

Synopsised comments of the [OneNeurology Partnership](#) to the draft Intersectoral Global Action Plan on Epilepsy and other Neurological Disorders (GAP), released by the WHO on June 18th, 2021.

We welcome the WHO secretariat's first draft GAP. We applaud WHO for its work leading up to creation of the Plan as well as for drafting the GAP itself. The draft GAP provides an ambitious, comprehensive, and multisectoral response to address neurological disorders, in order to improve the lives of people with neurological disorders, their families and carers, as well as to promote brain health.

We also acknowledge that WHO has taken on board many suggestions made by the OneNeurology Partnership during the first consultation on the GAP discussion paper. We are, now, working on a detailed joint submission to the current consultation. However, to accompany this detailed and targeted feedback, below we present our overarching position. This is based on the submissions of the OneNeurology Partners and Supporters, as well as on discussions held at the OneNeurology Global Advocacy Workshop on June 29th, referred to herein as 'Workshop'.

The OneNeurology Partnership has the following suggestions and comments to the draft GAP:

Accessible GAP with people at its centre

While strategic objectives are well set, at times they are also technical and highly conceptual. Concepts like governance are important but, at the same time, we should not forget that those living with neurological disorders should be at the centre of the plan, with the objectives built out from there.

This should be also reflected in the overall structure and wording of the GAP so that it is accessible, with clear relevance and has an overall tone of being about people and ensuring better outcomes in their daily lives. Perhaps this could lead to an accompanying version which is very much grounded in the real, lived experience of those affected by neurological disorders?

Along the same lines, Workshop participants expressed a clear need to prioritize advocating for the involvement of people living with neurological disorders – their families and carers – in the shaping, implementation and monitoring of the GAP. Equally important is ensuring that organizations representing these people are resourced to do so, particularly in LMIC settings where such advocates/groups are not always in direct contact with policy makers.

National neurological plans

National neurological/brain health plans will become critical vehicles for the GAP's implementation on the ground. Where possible, those should be stand-alone. This must be emphasized. It is not sufficient for Member States to state that neurology is implicitly covered by, for example, mental health strategies.

However, this does not preclude neurology also being an integral part of broader efforts in areas such as non-communicable diseases, ageing, disability, etc. In fact, it is imperative that neurology is strategically linked to these wider fields.

Similarly, disease specific efforts are also encouraged but should be rolled out within the context of a wider framework of activity on neurology as a distinct discipline. It is not acceptable for disease specific initiatives to be seen as hitting targets in this ten year plan. Against this backdrop, while welcoming the addition of a specific chapter on epilepsy, we also note that although epilepsy can represent an important entry point in many regions, it will not be applicable for some others. This should be clear in the text.

Finally, particular attention and efforts are needed to create an awareness among member states on the health and socio-economic benefits of a bundled approach to neurological disorders that can lead to development and deployment of these national plans/frameworks.

Dedicated budget

It is essential to ensure methodical mobilization of financial resources at all levels to safeguard a successful implementation of the GAP. Additionally, 75% countries with an identifiable budget line dedicated to neurology would be an important addition to target 1.1.

Integration of neurology and brain health into global health frameworks

As mentioned above, the integration and mainstreaming of neurological disorders within relevant global policies, action plans and frameworks will be critical. Currently, they are not sufficiently incorporated into broader global health priorities such as those on NCDs, SDGs or NCD-related COVID resources and assessments. For example, neurological disorders should be better visible as a group in “Global Health Estimates”, SDG 3.4, as well as properly included in the NCD Implementation Roadmap 2023-2030 or in NCD Country Capacity Surveys. In this work, WHO should fully depart from housing neurology under the category of ‘mental health conditions’. Given the high burden also coming from infectious diseases, and bearing in mind that they can cause neurological impairment, infectious disease linkages are also essential. The role of WHO Brain Health Unit will be instrumental to liaise internally with other WHO departments in order to align and strategically link up with work on NCDs and other portfolios. This is a key action for the secretariat.

Targets and indicators

Setting and monitoring indicators and targets was seen as the key action for the WHO Secretariat during the Workshop. In this regard, we very much support the GAP references about WHO offering technical support to Members States to *i. develop and/or reform national data collection systems, in order to strengthen multisectoral data collection for neurological disorders, ii. build national capacity and resources for systematic collection, analysis and facilitate the use of data related to neurological disorders, iii. develop a core set of indicators and targets in line with this action plan, other global action plans, WHO monitoring frameworks and national circumstances to monitor outcomes.*

However, we feel that the current targets/indicators should be strengthened, with targets on all important elements of the GAP included. This could cover: strengthening neurological workforce, improving quality of life, increasing patient and public involvement, further investment in research, etc.

Additionally, it will be important to set more intermediate and graduated targets, as well as a specific process for ongoing review – including baseline assessments and outcome measures to incentivize member states to start implementing the GAP as early as possible. Ultimately, targets will need to be tailored to fit the conditions of various regions. To this end, WHO regional offices can play a vital role in translating the GAP objectives into local realities. Finally, a global hub and mechanism to track the progress, understand the existing gaps, and generate more data would be a very important additional step. These processes are not obvious in the current GAP and should be added in more detail to ensure accountability.

Data generation and investment cases

It is important that WHO leads the way in generating data on cost effective interventions, risk and protective factors, return on investment case studies, best practices/buys, etc. This should include

updating existing and/or creating new evidence looking at socio-economic cost of neurological disorders globally. This is not only an action for the member states. We need better global data.

Furthermore, there is a great need to better understand how the main risk factors associated with other priority NCDs intertwine with those for neurological disorders, so that we can improve our understanding which will lead to a development of better disease-modifying strategies.

WHO Regional Offices

The importance of the WHO Regional Offices should be strengthened throughout the GAP. They can play an important role in mapping existing initiatives and unmet needs in their geographies, and can assist with monitoring, guidance, and technical support to member states in implementing the GAP. We suggest a specific role for regional offices is included in the text.

Other points

- We recommend that the **term “neurological disorders”** includes diseases of the peripheral nervous system, muscle diseases, as well as functional and rare neurological disorders.
- Due to their complex needs, as well as high levels of dependency and morbidity in later stages, neurological disorders require a range of coordinated health and social care measures. This includes **neurorehabilitation and long-term/palliative care** to provide relief from pain, physical, psychosocial and spiritual support and to enhance the quality of life. These are cross-cutting approaches that should be emphasised, and yet at the Workshop it was felt they were not given sufficient attention.
- More emphasis needs to be put on a **life-course focus, including antenatal influences** on brain development, childhood neurological disorders, to neurological disorders of later life.
- A stronger reference to **gender** should be made as a number of neurological **disorders impact women disproportionately**.
- **Importance of immunization** as a preventative intervention should be strengthened throughout the document.
- Ensuring **equitable access to quality care** for neurological disorders was voted as the key area for improvement during the Workshop. Adherence to treatment is equally important.
- Evidence based pathways should include uptake of **ICD 11 (e.g. stroke reclassification)**.
- **Clinical care guidelines** should be developed, where lacking, or updated as many are outdated, focusing on end points, which are not in line with patients’ unmet needs and therefore put barriers to meaningful clinical trials.
- More emphasis needs to be given to specific population groups e.g. **carers, young people, refugees, and asylum seekers**.
- The focus on raising **awareness of brain health** could be better **linked to raising awareness of neurological disorders**. It is important that those living with neurological disorders are not overlooked due to a wider focus on brain health promotion and disease prevention.
- Given the burden of neurological disorders, designating/endorsing a **global annual day** as well as a **global annual meeting** dedicated to neurological disorders/ brain health should be considered (e.g. mirroring the annual Global Mental Health Forum). This could include officially recognizing “the World Brain Day” or “Brain Awareness Week”.