

Personal information

Name

Tadeusz Hawrot

Organization

OneNeurology Partnership

Country

Global

Comments on the content of the first draft of the Intersectoral global action plan on epilepsy and other neurological disorders

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

There could be increased mention of the importance of immunisation in preventing neurological disorders considering that infectious disease is an important cause of neurological disorders.

2. Add in early life, including foetal life.

4. Economic costs are not mentioned and are significant. E.g. in Europe: *The economic cost of brain disorders in Europe. Eur J Neurol. 2012; 19(1):155-62 (ISSN: 1468-1331)*, and in the US: *The burden of neurological disease in the United States: A summary report and call to action Clifton L. Gooch MD, Etienne Pracht PhD, Amy R. Borenstein PhD*

Paragraph 4 clearly and correctly indicates stroke and migraine as the major contributors in terms of DALY, thus the reader (and the decision maker) might be a little confused about the focus put on epilepsy, while stroke, migraine and other highly disabling neurological diseases are relegated in the somehow diminishing definition of 'other' neurological disorders. Therefore, more context should be provided on why epilepsy is given specific attention.

5. Older populations can be also discriminated against (e.g. Alzheimer patients in COVID-19 triage).

A stronger reference to gender should be made as a number of neurological disorders impact women disproportionately. For instance, more women than men suffer from Alzheimer's. 65% of Alzheimer's patients in Europe are women. Men and women require different diagnostics and treatments, in the context of precision medicine.

Sex differences in Alzheimer disease - the gateway to precision medicine; Maria Teresa Ferretti et al. Nature Reviews Neurology 2018, <https://doi.org/10.1038/s41582-018-0032-9>.

6. Prevention of stroke is also highly important and should be stressed. In this context, a suggestion is to add/modify 6. as follows:

Many neurological conditions are preventable, as for instance epilepsy (25% of cases) and stroke (90% of cases).

6. Re. sleep, we should always keep in mind that each neurological disorder manifests in wakefulness and in sleep, and some manifest differentially in wakefulness and in sleep. Multiple neurological disorders have a strong impact on sleep (and wakefulness). But the relationship is bidirectional, and impaired or insufficient sleep has (mostly) negative impact on the manifestations/severity/cause of neurological disorders. Therefore, it is important that physicians

treating epilepsy and neurological disorders are aware of the differential manifestations and the mutual influences.

8. Add pregnancy related risk factors such as congenital infections, maternal intoxications, etc.

9. It is not only LMIC that have a low rate of dedicated policies for neurological disorders. No country in Europe has a stand-alone national neurology plan. One country – Norway has a brain health plan (bringing together neurological and mental health). This should also be referenced.

9. Not only health systems but all systems/sectors could provide improved health for those of all ages affected by neurological disorders. It should be emphasized more strongly that neurological disorders could benefit from intersectoral collaborations e.g. in education, employment, transportation, social sectors etc.

11. Despite the high burden of neurological disorders and frequent neurological manifestations related to COVID, neurological disorders currently are not sufficiently integrated in “broader global health dialogues” on NCDs, SDGs. etc. They are also not integrated into NCD-related COVID resources and assessments. Linking the IGAP with all those frameworks and action plans and fully integrating neurological disorders therein will be crucial. Some of these already include neurology, however this often happens in the framework of “mental health conditions”. Because language shapes the way we see the world, it is vital to always speak about neurology as a distinct discipline.. As such, WHO should fully depart from housing neurology under the mental health category. Wherever possible, the language in all relevant frameworks should be adapted to reflect this shift. Neurology should be more visible as a category in publications such as “Global Health Estimates”.

12. The term “neurological disorders” should also include diseases of the peripheral nervous system and muscle diseases which are very incapacitating. Therefore, the document should mention disorders like polyneuropathies, which have an estimated prevalence of 5-8%, depending on age (see: [PMC5832891](#)). Rare neurological disorders should be mentioned as well. Finally, functional neurological disorders are very prevalent and need to be included.

14. “Enhancing epilepsy prevention, treatment and care can represent an important entry point for, and foundation to build upon, services for other neurological disorders.”: “IN CERTAIN PARTS OF THE WORLD” could be added here - epilepsy as an entry point does not work everywhere.

Overall, the background text should deliver a main message that the GAP promotes leveraging integrated NDs prevention, treatment, rehabilitation, and care as the entry point for specific diseases. In support of the above, in paragraph 14, the following statement warrants specific mention in a stand-alone statement to emphasise the approach:

‘Rather than adopting a disease-specific structure, the Intersectoral global action plan on epilepsy and other neurological disorders uses an integrated, person-centred framework for the prevention, diagnosis, treatment, and care of people with neurological disorders, as many of these conditions share risk factors and/or require a similar systems-based approach.’

This is further supported by the current text in Objectives 1-4 that address neurological disorders, and do not single out specific diseases. The italicised statement above is followed by the italicised statement below that is contradictory and dilutes the advocacy for an integrated response.

15. The definition of good brain health must also encompass neural development, plasticity, functioning and recovery across the life course.

Further to this, the peripheral nervous system should also be included, and Brain health does not explicitly cover all “neurological” health. In this context, a suggestion is to add/modify 15. as follows:

The prevention of neurological disorders rests upon the promotion and development of optimal central and peripheral nervous system health across the life course. Good Brain/Neurological health is a state in which every individual can learn, realize their potential, and optimize their cognitive, psychological, neurophysiological, and behavioural responses while adapting to changing environments throughout all parts of the nervous system. Also, for information: <https://www.gbhi.org/news-publications/concept-analysis-and-definition-brain-health>

Given that brain health is influenced by eco-biopsychosocial determinants, it is important to ensure a good quality of life and wellness. A definition including emotional, physical and cognitive domains is important for policy, advocacy, research and practice.

Paragraph 15 calls for an additional point: the development of optimal brain health cannot happen unless research and innovation are supported and implemented. Research & Innovation are part of the strategies and they should also be mentioned here.

There is the need to ensure that palliative care is available for all people with neurological diseases or conditions if required and palliative care should be included in the development of all policies relating to neurological conditions.

Table 1 could include:

- reference to the 67th World Health Assembly in 2014 which recognised that “palliative care, when indicated, is fundamental to improving the quality of life, wellbeing, comfort and human dignity for individuals” and urged Member States to “develop, strengthen and implement palliative care policies “ (67.19, Agenda item 15.5).

- ‘Immunisation agenda 2030’ within the health systems category
<https://www.who.int/teams/immunization-vaccines-and-biologicals/strategies/ia2030>

2. Do you have any comments on the vision?

19. Significantly improving our understanding of brain functioning, both in its healthy and pathological aspects, is a vital step leading to reducing the onset of neurological disorders. Therefore, better understanding/decoding of the human brain could be an important part of the vision.

Treatments for neurodegenerative diseases are still lacking. Precision medicine, early diagnosis and tailored treatments for these diseases need to be improved.

Add. iv) Research on normal and on pathological brain and nervous system in general is not only supported but is one of the key areas that could bring benefits to improving global health. Understating the mechanisms of normal and pathological brain could bring innovation in terms of diagnostic, therapy, and restoration.

20. Add: acquired brain injuries, (due to any cause) are preventable.

It is important to ensure that people with neurological disorders, particularly those with progressive neurodegenerative diseases, are able to be cared for, with as good a quality of life and are able to die without avoidable distress. Palliative care is crucial in providing this care.

3. Do you have any comments on the goals?

80% of the 50 million people with epilepsy live in LMICs. Epilepsy is particularly important in LMICs and as such the entry point to NDs for LMICs may be epilepsy, whereas for other diseases

and other geographic areas this does not hold true. Considering that GAP needs to be global, every country should have its own, realistic entry point, corresponding to country's specific conditions, opportunities, and limitations. This will follow the main goal of the GAP, which is to recognize that neurology is a public health issue for all countries. To sum up, entry point could be epilepsy for some countries, perinatal care for other countries, organization of care for those affected by neurodegenerative disorders for other countries etc. There is NOT one entry point that fits all. Each country should define its own. This must be better reflected in the goals.

In this context, a suggestion is to amend paragraph 21 as follows:

In order to achieve the above stated vision and goal, leverage epilepsy prevention, treatment and care as an entry point in LMICs.

Alternatively, "where appropriate" could be added, so as not to suggest that the only way to achieve the stated goal is by using epilepsy as an entry point. As demonstrated above, this will not be applicable to many regions and countries.

In line with the above, paragraph 22 should emphasise neurological disorders. In this connection, it could be revised as follows: To strengthen the public health approach to neurological disorders and, in LMICs in particular, promote synergies with epilepsy.

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

23. ii. We are supportive to the overall life course approach. This is important from a dementia perspective too, which is often compartmentalised into an older persons condition but the risk reduction life course approach proves valuable in not only reducing risk but also broadening the perspective of the condition.

ii – to ensure an integrated approach to care across the life course palliative care, including end of life care, should be included.

v. "Empowerment, INVOLVEMENT, AND RESOURCING of persons with neurological disorders AND THEIR CARERS"

In general, participants to the OneNeurology Global Advocacy Workshop on June 29th 2021 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 Global Action Plan. It was felt that the plan needs to be grounded more and contextualised in the needs of those affected and their carers, using language to reflect this scope.

vi. Gender, equity and human rights – we support the emphasis on mainstreaming a gender perspective on a systems-wide basis in all efforts to implement public health responses to neurological disorders. This is central to creating inclusive, equitable, economically productive and healthy societies.

In terms of neurorehabilitation, it is important to underline universal accessibility to services for persons who are in need, timeliness of interventions, continuity of care, appropriateness and effectiveness of treatments.

The concept of work/employment could be introduced in Guiding Principles. Many neurological disorders are chronic lifelong diseases that may have a huge impact on work. But work is a means of accomplishment in life, thus it is important that attention is also devoted to help neurological patients to accomplish this right as best as they can, living and enjoying as possible also this important part of social life.

24. Add: maternal health.

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

General comments on objective 1:

25. Also: 'The integration and mainstreaming of neurological disorders within relevant GLOBAL policies'

1.1 ADVOCACY

General comments:

Awareness campaigns should be also tailored to those already living with neurological disorders. This could be linked to wider brain health promotion/disease prevention approaches. Public awareness campaigns and effective advocacy should also be based on an interdisciplinary approach, involving all stakeholders in the field and seeking to establish close cooperation between them in raising awareness on neurological diseases – advocacy experts, patients, therapists, doctors, carers, researchers etc.

29. This point could also mention immunization, seeing as universally recommended vaccines PCV and Hib prevent meningitis. Similarly, mentioning neurorehabilitation for improving the quality of life of those affected. Finally, palliative care, including end of life care and bereavement support, should be included.

Actions for Member States:

31. To include neurological disorders with palliative care policies and programmes, as in many areas these are restricted to cancer.

Actions for Secretariat:

Given the burden of neurological disorders, designating 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".

Encouraging the collection and exchange of health data and research findings between medical experts is crucial.

34. Building and enhancing these interlinkages will be crucial.

35. Provide technical support, **in cooperation with medical societies, national neurological societies and patient organisations**, to policy-makers at national, regional and global levels to recognize the need to prioritise neurological disorders and integrate them into policies and plans at all levels.

Actions for International partners:

36. Given that neurological disorders are the second leading cause of global mortality, it is essential to fully integrate them in SDGs and in particular SDG 3.4.

36. Raising awareness could also refer to preventative measures such as immunization.

36. In partnership with other stakeholders, advocate for increasing the visibility of neurological disorders in SDGs and other existing and new global commitments, and to prioritize neurological disorders in policy agendas by raising awareness **that i) they are one disease family with many common symptoms that require an integrated response across the life course and within healthcare systems, ii) of the social and economic impact of neurological disorders and iii) the benefits of effective treatments**

37. Ensure people with neurological disorders are **equally** included in activities of the wider community...

38. Creation of exchange and dialogue platform will be an important step forward. Exchange of research and knowledge between experts in the field is crucial, especially on an international level (exchange of best practices and findings).

1.2 POLICY, PLANS AND LEGISLATIONS

General comments:

Actions for Member States:

Include monitoring mechanism for collection, evaluation, and reporting of data regarding neurological conditions across the population.

43. Where possible, ideally member states should aim at creating stand-alone neurological or brain health strategies.

Particular attention and efforts are needed to create an awareness among member states on the health and economic benefits of a bundled approach to neurological disorders that can lead to development and deployment of those national neurological plans.

Also important to ensure palliative care policies are developed, funded and include neurological disorders within their remit.

45. Regarding a need for assessment for neurodisability in the context of meningitis, we know that even in the UK with a NICE guideline that says all children should be followed up after meningitis and assessed for sequelae, including neurological and referred to appropriate services, it does not always happen. And as meningitis incidence is highest in babies, neurodisability won't be evident until much later and link to meningitis forgotten/not considered. In LMIC countries this is much worse. Assessment for neurodisability isn't standardised. There are many different instruments measuring development and cognition in dissimilar ways, so comparability across studies and cultures is difficult. This can also include assessments of sensorineural disability i.e. hearing loss, given that is one of the biggest after effects from meningitis. And sight loss due to damage to the occipital lobe (cortical blindness).

Actions for Secretariat:

WHO Regional Offices can play an important role in ongoing monitoring, guidance, and technical support to member states in implementing the Global Action Plan according to participants of OneNeurology Global Advocacy Workshop on June 29th 2021. The role of the regional offices should be strengthened throughout the plan.

Support strategies for equal collection, evaluation, reporting of health data about neurological conditions across member states.

46. i. share knowledge and evidence-based best practices to inform the development, strengthening and implementation, **and evaluation of** national and/or subnational policies.

Actions for International partners:

1.3 FINANCING

General comments:

There is a need to update existing and/or create new evidence looking at socio-economic cost of neurological disorders globally.

We need to better understand the socio-economic impact and health gains of best practice healthcare interventions with an economic evaluation e.g. through effective neurorehabilitation measures.

Discussions should be shifted from thinking about costs to thinking about investment. More overt reference is needed to economic impact of proactive interventions to avoid a focus purely on costs, which can be a major barrier to governments.

There is the urgent need to tackle existing disproportionate investment in after-hospitalisation care settings and services across member states.

51. Palliative care should be available for all people, including neurological disorders, and funded services should be provided in all areas.

52. The multidisciplinary palliative care of people with neurological disorders has been shown to reduce costs as well as improving quality of life.

52. Resource mobilization strategies and approaches to increase investment could also mention vaccination.

52. Recent studies have shown the neurological work force to be insufficient in LMICs, but also in general. In this regard, the following modification is suggested:

There is an urgent need for resource mobilization strategies and approaches to increase investment in different areas including early interventions, new technologies, diagnostic methods and training of specialists and non-specialists **in neurological health, and exchange of expertise with LMICs. especially in LMICs.**

Actions for Member States:

53. Ensure sustainable funding for policies, plans and programmes for prevention and management including rehabilitation **based on an integrated response across life course approach for** neurological disorders through dedicated domestic budgetary allocations, efficient and rational utilization of resources, voluntary innovative financing mechanisms and other means including multilateral, bilateral, pooled funding, and public-private partnerships.

53. Palliative care should be funded appropriately to provide care for patient and families at all levels of health care.

53. Neurorehabilitation should be considered as a health intervention and thus should be provided as part of the essential care for children, adult, and old patients with neurological disorders.

54. Produce and/or utilize the most recent data on the epidemiological, ~~and~~ economic, **and social** burden of neurological disorders...

Actions for Secretariat:

Cost-effective, high-impact interventions for a larger number of neurological disorders should be developed and scaled up.

A strategic approach is needed to influence government's choices, aimed at achieving clear and specific outcomes in various neurological disorders. The secretariat could engage in activities to develop return on investment case studies, protective and risk factors, cost effectiveness analysis, etc.

56. Enable collaboration to develop palliative care services for progressive neurological disorders.

Actions for International partners:

The neurorehabilitation interventions can be expensive. It is important to identify functional gaps in resource allocation and help to facilitate economic resources for rehabilitation of neurological disorders.

International partners could also be involved in identifying and addressing 'waste' within healthcare systems and improving efficiency.

59. Ensure palliative care is included within developments, to maximise the use of health funding.

60. International global scientific and patients' association should participate in the definition of national strategies for brain health, neurological care, and for the definition of resource allocation, thus finding solutions to rank priorities fitting the national health needs.

61. Patients and the groups supporting patients should be involved in the decision making processes.

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

General comments on objective 2

Improved diagnosis and better coordinated care could be integrated with efforts on rare diseases. In Europe, there exists the European Reference Networks that pools resources in the rare diseases domain. There is also a global initiative for the undiagnosed: Undiagnosed Diseases Network International. Where similar initiatives don't exist, regions could be encouraged to pull resources together to create such networks.

This goal might be challenging in the case of rare neurological disorders such as Huntington's disease, as lack of awareness and stigma jeopardize an "effective, timely and response" approach to rare patients. Therefore, later in the feedback form, additional contents/clarifications to the GAP will be provided to address this.

Palliative care is no longer included in the care from primary health care (63). We support its inclusion not only at the primary care level but this also at secondary and tertiary health care levels, with collaboration with specialist palliative care services

Palliative care, including care at the end of life, will help to maintain quality of life and enable improvement in the quality of death, with the support and minimisation of distress for patients and families at the end of life, reducing further issues in bereavement.

There are parallels and substantial overlap between objective 2 and Pillars 2 and 4 of the Defeating Meningitis by 2030 global roadmap. Though the GAP does reference the Meningitis in 2030 roadmap in several places, in addition it would be helpful if it cross referenced to the relevant strategic objectives of the defeating meningitis road map where appropriate.

63. The link of neurological disorders with UN SDGs is very weak at the moment and has to be prioritized.

2.1 CARE PATHWAYS

Comments:

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, including long-term and palliative care to provide relief from pain, physical, psychosocial and spiritual support and to enhance the quality of life. Neurorehabilitation and palliative care are cross-cutting approaches that should be emphasised.

It is essential that the GAP emphasises the essential nature of not only hospital care, but the ongoing care that the vast majority of people with neurological disorders will need to ensure they live a good quality of life after they leave hospital.

We must ensure that the GAP refers to the importance and vital role that support organisations provide. These should be included in the care pathways.

65. There is increasing evidence for the effectiveness of multidisciplinary team care, including palliative care for neurological patients.

67. Consideration of a pathway “orientated to each stage of life” should include birth to death. End of life care is crucial and is part of the wider palliative care – which should be available for all patients according to need rather than disease or stage of progression.

69. Coordinated care is essential to manage complex issues – physical, psychological/emotional, social and spiritual, with earlier palliative care involvement not only maintaining or improving quality of life but allowing preparation for end of life.

Actions for Member States:

There is a need to develop strategies to provide effective and timely care to people at risk or suffering of neurological conditions in times of national/global emergency health crisis, like the COVID - 19 pandemic.

Technical support and policy guidance are needed to develop strategies for effective and timely care during emergency health crisis, like global pandemic.

71. Evidence based pathways should include uptake of ICD 11 (in particular the reclassification of stroke).

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.

71. and 72.: The inclusion of palliative care in the care pathways at all levels is important and there is the need for the development of the involvement of palliative care at all levels.

72. We support the implementation of integrated models of care from diagnosis to end of life, and would encourage the inclusion of palliative care services within these pathways.

73. The development of palliative care services, with appropriate funding, is important to ensure neurological disorders are cared for and included with palliative care services.

74. ... such as socioeconomically disadvantaged individuals, older people, **people in rural areas**, and others specific to each national context.

Actions for Secretariat:

77. It is important that WHO leads the way, in cooperation with groups like OECD, in generating data on cost effective interventions and best practices/buys.

78. Add: special schools / education or neurocognitive follow up to detect deficiencies over the long term (growing into deficits).

Actions for International partners:

We need to ensure gender-balanced representation.

2.2 MEDICINES, DIAGNOSTICS AND OTHER HEALTH PRODUCTS

General comments:

Ensuring equitable access to quality care for neurological disorders was voted as the key area for improvement during the OneNeurology Global Advocacy Workshop on June 29th 2021.

85. Limited availability/access is often an issue in high income countries too.

85. Essential medicines should be available in all areas, to support palliative care.

There is strong overlap between paragraph 86 and 90 and strategic goal 6 of the defeating meningitis roadmap. However, it is also important for neurological sequelae after meningitis to be recognised and appropriately diagnosed following the acute illness. This is covered by Strategic Goal 13 in the defeating meningitis by 2030 roadmap.

Actions for Member States:

88. Also ensure up-to-date, evidence-based diagnostic and treatment guidelines for neurological disorders.

88. Awareness of training especially in diagnostics for children and adolescents.

Re. 90 and 91: These transparent regulatory frameworks, resources, and capacity can ensure quality, safety and ethical standards that need to be established not only for medical products or devices but also for medical diagnostic procedures such as genetic testing (namely, predictive genetic testing and prenatal genetic testing).

Actions for Secretariat:

95. Those living with neurological disorders should be consulted about additions to the essential medicines list. Therefore, patient/carer involvement should be encouraged and enhanced in the regulatory and reimbursement processes of new technologies so that decision on access to care and prevention are patient centred.

With the plethora of medicines and other products it is difficult even for professionals to make the right choices. Guidelines from reliable sources are important help. This is recognized by WHO in paragraph 96.

We believe this is important to emphasize also in other sections:

84. Medicines, diagnostics, and other health products such as assistive technology, biological products, cell and gene therapy are essential for prevention, diagnosis and treatment to reduce mortality and morbidity and improve the quality of life of people with neurological disorders. **Up-to-date, evidence-based diagnostic and treatment guidelines for neurological disorders are the basis for rational employment of medicines, diagnostics, and other health products.**

89. Add at the end: Ensure up-to-date, evidence-based diagnostic and treatment guidelines for neurological disorders.

98. Add at the end: Help in ensuring up-to-date, evidence-based diagnostic and treatment guidelines for neurological disorders.

Actions for International partners:

98. Also help in ensuring up-to-date, evidence-based diagnostic and treatment guidelines for neurological disorders.

Neurorehabilitation can contribute to encouraging all relevant stakeholders to promote national efforts for affordable, safe, effective and quality medicines, and other health products for improving quality of life.

2.3 HEALTH WORKERS' CAPACITY BUILDING, TRAINING AND SUPPORT

General comments:

Suggestion to revise by moving text below to Action for Member States, under point 103 for separate and specific mention:

100. Building primary health care capacity, starting with general physicians, nurses, and paediatricians, provides an important opportunity to improve prevention, diagnosis, treatment, rehabilitation and for people with neurological disorders and promote brain health across the life course.

The collaboration among specialists of different disciplines characterizes the neurorehabilitation work. The neurorehabilitation team includes neurologists, neurosurgeons, neuroradiologists, neuropsychologists, neurophysiologists and nurses, physiotherapists, occupational therapists, speech therapists....) The specific education in taking care of patients with neurological disabilities ensures the appropriateness of interventions.

101. There is a need for training of neurologists and primary care in palliative care and palliative care teams in the care of people with neurological disorders.

103 mentions 'strengthen health and social care workforce capacity to rapidly identify and address neurological disorders, including common comorbid conditions such as infectious diseases'. There is considerable overlap with Strategic Goal 6: Improve diagnosis of meningitis at all levels of care. Especially the following key activity which underpins this: Establish appropriate training and supervision of health workers at each level of care for timely identification, diagnosis, referral and treatment of meningitis in all age groups.

Actions for Member States:

103. ... primary healthcare workers and include (...):
Rapid identification and approach to neurological disorders by the health and social professionals is at stake for complex rare neurological disorders such as Huntington's disease. Thus, training initiatives about the specificities of rare neurological diseases should be promoted among primary healthcare workers and other key professionals.
ii. developing career tracks for neurological workforce by strengthening postgraduate **multi-disciplinary and multi-sectoral** training and work in partnership with medical societies to raise awareness on the attractiveness of working in brain/neurological health;

Suggestion to include acquisition of digital skills as a priority for all health personnel.

Actions for Secretariat:

105. There is a need to develop a collaborative, international approach to develop training and education in palliative care, with the appropriate funding and resources to provide this training.

106. The development of social care is important

Actions for International partners:

108. International exchange programmes for training and education can be of great value – similar to Erasmus+, but for healthcare staff.

2.4 CARER SUPPORT

General comments:

Women are more likely to be carers than men.

<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4804270/>

The COVID-19 Pandemic has increased the caring responsibilities on women.

<https://www.independent.co.uk/news/uk/home-news/women-childcare-job-quit-gender-inequality-b1814526.html>

Add supportive care for teachers in school with children with neurological disorders. For example, in the case of epilepsy, not all recognise (subtle) seizures or know what to do when a more severe seizure occurs.

There is considerable overlap between paragraph 114 and SG 14 of the defeating meningitis roadmap: Increase the availability of and access to appropriate care and support for: (i) people affected by meningitis; (ii) their families and carers.

It would be helpful for the carer support section to cross reference to the defeating meningitis roadmap and perhaps apply some of these activities to neurological disorders in the wider sense as they are applicable to all neurological disorders, not just meningitis.

112. Challenges for carers include stress, role strain, financial burden, social isolation **and discrimination, as well as** bereavement.

Actions for Member States:

Develop accessible and cost-effective services for mental health support to carers of people with neurological disorders.

114. Provide accessible and evidence-based information on available resources in the community such as training programmes, to navigate the health and social system, respite services and other resources tailored to the needs of carers of people with neurological disorders to enable people with neurological disorders to live in the community and to prevent carer stress and health problems.

116. There is the need for support of carers practically and financially – with policies to allow families to be involved in care, if they wish to do so.

117. It is important to be aware of the wishes and preferences of families, but if the patient has capacity to make decisions, these should always be respected.

Rare neurological disorders such as Huntington’s disease may represent an additional stress to the emotional balance of informal carers - mainly because of isolation and stigma. Therefore, training opportunities to know and meet other carers should be explicitly included in the social support resources provided by the community.

Actions for Secretariat:

Actions for International partners:

It is essential to increase awareness of educational programmes addressed to informal carers. In particular when the rehabilitation care is provided within a Community Delivered Rehabilitation setting.

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

General comments on objective 3:

In general, the promotion of brain health can be linked to raising awareness of neurological disorders.

122. A host of neurological disorders share similar risk factors with other major NCDs. We know from studies that more effective risk factor modification is required to reduce the increased burden. However, researchers found little or no causative explanation for the neurological diseases among the 84 risk factors that were quantified in the neurological disorders in the Global

Burden of Disease, apart from stroke and to a lesser extent, Alzheimer's disease and other dementias and idiopathic epilepsy. Therefore, there is a great need to better understand how the main risk factors associated with other priority NCDs intertwine with risk factors for neurological disorders, so that we can improve our understanding which will lead to a development of better disease-modifying strategies.

123. Implementing interventions also to help reducing stress and encouraging mental health and well-being.

125. UHC is one component but brain health is the result of a coordination of all policies towards the promotion of healthier citizens. Thus together with UHC it should be recognized that education, labour, social, and other policies contribute to brain health.

3.1 PROMOTION OF OPTIMAL BRAIN DEVELOPMENT IN CHILDREN AND ADOLESCENTS

General comments:

126 Enable early diagnosis. Newborn screening is imperative to detect and prevent morbidity in treatable neurological disorders.

131. Provide the resources for children to participate in physical activity, e.g. park / playground facilities for children with disabilities.

130 and 132: Add the development, funding, and support/enhancement of local policies regarding healthy environment with natural resources, to stop water exploitation, air pollutants, and deforestation. Additionally, as indicated above, brain health is the result of a coordination of all policies towards the promotion of healthier citizens. It should be recognized that education, labour, social, and other policies contribute to brain health.

136. ... the harmful use of alcohol, **tobacco and other harmful illicit drugs**, particularly during pregnancy.

139. Also strengthen surveillance mechanisms for brain health and development in children and adolescents having a background of neurological conditions in the family.

Actions for Member States:

132. As a first step, more data is needed on protective and risk factors.

132 Enable early diagnosis.

136. Include during pregnancy and pre- conception.

139. Strengthening surveillance mechanisms for core indicators of brain health will be critical across the whole life span.

Actions for Secretariat:

140. We recommend stressing the need for the secretariat to work internally with other WHO departments to align and strategically link up with work on NCDs and other portfolios. This should include a proper recognition of neurology (not merely nominally) in publications such as "Global

Health Estimates”, full inclusion of neurology in NCD Implementation Roadmap 2023-2030, NCD Country Capacity Survey etc.

140 i. enhancing leadership within health ministries and other relevant sectors for the development, strengthening, implementation, **and evaluation** of evidence-based national and/or subnational strategies or plans

Concerning children’s health, closer collaboration with relevant international organizations such as UNICEF, UNESCO, could contribute to enhance children’s brain health.

Actions for International partners:

141. There is a need to provide access to trained child health care workers and experts who appreciate developmental needs of children and adolescents.

3.2 PROMOTING HEALTHY BEHAVIOUR ACROSS THE LIFE COURSE

General comments:

Promoting healthy behaviours should include healthy diet, physical and mental exercise, healthy sleep, social interaction.

There is a need to generate more evidence on risk factors as well as to communicate and inform the public about risk factors, in order to strengthen prevention.

In addition, there is a need to further strengthen 1. health literacy, among the lay public, on brain and brain health (the brain is an organ like any other); 2. the consideration of sex and gender specific risk factors for designing preventative strategies.

Secondary prevention is one of the objectives of neurorehabilitation to promote healthy lifestyles to prevent and control cerebrovascular and neurodegenerative diseases and to maintain the recovery achieved after neurorehabilitation treatments.

The removal of urban barriers represents an important goal for access, e.g. to sports facilities and can increase the physical activity’s importance among population.

142. Emphasise the need to promote healthy behaviour in early life and educate children in a healthy lifestyle to prevent neurological future problems.

142. Promoting and emphasizing brain/**neurological** health...

These risk factors include physical **and mental** inactivity, obesity, unbalanced diets, **missing social interaction, unhealthy sleep patterns**, tobacco use, and the harmful use of alcohol.

144. Provide the resources for children to participate in physical activity, e.g. park / playground facilities for children with disabilities.

146. Add that foetal alcohol syndrome, and alcohol/drug abuse in childhood/adolescence, if not prevented, can result in neurological disorders.

146. Add the use of other (smart) drugs in adolescents.

147. Healthy sleep is important for brain, body and mental health in child- as well as in adulthood. Sleep loss and disorders represent risk factors for multiple neurological disorders, including stroke, epilepsy and dementia.

Therefore, the outstanding importance of sufficient good quality sleep cannot be underestimated, and at all levels of interventions; from government/ public health to local institutions, every attempt should be made to increase awareness, and to empower professionals to understand the importance of sleep, take suitable measures to improve sleep environment and sleep conditions, and to recognize and adequately treat independent comorbid or associated sleep disorders. Against this backdrop, the GAP should put more emphasis on sufficient good quality sleep across all its levels.

Actions for Member States:

148. 'Support actions shown to reduce the risk of neurological disorders across the life course' does not mention vaccination as a healthy behaviour. This is a significant gap because prevention of neurodisability is a strong reason to get vaccinated against meningitis. This could be added to tie in with SG1, 18 and 19 of the defeating meningitis roadmap.

Actions for Secretariat:

150. A need to strongly emphasize a role of WHO in terms of linking up neurology with wider NCD and other agendas.

151. This should include proactively looking at evidence generation.

Actions for International partners:

3.3 INFECTIOUS DISEASE CONTROL

General comments:

Further impacts of meningitis to consider: Specifically sensorineural hearing loss and sight loss, developmental delay (in children too young to be shown to have cognitive deficit), and communication deficit (which may be due to cognitive impairment and inability to learn language or loss of language already learned, hearing deficit, or motor impairment affecting movement of mouth, tongue, vocal chords, etc).

155. Include: Torch syndrome and Rubella is preventable by vaccination.

Actions for Member States:

157. Could also mention aligning with the strategic goals under pillar 2 of the defeating meningitis roadmap – diagnosis and treatment – because prompt recognition of meningitis, prevention of GBS through improved diagnostics and improved treatment for meningitis would reduce rates of neurological disability as an after effect of meningitis and neonatal sepsis.

Actions for Secretariat:

Actions for International partners:

162. In the present pandemic situation, the long COVID neurological consequences impose that international scientific and lay association promote a better dissemination of patients' support measures in terms of diagnostic, and therapeutic, care, since many of the symptoms are to be better defined and there is a gap in knowledge that will need to be filled.

3.4 PREVENTING HEAD/SPINAL TRAUMA AND OTHER INJURIES

Comments:

Traumatic brain injury and spinal cord injury represent a big challenge for neurorehabilitation. It is important to stress the importance of campaigns to prevent traffic, work and sports accidents.

163. Provide education and guidance on the management of children especially to avoid non-accidental head injury.

163. The prevention of traumatic brain injury and spinal cord injury should specifically include the association of repeated mild head trauma with chronic traumatic encephalopathy and the increase in dementia risk. In this context, it is suggested to revise:

...are also preventable. Furthermore, **repeated mild head trauma is associated with chronic traumatic encephalopathy and with the increase in dementia risk.**

Actions for Member States:

168. Define strategies for long term care for the survivors of TBI that remain with mental and physical impairments and that often are abandoned by the health and social systems as unable to provide to themselves and not able to enter into a protective disability policy support. Avoid euthanasia of those surviving with disorders of consciousness due to TBI, thus plan for support systems for patients and their families.

Actions for Secretariat:

172 Coordinate long term strategies to support patients with long term cognitive or physical consequences of TBI.

Actions for International partners:

174. Avoid discrimination of those surviving with disorders of consciousness due to TBI, thus plan for support systems for patients and their families and in those countries where no association is available, the international associations should support the development of national associations.

3.5 REDUCING ENVIRONMENTAL RISKS

General comments:

178. Climate change will in the future change the pattern of infectious disease, e.g. malaria in countries not exposed to this disease. Vaccination is an important tool to prevent infectious disease.

Children can suffer from high temperatures and seizures in places with hot climates.

Environmental factors can present a risk to pre-natal development.

Actions for Member States:

179. Emphasize a need for evidence generation.

Actions for Secretariat:

Actions for International partners:

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

General comments on objective 4:

It is important to emphasize that it is the immense complexity of the brain that explains why the progress in this field is slow and costly. This calls for allocating more resources for neuroscience.

Innovative health technologies are useful not only in prevention, risk reduction, early diagnosis, but also in rehabilitation treatment.

While significant investments in neurological research have been made in high-income countries, a small proportion of funding concerns neurorehabilitation. This research imbalance needs to be improved in all countries and in particular in LMICs.

185. There is a need for research into the most effective palliative care / end of life support which can apply in all areas of care.

Information systems for neurorehabilitation have to be implemented to facilitate the knowledge about the prevalence of neurological disabilities and to support policy for programmes and resources accordingly.

4.1 INVESTMENT IN RESEARCH

General comments:

191. Research is needed in all aspects of care as well as prevention / treatment to facilitate the most appropriate and effective care for people with neurological disorders.

194. Concerted action to build research infrastructure, strengthen human resource in research and development, and increase collaboration among the research community, manufacturers, health professionals, **patients' representatives**, and programme managers...

213. overlaps with SG14 of the defeating meningitis roadmap especially the following key activity - Map out existing services and support systems available by country for: (i) children and people with disabilities, including those with meningitis sequelae, and (ii) families/carers of people affected by meningitis; identify barriers to access, availability, and use, with the involvement of organizations for persons with disabilities and other networks where possible, and undertake a gap analysis to improve service provision.

Cross referencing to the meningitis roadmap may help avoid duplication of efforts at country level.

Actions for Member States:

196. The use of international organisations and collaboratives will enable a worldwide approach to research – using the available networks.

The collaboration of all involved in the care of people with neurological disease is important in developing a research strategy, and care research should be included.

196. Clinical trials for developing new drugs to take place on children in the early stages.

199. Also, involve patient organisations in the process.

Actions for Secretariat:

200. Research will need to be facilitated and collaborations encouraged.

201. All WHO centres, including those involved in palliative care, should be involved.

Actions for International partners:

4.2 DATA AND INFORMATION SYSTEMS

General comments:

209. This is often also the case in high-income countries.

210. and 211. Routine information should include details of symptoms / issues / place of care and place of death – to allow monitoring of palliative care service.

The development of patient outcome measures will allow the palliative care and other issues that are important to patients and their families to be monitored and appropriate management put in place.

Actions for Member States:

Also encourage international exchange of research information.

Actions for Secretariat:

214. We strongly support those actions, and in particular developing a relevant core set of indicators and targets.

214. The development of systems that can be shared internationally should be a priority.

Actions for International partners:

216. The involvement of people with neurological disorders, their families and carers in the will be fundamental in this effort.

216. Support national and international registries to generate collaboration and evidence to raise awareness of neurological problems.

217. Inclusion of patient outcome measures should be encouraged to ensure the care of patients and families are truly represented.

OBJECTIVE 5: TO STRENGTHEN THE PUBLIC HEALTH APPROACH TO EPILEPSY AND PROMOTE SYNERGIES WITH OTHER NEUROLOGICAL DISORDERS

General comments:

Change the title: TO STRENGTHEN THE PUBLIC HEALTH APPROACH TO NEUROLOGICAL DISORDERS, INCLUDING EPILEPSY

Epilepsy is one of the many neurological disorders that affect people worldwide. It could be used as an entry by some countries where neurological care is not existing, serving as a case model to organize prevention, care, rehabilitation and social support. Following this approach, other neurological disorders could be selected by each country to increase brain health by tackling one or more neurological disorders from bench to bedside and to social integration.

Death may occur in epilepsy, and the care of carers and families coping with sudden death in their bereavement is important. Palliative care services have a role in supporting such care and the experiences can be transferrable to epilepsy and neurological services, so that extra support is available.

5.1 ACCESS TO SERVICES FOR EPILEPSY

General comments:

226. The inclusion of support for families and professional teams in bereavement, particularly after sudden, unexpected death, is important and should be included within the public health approach.

Actions for Member States:

229. The medicine adherence is also a major problem in Epilepsy that needs to be accounted for.

230. Promoting synergies with other neurological disorders also provides a useful rationale for highlighting where the GAP overlaps with existing global initiatives such as the defeating meningitis by 2030 roadmap.

Actions for Secretariat:

Actions for International partners:

5.2 ENGAGEMENT AND SUPPORT FOR PEOPLE WITH EPILEPSY

General comments:

252. Good multidisciplinary team care can be transferred to the care of other neurological disorders, with evidence of improvement in quality and length of life.

Actions for Member States:

Actions for Secretariat:

Actions for International partners:

The global approach as well a structured organization are pre- requisites to establish a neurorehabilitation vision and to develop appropriate and equitable pathways of care for people with epilepsy and other neurological disorders.

5.3 EPILEPSY AS AN ENTRY POINT FOR OTHER NEUROLOGICAL DISORDERS

General comments:

250. Use epilepsy as case study and as public health success keeper. If a country is unable to deal with one of the few neurological disorders where treatment is available and can be successful, how can the country be successful in the other disorders in providing all the necessary steps for optimal research, prevention, diagnosis, care, treatment, and recovery?

It is important to underline here that this approach can be applicable in some parts of the world and not necessarily relevant in some others.

Actions for Member States:

Epilepsy can be chosen as starting point for the development of a national plan to promote brain health and fight neurological disorders. If no neurological care exists, starting with care of epilepsy is sensible.

Otherwise, if neurological care is in place, monitor epilepsy care as case model.

In ranking national priorities it should be defined which are the national neurological priorities to be tackled at first. For some countries this could be epilepsy, for others stroke and its consequences, for others dementias and neurodegenerative disorders, for other migraine and headaches.

Actions for Secretariat:

Actions for International partners:

National partners should be aware of epidemiology of neurological disorders at national level. The burden of diseases studies can help in setting national neurological priorities, if no other data is available.

ANNEX: COMMENTS ON GLOBAL TARGETS AND INDICATORS FOR EACH STRATEGIC OBJECTIVE

Strategic objective 1:

GENERAL COMMENTS TO TARGETS

Setting and monitoring indicators and targets was voted as the key action for the WHO Secretariat during the OneNeurology Global Advocacy Workshop on June 29th 2021.

Ultimately, targets will need to be tailored to fit the conditions of various regions and income levels. To this end, WHO regional offices can play a vital role of translating the GAP objectives into local realities and setting national targets.

It will be important to set more intermediate targets, as well as a specific process for ongoing review, and outcome measures to incentivize member states to start implementing the GAP as early as possible.

A global hub and mechanism to track the progress, understand the existing gaps, and generate more data would be a very important additional step.

It would be helpful to already have more clarity on how WHO will map the baseline, ongoingly measure and advise, etc.

The following additional targets could be included:

- Increasing neurological workforce across the whole care pathway. E.g. increase specialization in neurology by x% every 2 year
- Improving training in brain health and neurology to PHC providers
- Patient involvement in publicly funded R&D, regulation, reimbursement
- Improving quality of life of patients and carers
- Integration of neurology into NCD related global programmes
- Target on rehabilitation (as stated in this draft, currently only 16% of countries report specialized neurorehabilitation services and only 17% report general rehabilitation units that offer neurorehabilitation)
- Palliative care target

SPECIFIC COMMENTS TO TARGETS:

1.1 Where possible, neurology/brain health should have standalone national plans. Where this will not be the case, it will be important that neurological disorders are explicitly included in wider strategies rather than for example be covered in mental health conditions plans – in which case these often don't go beyond conditions like AD and epilepsy.

75% countries with an identifiable budget line dedicated to neurology would be an important addition to this target.

Re. synergies with Dementia GAP and country plans, it would be helpful to have some clarity here that emphasises the importance of developing national dementia plans/strategies (a key action of the Dementia GAP), which can be improved/enhanced with the inclusion of neurological actions/targets. Otherwise, in some cases, governments could develop watered down dementia responses as part of a broader neurology based response. In view of dementia plans and Dementia GAP targets, a group condition plan/strategy would be fine if it contained the specific actions of the Dementia GAP but experience shows that this tends not to happen

1.2 Indicator should make it clear that the campaign must address more than one neurological disorder and a cross cutting issues, as opposed to for instance ticking the box by having a campaign on stigma or one neurological disorder only.

Strategic objective 2:

Medicines should be available and affordable

There is considerable overlap between this objective and Pillars 2 and 4 of the defeating meningitis roadmap – so some targets from the meningitis roadmap could be relevant or adapted to address neurological disorders more broadly.

<https://apps.who.int/iris/bitstream/handle/10665/342010/9789240026407-eng.pdf>

Strategic objective 3:

Strategic objective 4:

4.1. Core set on indicators should include place of death and consider patient outcome measures.

There is overlap between this objective and Pillar 4 of the defeating meningitis roadmap – especially in relation to strategic goal 14, so some targets from Pillar 4 of the meningitis roadmap could be relevant or adapted to address neurological disorders more broadly.

<https://apps.who.int/iris/bitstream/handle/10665/342010/9789240026407-eng.pdf>

Strategic objective 5:

Add a target: to have in the national health plan a clear identification of neurological problems at country level.

Add a key indicator: to have chosen at least one neurological disease that is epidemiologically relevant for the country and identify proportion of patients that use the services identified for that neurological disorder

Indicator set in Global target 5 (increased service coverage for epilepsy by 20% by 2031) could be expanded to cover all neurological disorders and ii) a corresponding adjustment of the indicator could be made in relation to the suggested expansion to cover all neurological disorders.

6. Please provide any general comments on the discussion paper of the intersectoral global action plan on epilepsy and other neurological disorders in the field below.

The OneNeurology Partnership welcomes 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 very much hope that our comments provided to the GAP draft will contribute to adopting a plan that will truly contribute to improving the lives of those affected by neurological disorders, as well as to promoting brain health across the globe.

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.