP would be financed was questioned repeatedly. Human and financial resources are needed. Is this, therefore, a role for private actors? It was suggested that OneNeurology could think about better linking to this groups.*

WHAT WE LEARNED AND QUESTIONS TO BE ADDRESSED

- Member states hold the key. OneNeurology must build up its regional structures – this could include identifying advocates, organising training/capacity building activities and supporting the creation of alliances. A mapping will take place with OneNeurology Partners but also other international civil society groups e.g. NCDA and IAPO. The autumn capacity building workshop could be replaced by a series of regional webinars. **What role can partners take here? How should this be reflected in the future direction and structure of OneNeurology?**
- We need to prioritise 2-3 cross-cutting topics and themes if we want to engage disease specific groups and advocates. **What should these be?**
- We need to better communicate the added value of ONE neurology, as well as packaging our evidence in a striking way to ensure political will and public acceptance.
- We need better outcome measures and indicators to ongoingly monitor progress and hold policy makers to account. **Can OneNeurology play a role here?**

- The role of the private sector is important and was not considered during the workshop. **Can we facilitate conversation with key players – particularly around topics such as global financing mechanisms, global access schemes, etc.? How do we include them in our Global Partnership?**

NEXT STEPS

- Participants encouraged to sign up as partners (if they meet the criteria), endorsers or subscribers.
- OneNeurology Partnership's GAP Joint Comments by 5 August 2021 – participants to send their feedback for inclusion to: info@oneneurology.net
Participants will also be invited to use the OneNeurology template to build their own response.
- OneNeurology outreach to member states in advance of regional hearings in late July. Participants will be sent a template letter which they can personalise and send to their national governments and/or missions to the WHO.
- OneNeurology mapping of advocates worldwide via Global Partnership and other international public health NGOs. Please let us know if you have contacts in the regions identified during the meeting e.g. AFRO.
- Autumn workshops – regional or global? – based on the second draft of the GAP, with a focus on supporting advocacy at member state level. Let us have your thoughts on useful agenda items for inclusion.
- EU OneNeurology Summit December 2021 – invite to follow after summer.

RESOURCES

Link to the full slide deck with presentations and videos embedded (read-only file):

<https://tinyurl.com/ym6wchtt>

Link to the recording of session 2

<https://us02web.zoom.us/rec/share/IGTtLAoZYEKXsM6LXPR9ItF187SrOzrzXCGVtPpd2LFd0RMaCfNUtx2v42U6SoO2.bgScogcsvzoTiffj>

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Link to GAP draft and consultation process: <https://www.who.int/news-room/articles-detail/Web-based-consultation-on-the-first-draft-of-the-Intersectoral-global-action-plan-on-epilepsy-and-other-neurological-disorders>

And find out more at: www.oneneurology.net

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