

FIRST DRAFT OF THE INTERSECTORAL GLOBAL ACTION PLAN ON EPILEPSY AND OTHER NEUROLOGICAL DISORDERS

SUMMARY OF COMMENTS AND VIEWS

(NOT AN OFFICIAL DOCUMENT)

In November 2020, the Seventy-third World Health Assembly (WHA) adopted resolution WHA73.10 on **GLOBAL ACTIONS ON EPILEPSY AND OTHER NEUROLOGICAL DISORDERS**, requesting the Director-General, inter alia, to develop an intersectoral global action plan on epilepsy and other neurological disorders in consultation with Member States to ensure a comprehensive, coordinated response across multiple sectors.

The World Health Organization (WHO) Secretariat is following a clear process to develop the Intersectoral global action plan on epilepsy and other neurological disorders. In March 2021, the WHO Secretariat published a discussion paper on the Intersectoral global action plan on epilepsy and other neurological disorders on which Member States, United Nations (UN) agencies and relevant non-State actors shared their comments through virtual and web-based consultations. This then led to the development of the first draft of the Intersectoral global action plan on epilepsy and other neurological disorders. The Secretariat subsequently implemented the following consultation process on the first draft of the action plan:

- From June 2021 until August 2021 web-based consultations were carried out to seek comments from Member States, UN agencies and relevant non-State actors on the first draft.
- The first draft was also presented to Member States, UN agencies and relevant non-State actors in virtual meetings and feedback was obtained. This included regional consultations to obtain feedback from Member States.
- A series of virtual consultations was also held with people with neurological disorders, carers and families for specific input from those with lived experience

In total, feedback on the first draft was received from 71 Member States and 75 relevant non-State actors. The consolidated comments received from all stakeholders are presented here following the structure of the first draft: overall feedback; feedback on the scope, vision, goals and guiding principles; feedback on each strategic objective including on actions for Member States, Secretariat and international and national partners; and feedback on the global targets and indicators.

OVERALL FEEDBACK ON THE FIRST DRAFT

The first draft of the Intersectoral global action plan on epilepsy and other neurological disorders was noted to be a timely and important document, with the focus to promote brain health and prevent neurological disorders across the life course appreciated. It was noted that the draft 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 globally. The multi-stakeholder and multisectoral approach of the action plan was welcomed, as were the links to other resolutions and global commitments relevant to neurological disorders with complementarity and alignment with existing efforts. Also appreciated were the engagement and involvement of people living with epilepsy and other neurological disorders. Multiple comments were received on alternate wording and edits to specific paragraphs and while these are not all listed here, they have been noted. Many comments received are also relevant across different sections of the first draft. These suggestions are listed once below, noting that they are applicable to multiple sections of the draft.

- The inclusion of a strategic objective on the public health importance of epilepsy was appreciated with further comments on the need to highlight epilepsy within different sections of the action plan. Simultaneously, the inclusion of all neurological disorders within the action plan was supported by many and it was suggested that each country prioritize conditions according to their own context and challenges.
- The importance of ensuring that people with neurological disorders are actively involved in all areas of policy making, legal review, design, and planning of services from the onset of each process was noted.
- The need to include further attention to the specialized needs of children, adolescents and young adults transitioning into adulthood was noted.
- There was appreciation on the emphasis on disparities in low- and middle- income countries (LMICs) when it comes to epilepsy care, particularly around access to service and disease prevalence. It was further noted that the plan could also highlight disparities in other neurological disorders.
- Regarding global targets and indicators, comments were received on the need to strike a balance between being aspirational while also considering the feasibility of measurement and reporting.
- There were suggestions to change the order in which the strategic objectives are presented to improve the readability and flow of the action plan. For example, it was suggested that current strategic objective 1 on raising the prioritization and strengthening governance for neurological disorders be placed as the last strategic objective and strategic objective 5 on strengthening the public health approach to epilepsy and promoting synergies with other neurological disorders be placed before the objective on research and information systems.
- There were suggestions to consider changing the order of “prevention, diagnosis, treatment and care for people with neurological disorders” to read “diagnosis, treatment, care and prevention” to keep the listing consistent throughout the document.

GENERAL COMMENTS ON SCOPE, VISION, GOALS AND GUIDING PRINCIPLES

BACKGROUND AND SCOPE

Overarching comments on the background and scope suggested the inclusion of an explanatory paragraph on the synergies between epilepsy and other neurological disorders incorporating information from the 2019 WHO report “Epilepsy: a public health imperative” and from the successful WHO Programme on reducing the epilepsy treatment gap, in order to provide information and clarify on why epilepsy specifically is a focus of the action plan. It was further noted that national neurological policies should strive to be standalone plans and encompass neurology as a whole, rather than focusing on one or two diseases. The value of having all three levels of WHO, i.e. Headquarters, Regional and Country Offices, supporting implementation of the action plan

was highlighted. While many suggestions were received to enhance the background section and scope, feedback was also received that the action plan should strive to be more of a policy document than a technical document.

Specific comments included:

- To balance the representation of all neurological disorders by including diseases of the peripheral nervous system and muscle diseases such as polyneuropathies and neuromuscular disorders.
- To address cancers of the nervous system, congenital neurological disorders and rare neurological disorders and the importance of prevention, recognition, early diagnosis, treatment and care for these disorders.
- To highlight the significant economic costs of epilepsy and other neurological disorders.
- To consider a paragraph on research and innovation as part of the scope leading to diagnosis, treatment, rehabilitation and health systems improvements.
- To include an increased focus on gender, considering that a number of neurological disorders disproportionately impact women.
- To include the importance of palliative care availability and accessibility soon after diagnosis and throughout the disease trajectory in order to optimize quality of life.
- To consider the differences among countries and their various needs according to domestic context and provide flexibility for implementation of the action plan, while incorporating experiences from other countries or communities that are further along with the action plan objectives.
- To further highlight the effect of the COVID-19 pandemic on people with epilepsy and other neurological disorders including disruption of services, medication inaccessibility, interruption in vaccination programs and increased mental health issues.

VISION

Many stakeholders agreed with the stated vision. Some feedback received included the recommendation to divide the vision into three areas including prevention, mortality/morbidity and quality of life in order to facilitate measurement and assessment. In addition to highlighting the medical care aspect of neurological disorders, it was also suggested that socio-economic and environmental determinants of neurological disorders and the issue of stigma be included. Finally, it was noted that the concept of “fulfilling potential” is ambiguous and may be difficult to accurately assess and can be replaced by reference to “quality of life”.

Other suggestions were to formulate the vision to also capture the benefits for carers, and the economic gains of better neurological care for the individual, community and society.

GOALS

The goals of the action plan were appreciated by many. The main comment for the goal section was to include the importance of raising public awareness, education and knowledge of epilepsy and other neurological disorders and to identify and address the unique problems in those who are socioeconomically disadvantaged and suffering from gender bias and stigma. Further emphasizing the role and challenges faced by carers and family members, including siblings, was also recommended. Specific comment included:

- To consider adding the words “where appropriate” in order to clarify that epilepsy may not be a feasible entry point in many regions and countries to achieve the stated goals.

GUIDING PRINCIPLES

Comments received were in general agreement with the guiding principles stated in the first draft. It was suggested that an additional guiding principle be added, referencing the need for focused, specialized, and age-appropriate care for adolescents transitioning to adulthood and adults transitioning to older ages. The empowerment, involvement and resourcing of carers was also emphasized.

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

GENERAL COMMENTS

There was appreciation for highlighting the engagement of people with neurological disorders and carers and protecting their human rights.

Additional comments included:

- To consider providing more clarity on what is involved in strengthening “governance” for neurological disorders.
- To emphasize the need for social protection of carers; for example, by revising workplace policies, cash transfer programs, or programs for persons with disabilities. To improve those policies to include persons with neurological disorders and their caregivers.
- To underscore the importance of changing the major structural and attitudinal barriers to achieving positive brain health outcomes.
- To emphasize the importance of offering “a voice to the voiceless” especially with regards to underprivileged persons. Increasing knowledge, awareness and dispelling myths should be addressed for all stakeholders to reduce stigma and discrimination, promote the human rights of people with neurological disorders and improve medical care and quality of life.
- To consider monitoring and reviewing of disability laws, especially from a perspective of being more inclusive for neurological disabilities.

1.1 ADVOCACY

GENERAL COMMENTS

Many comments supported this action area. Specific comments included:

- To consider linking advocacy to wider brain health promotion/disease prevention approaches.
- To consider the inclusion of education on health seeking behaviours for neurological conditions within public awareness campaigns.
- To emphasize that people with neurological disorders and their organizations should be at the centre of all advocacy efforts.

- To consider adding specific references to sectors such as the justice system and the financial sector when making the point about the need for dialogue and engagement with different sectors.
- To consider inclusion of health education programs with clear guidance of the patient journey from detection and diagnosis to treatment (e.g. pharmacological side effects), and care access including follow up rehabilitation services to empower patients and caregivers.

ACTIONS FOR MEMBER STATES

- To highlight the importance of public awareness campaigns and effective advocacy that should be based on an interdisciplinary approach, involving all stakeholders and seeking to establish close cooperation in raising awareness of neurological diseases and conditions – for example, advocacy experts, therapists, doctors, people with neurological disorders, carers, researchers etc.
- To emphasize the need for flexible educational and work environments for people with neurological disorders.

ACTIONS FOR SECRETARIAT

- To document the different models and best practices in countries' responses to neurological disorders, as this could help others start actions in their countries.
- To consider designating a global annual day as well as a global annual meeting dedicated to neurological disorders/ brain health (e.g. mirroring the annual Global Mental Health Forum). This could include officially recognizing "World Brain Day" or "Brain Awareness Week".
- To emphasize the role of medical societies, national neurological societies and patient organizations in providing technical support to policy-makers at national, regional and global levels to recognize the need to prioritize neurological disorders and integrate them into policies and plans at all levels.
- To consider adding stigma training for policy makers.
- To provide support to Member States with specific guidance on prioritization of advocacy efforts and a checklist of actions that could be chosen as part of their response.
- To create an advocacy toolkit that can help people advocate in their own countries and implement the action plan.
- To offer support and guidance on how Member States can encourage inclusion of people with neurological disorders across all age groups, including adolescents and older adults with neurological problems, in society and service planning.

ACTIONS FOR INTERNATIONAL AND NATIONAL PARTNERS

- To highlight the need for raising awareness i) that neurological disorders 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) of the benefits of effective treatments.
- To emphasize the need to raise awareness on evidence-based treatments to prevent incorrect and/or inadequately supported care.

1.2 POLICY, PLANS AND LEGISLATION

GENERAL COMMENTS

- To highlight that all laws relevant to persons with neurological disorders should be updated to align with current international human rights standards.
- To underscore the importance of supporting the integration and mainstreaming of neurological disorders within relevant national and local palliative care policies.
- To underscore the need for insurance coverage and reimbursement of neurological care for individuals and families.
- To emphasize the need for policies and plans to include ethical and humane advance care planning considering the chronic nature of some neurological disorders such as neurodegenerative conditions.
- To highlight, where possible, that neurology/brain health should have standalone national plans. Where this is not the case, neurological disorders should be explicitly included in wider strategies rather than only in mental health action plans so that the range of neurological disorders is included.

ACTIONS FOR MEMBER STATES

- To highlight that development or review of national and/or subnational policies, plans and legislation should be done in close collaboration with all stakeholders, including scientists, and based on context-specific evidence relating to neurological disorders.
- To emphasize that countries need to map the barriers to progression of the neurological agenda, which may be unique to specific context.
- To highlight that Member States could aim to create standalone neurological or brain health strategies. Alternatively, neurological care can be included within countries' primary health care or UHC plans, as appropriate.
- To create an awareness among Member States on the health and economic benefits of a bundled/integrated approach to neurological disorders that can lead to development and implementation of national neurological plans.
- To ensure that palliative care policies are developed, funded and to include neurological disorders within their remit.
- To consider reviewing the criteria to access disability benefits for people with neurological disorders so that they are available to those who need them.
- To consider providing more specificity with examples of the revisions needed in disability laws, such as: including additional funding to support people with disabilities in employment, quota systems for active hiring, and making working environments more accessible for those with neurological disorders.
- To highlight that Member States should review all policies and laws related to persons with neurological disorders – not just disability policies and laws – (i.e policies, laws related to dementia, epilepsy, mental health, health, disability, education, employment, housing, social protection etc). This requires coordination between health and social care sectors amongst others to address specific needs, for example the need to be able to drive to work, appropriate lighting, regular breaks for people with neurological disorders.

ACTIONS FOR SECRETARIAT

- To consider provision of technical support for the evaluation of national and/or subnational policies for neurological disorders.
- To emphasize the role of WHO across the three levels, including Regional and Country Offices, in ongoing monitoring, guidance, and technical support to Member States in implementing the Intersectoral global action plan on epilepsy and other neurological disorders.

- To provide assistance in outlining mechanisms that proactively encourage and support the active participation of people with neurological disorders in all aspects of policy-making, planning and financing services.

ACTIONS FOR INTERNATIONAL AND NATIONAL PARTNERS

- To emphasize the importance of involving organizations supporting people with neurological disorders in the engagement and implementation of policies for neurological disorders.

1.3 FINANCING

GENERAL COMMENTS

- To emphasize to Member States the importance of including neurological disorders in universal health care benefit packages.
- To highlight the importance of updating existing and/or creating new evidence looking at socio-economic cost of neurological disorders globally.
- To emphasize that investment in prevention, diagnosis, treatment and care for people with neurological disorder will be offset by a consequential reduction in the cost of neurological disability and lessen the long-term cost for governments.
- To support increasing financing for healthcare systems, including infrastructure, especially in the context of preventing collateral damage during emergencies such as a pandemic.
- To emphasize the need for investments in neurorehabilitation, particularly in LMICs.
- To facilitate public-private partnerships with regards to planning, developing and deploying innovative finance solutions for sustainable neurological care.
- To consider comparing the cost of prevention to the cost of DALYs of living with neurological illness on society as a tool to garner support for allocation of financing to prevention, early detection and treatment.

ACTIONS FOR MEMBER STATES

- To highlight the importance of preventing high treatment costs by introducing barriers to inappropriate expenditures and levelling the cost of products with similar efficacy.

ACTIONS FOR SECRETARIAT

- To consider engaging in activities to develop return on investment case studies, protective and risk factors, cost-effectiveness analysis, etc. to influence governments' choices, at achieving clear and specific outcomes in various neurological disorders.

ACTIONS FOR INTERNATIONAL AND NATIONAL PARTNERS

- To participate in the defining of national strategies for brain health, neurological care, and for the definition of resource allocation for improved efficiency, thus finding solutions to rank priorities fitting the national health needs.

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

Overall, stakeholders commented that the actions in this objective were relevant and valuable, particularly the inclusion of a wide array of neurological disorders. It was highlighted that the needs of children with neurological disorders and their carers are different from those of adults and emphasis is needed on adding focused, specialized and age-appropriate care for children and adolescents transitioning into adulthood, as well as adults across the life course. Additional suggestions included:

- To replace the term “multi-disciplinary health” with “interdisciplinary health” throughout the action plan.
- To highlight the need for access to trained health workers with improved diagnostic capabilities as required by most neurological disorders, as the large diagnostic gap in most countries represents a major barrier, and to enable the use of available treatments already proven to be effective.
- To emphasize provision of support and care for people with some neurological conditions such as rare neurological disorders while they are awaiting a diagnosis. These may present with non-neurological manifestations, hence an interdisciplinary approach is necessary.
- To emphasize the need for neurorehabilitation in improving the quality of life of those affected and palliative care, including end of life care and bereavement support for families.
- To include the need for resilient health systems, especially important in light of disruptions that have occurred during the COVID-19 pandemic.

2.1 CARE PATHWAYS

GENERAL COMMENTS

The section on care pathways was well received with general appreciation for integrated pathways. The need to highlight the differences in care pathways in rural or urban locations was noted, as well as the importance of tailoring pathways to each stage of life across the life course. Ensuring emergency care for those with neurological disorders within humanitarian disasters and vulnerable populations, such as children in conflict settings, and during times of national or global emergency health crises, such as the COVID-19 pandemic, was emphasized, as well as promoting and encouraging self-care when possible. The importance of ensuring that people with neurological disorders and their families are actively involved in all areas of design and planning of services from the onset was noted. Further comments included:

- To underscore the importance of operational linkages between the primary healthcare system in any country with well-equipped and sufficiently resourced secondary and tertiary care.
- To emphasize the importance of palliative care in the early stages of disease progression as well as in long-term care ensuring that coordinated care is provided. It was noted that introducing palliative care early improves the quality of life for people with neurological disorders and allows preparation for end of life as necessary.
- To improve and encourage the use of the International Classification of Diseases (ICD) 11th Revision in evidence-based pathways, in particular the reclassification of stroke.
- To strengthen and/or develop clinical care guidelines including for non-neurological comorbidities associated with neurological disorders.

- To consider incorporating programs within schools for neurocognitive assessment in order to detect developmental delays early.
- To place emphasis on care pathways for people with altered consciousness such as coma.
- To highlight the importance of serious health concerns among adults with neurodevelopmental disorders (e.g. increased morbidity, mortality and suicide), to inform public health policy, programs and services.

ACTIONS FOR MEMBER STATES

- No comments

ACTIONS FOR SECRETARIAT

- To provide guidance on program implementation that could be applicable in different countries with different health systems and resources.
- To expand on the role digital technologies can play in providing care and support.

ACTIONS FOR INTERNATIONAL AND NATIONAL PARTNERS

- To strengthen collaboration with palliative care organizations at international and national levels.
- To promote organizations to offer support and guidance to help those with neurological disorders such as epilepsy to manage anxiety, stigma, loss of friends and loss of jobs.

2.2 MEDICINES, DIAGNOSTICS AND OTHER HEALTH PRODUCTS

GENERAL COMMENTS

Comments were provided on the importance of this action area, including appreciation for the inclusion of assistive technologies and imaging modalities such as MRI and CT and the importance of having trained personnel for maintenance of medical devices and equipment. Improving access and appropriate use of new technologies was particularly appreciated, as was the importance of WHO supporting up-to-date, evidence-based diagnostic and treatment guidelines for neurological disorders. Specific comments included:

- To recognize that even low-cost medicines, such as anticoagulants and anti-epileptics, and other health products, such as assistive devices, can have limited accessibility in both LMICs and high income countries (HICs) due to affordability and supply chain obstacles.
- To highlight the importance of video EEG and MRI in diagnosing epilepsy and other neurological disorders.
- To consider that, in comparison to epilepsy being proposed as an entry point, access to medicines for multiple sclerosis (MS) and the rapid production of new medications for MS can serve as a model for other neurological disorders.
- To focus attention on the importance of availability and accessibility of new technologies for diagnosis such as PET scans and blood-based biomarkers.
- To clarify in this section which products are specified by “technology” and “health products” and provide examples such as wheelchairs, communication boards and protective helmets.

ACTION FOR MEMBER STATES

- To highlight the need for sustainable supplies of medicines and ensure that the supply chain for medications is constant, as a disruption in supply can cause death from sudden withdrawal in some situations.
- To foster transparency of regulatory frameworks, resources and capacity to ensure quality, safety and ethical standards for medical products and devices, as well as for diagnostic procedures such as genetic testing, including pre-implantation genetic testing.
- To encourage construction and development of MRI and CT machines and the availability of more advanced imaging such as PET scans, biological biomarkers and other approved diagnostics.

ACTIONS FOR SECRETARIAT

- To review, in consultation with people with neurological disorders and their carers, the WHO Model List of Essential Medicines, essential diagnostics, including in vitro diagnostics (WHO Essential Diagnostics List), the WHO Lists of Priority Medical Devices, the WHO Priority Assistive Products List and other relevant documents provided by WHO to ensure they are person-centred and incorporated into the action plan.
- To provide technical support and guidance for ensuring up-to-date, evidence-based regional/national/resource-stratified diagnostic and treatment guidelines such as basic medication guides.
- To promote areas highlighted by WHO's pre-qualification programme and Fair Pricing Forum to improve access to health technologies and increase the number of safe, effective and affordable essential medicines for neurological conditions.

ACTIONS FOR INTERNATIONAL AND NATIONAL PARTNERS

- To foster international collaboration with the private sector to develop and implement access plans and transparent, sustainable strategies to prioritize affordable medications for neurological conditions in LMICs.

2.3 HEALTH WORKERS' CAPACITY BUILDING, TRAINING AND SUPPORT

GENERAL COMMENTS

There was strong support for inclusion of training of health workforce into the action plan. Emphasis on training non-specialists to identify and treat neurological conditions in order to free up specialists to treat more complex cases was encouraged. The clear need for more specialist physicians and nurses was also noted. Simultaneously, while expanding neurological specialties is needed as a long-term strategic goal, the short-term strategy should be training and capacity building of primary care physicians and other non-specialists such as clinical officers, as they provide the majority of neurological care at multiple levels from primary to secondary care. Specific comments included:

- To further highlight and reinforce the need for a significantly larger neurological workforce and support of training capacity based on the rapidly growing prevalence of neurological diseases.
- To emphasize the gender aspect of the neurological healthcare workforce, which is comprised predominantly of women, and encourage efforts to protect their health and provide fair compensation and protection of their rights at various levels.

- To emphasize the role and importance of community health workers (CHW) specifically in resource constrained settings and the integration of CHWs within the primary care level.
- To mention and take steps to address adverse mental health conditions, including stress and burnout in healthcare workers, which is a particular issue during the COVID-19 pandemic.
- To address the lack of confidence that healthcare workers may experience in treating neurological conditions due to lack of knowledge and experience and to make efforts to address this in training and supervision.
- To highlight the vital importance of nurses, in particular specialist nurses, including neurosurgical, and ancillary healthcare workers such as dieticians in treating neurological disorders, where their role in prevention and education is fundamental and they have a positive influence on the quality of life and well-being of those with neurological disorders.
- To support the training of specialists for neurological disorders through education and training initiatives.
- To consider inclusion of emergency care providers within the scope of the neurological workforce.
- To include an additional paragraph addressing the need for specialized training of health care workers who care for children, adolescents and young adults transitioning to adulthood.
- To recognize the need for health care workers and experts trained in neurodevelopment who appreciate the diverse developmental needs of children and adolescents.
- To make a clear distinction between health workers and other informal or unpaid carers and not to include family/friend caregivers as part of the health workforce as they are informal care providers.
- To recommend the inclusion of a standalone section highlighting the importance of rehabilitative technologies, products, techniques or workforce in light of the particular importance that neurorehabilitation has for people with neurological disorders.

ACTIONS FOR MEMBER STATES

- To encourage the use of information and communication technology use by healthcare and social care workers. This includes telemedicine and internet/mobile phone technologies in order to scale up remote neurology services, thus expanding neurological care to remote and low-resource settings and supporting home-based services.
- To incorporate training into national curricula with available funding and ensure that training priorities and learning objectives are standardized, which would set an appropriate equitable standard of care across a country.

ACTIONS FOR SECRETARIAT

- To include the need to collect and monitor information on the neurological and neurosurgical workforce within Member States to track trends globally.

ACTIONS FOR INTERNATIONAL PARTNERS

- To consider that international organizations can provide support in developing the educational curriculum for neurological disorders, including neurorehabilitation and including curricula for palliative care, utilizing the expertise of international organizations.
- To promote flexible continuous professional development educational programs for healthcare workers who work with people with neurological disorders.

2.4 CARER SUPPORT

Overall, there was strong support and endorsement for emphasizing the need for carer support within the action plan with an emphasis on also recognizing the mental health needs of families of those with neurological disorders.

GENERAL COMMENTS

- To stress the importance of taking into account a patient's capacity to make decisions, which should be respected in addition to the wishes and preferences of families.
- To draw attention to the fact that bereavement support for carers is crucial for those who have cared for someone through a progressive illness who then suffered a sudden unexpected death, such as sudden death in epilepsy.
- To recognize and emphasize that women are more likely to be carers than men, as well as the need for additional support for them to fulfil their role.
- To further highlight the stigma and discrimination experienced by carers and the importance of providing mental health support for carers.
- To include a separate paragraph about the siblings of children with neurological disorders and the ramifications and downstream effects (neglect, mental health issues) of having someone with a neurological disorder in the family.

ACTIONS FOR MEMBER STATES

- To further support the development of funded respite centres to provide practical and financial support to carers.
- To cross-reference carer support sections from other guidelines and roadmaps and apply some of these activities to neurological disorders.
- To consider other neurological disorders with behavioural symptoms, such as Huntington's disease or Alzheimer's disease, which may represent additional stress to carers due to isolation and stigma.
- To support inclusion of training and networking with other carers in the social support resources provided by the community.
- To create programs that incentivize and expand access to home care for people with neurological disorders in order to support those providing care.

ACTIONS FOR SECRETARIAT

- To highlight and clarify the role that Member States can have in supporting carers.

ACTIONS FOR INTERNATIONAL AND NATIONAL PARTNERS

- No comments

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

Overall comments for this action area included appreciation for key principles while demonstrating some of the gaps to be addressed, such as more focus on older age groups. There was also appreciation for the focus on addressing modifiable risk factors as well as a focus on the structural environment and urban planning aspects of this section and their impact on brain health. A recognition of an intersectoral approach under the umbrella of universal health care (UHC) was emphasized, involving for example, education, labour, and social care sectors to facilitate healthy lifestyle choices for brain health.

GENERAL COMMENTS

- To consider whether the strategies outlined in this section don't already overlap considerably with other action plans on other non-communicable diseases (NCD) and can be simply referenced to these plans.
- To further highlight that drug use besides alcohol and tobacco is a risk factor for the development of neurological disorders and further align with the Sustainable Development Goals 3.3, 3.4 and 3.5, which cover this area.
- To consider that prevention may also need to encompass counselling on genetic causes of disease and access to related diagnostic facilities.
- To further highlight the importance of education as a known preventive measure against neurological disorders such as dementia.

3.1 PROMOTION OF OPTIMAL BRAIN DEVELOPMENT IN CHILDREN AND ADOLESCENTS

This action area was welcomed and feedback was focused on providing for the needs of infants, children and particularly adolescents (including those transitioning to adulthood) as well as during the prenatal, birth care and postnatal period. The effect of substance use on the foetal and birth stages of development was appreciated, however, expanding this reference to include drug use and carbon monoxide exposure was also recommended.

GENERAL COMMENTS

- To highlight the role of folic acid in early pregnancy to prevent some neurodevelopmental disorders, such as neural tube defects, as well as other simple nutritional measures, such as breastfeeding, that are accessible and prevent many neurological disorders, ultimately preventing disability.
- To note that early accurate diagnoses and treatment is crucial for brain health in children and can have a lifelong impact.
- To encourage and strengthen neurocognitive follow up surveillance mechanisms for brain health and development in children and adolescents – in particular those with a family history of neurological conditions.
- To specifically include mention of foetal alcohol spectrum disorder (FASD) as a risk factor within this section and the use of other drugs in adolescents.
- To emphasize the risk of congenital malformations on cognitive development for the offspring of women of childbearing age who need treatment for neurological conditions during pregnancy, e.g. for epilepsy.
- To further emphasize the vulnerable position of adolescents who grow up in countries with high rates of poverty leading to HIV, other infectious diseases, undernutrition, poor sexual and reproductive health, head trauma, violence, and noncommunicable diseases (NCDs).
- To note that young people do not always get access to much needed rehabilitation services.

ACTION FOR MEMBER STATES

- To consider incorporating accessibility to education and the reduction of barriers for people with neurological disorders, in line with the United Nations Convention on the Rights of Persons with Disabilities.
- To recognize the importance and need for generating more data on protective and risk factors of children and adolescents with neurological disorders.

ACTIONS FOR SECRETARIAT

- To further align and strategically link with work on NCDs and relevant initiatives such as the WHO NCD Implementation Roadmap 2023-2030 and NCD Country Capacity Survey.

ACTIONS FOR INTERNATIONAL AND NATIONAL PARTNERS

- No comments

3.2 PROMOTING HEALTHY BEHAVIOUR ACROSS THE LIFECOURSE

In general, the actions included in this area were well received. The need for better understanding of the main risk factors for NCDs interlinked with those for neurological disorders was highlighted to improve understanding and lead to the development of better disease-modifying strategies. In addition, it was emphasized that sleep loss and sleep disorders represent risk factors for multiple neurological disorders, including stroke, epilepsy and dementia.

GENERAL COMMENTS

- To further emphasize the need for more evidence on risk factors for neurological disorders and to communicate and inform the public about risk factors to improve prevention efforts.
- To reiterate the fact that a host of neurological disorders share similar risk factors with other major NCDs and that effective risk factor modification and lifestyle interventions are required to reduce morbidity and mortality across the lifespan.
- To note that poor hygiene should be added to the list of risk factors, considering that healthy hygiene practices can prevent many infectious neurological diseases.
- To encourage urban planning that improves access to community spaces, senior centres, and gyms in order to promote activity and provide alternatives to a sedentary lifestyle.
- To highlight the importance of promoting vaccination campaigns and sharing knowledge about the usefulness of vaccinations during pandemics as a method of reducing neurological disabilities.
- To include collaboration with local populations including indigenous people to explore culturally appropriate ways of prevention of neurological disorders which respect local customs and values.

ACTIONS FOR MEMBER STATES

- To implement legislation incentivizing healthier choices such as physical activity and healthy diets.
- To promote the removal of urban barriers, e.g. to sports facilities, in order to facilitate and emphasize physical activity.

ACTIONS FOR SECRETARIAT

- To further emphasize the important role of WHO in linking neurological disorders with wider NCD and other agendas.
- To contribute to strengthening health literacy about brain health among the public and the consideration of gender specific risk factors for designing preventative strategies.

ACTIONS FOR INTERNATIONAL AND NATIONAL PARTNERS

- No comments

3.3 INFECTIOUS DISEASE CONTROL

Many comments were provided on the importance and value of this action area with an emphasis on both human and animal (e.g. dog, pig) immunization against infections such as rabies and neurocysticercosis, as well as highlighting certain preventable neurological conditions such as polio, TORCH syndrome agents (toxoplasmosis, rubella, cytomegalovirus, herpes simplex virus) and COVID-19. Once again, the COVID-19 pandemic was emphasized as an opportunity to further develop neurological services in LMICs as it has demonstrated the necessity for infectious disease control with both acute and long-term complications. It was further appreciated that the action plan frames infectious disease control as a preventive measure for the development of future neurological disorders.

GENERAL COMMENTS

- To consider incorporating the addition of a One Health approach for neurological disorders, i.e. an approach to designing and implementing programmes, policies, legislation and research in which multiple sectors (public health, animal health, plant health and the environment) communicate and work together to achieve better health outcomes especially with regards to neuroinfectious conditions.
- To include the impact of infectious disease control on preventing avoidable hospitalizations and death for people living with neurological disorders such as dementia.
- To expand on the sequelae of infectious diseases such as meningitis, including vision and sensorineural hearing loss, developmental delay, cognitive or motor impairment.
- To include TORCH syndrome (toxoplasmosis, rubella, cytomegalovirus, herpes simplex) and other infectious agents such as syphilis that can infect the nervous system of the developing foetus or newborn as an example of prevention by vaccination.
- To highlight the COVID-19 pandemic and the neurological consequences, both short- and long-term, and the current gaps in knowledge.
- To reference neurocysticercosis as the most common cause of seizures in low-income countries.

ACTIONS FOR MEMBER STATES

- To draw attention to the consequences of the COVID-19 pandemic on neurological disorders, which require support and care including neurorehabilitation interventions for motor, cognitive and emotional problems that stem from the COVID-19 pandemic.

ACTIONS FOR SECRETARIAT

- To consider adding technical support and guidance to Member States to strengthen infectious disease control such as reducing the risk of zoonotic infections, antimicrobial and insecticide resistance and animal or livestock trading and farming policies.
- To develop guidelines for diagnosis and treatment of infectious diseases of the nervous system, such as the one already available on the management of *Taenia solium* neurocysticercosis.

ACTIONS FOR INTERNATIONAL AND NATIONAL PARTNERS

- To highlight the importance of neurological manifestations of the post-COVID-19 condition and promote better dissemination of patient support measures in terms of diagnostic, therapeutic, and healthcare.

3.4 PREVENTING HEAD/SPINAL TRAUMA AND OTHER INJURIES

Comments for this action area included appreciation for highlighting the importance of traumatic brain injury (TBI) and spinal cord injury (SCI) particularly in young people. Areas of comment included the risk of repetitive mild head trauma, domestic abuse and the promotion of safer contact sports, traffic accidents, preventing physical abuse and strengthening policies for safe behaviours in the workplace and on the roads.

GENERAL COMMENTS

- To underline that repetitive mild head trauma is associated with chronic traumatic encephalopathy, which increases dementia risk.
- To promote strategies for the long-term care of survivors of TBI who have residual deficits and who are often abandoned by the health and social systems.
- To emphasize the range of contributing factors to TBI and SCI from road trauma, including illicit and prescription drugs, alcohol, distractions such as with mobile devices and fatigue.
- To draw attention to the vulnerability of young children who are unrestrained in motor vehicles, both privately owned and in public vehicles, and to encourage the importance of seatbelt use, fences along busy roads and walk-ways under roads.
- To note that the highest number of head injuries occur in LMICs where neurosurgical treatment of head and spinal cord injuries is limited primarily due to lack of neurosurgical capacity and trained neurosurgeons.

ACTIONS FOR MEMBER STATES

- No comments

ACTIONS FOR SECRETARIAT

- To coordinate strategies to support patients with long-term cognitive or physical consequences of TBI and suffer from discrimination and stigma.

ACTIONS FOR INTERNATIONAL AND NATIONAL PARTNERS

- To encourage international associations to support the development of national associations addressing support systems and addressing discrimination for patients with TBI and SCI and residual disorders of consciousness.

3.5 REDUCING ENVIRONMENTAL RISKS

The focus on environmental risks related to brain health was appreciated. The importance of climate change, population movement, deforestation, land-use patterns, biodiversity losses, freshwater surface configurations, and human population density was highlighted, for example, through the transmission of vector-borne neurotropic viruses such as Zika, Japanese encephalitis and West Nile disease. It was recommended that a One Health approach be implemented in line with WHO's guidance on preventing disease through healthy environments.

GENERAL COMMENTS

- To promote joint collaborations across national ministries (environment, health, water, sanitation) to maximize the implementation of environmental policies to protect health.
- To highlight the effect of climate change on the patterns of infectious disease and emphasize immunization as an important tool to prevent infectious disease.
- To consider including other toxins such as carbon monoxide that can cause brain injury in both the developing and mature brain.

ACTIONS FOR MEMBER STATES

- To note that seizures can be triggered by environmental factors such as bright lights, excessive heat, and other environmental risks.
- To draw attention to *Taenia solium*, which causes neurocysticercosis and epilepsy and occurs in poor, vulnerable communities in which pigs roam free, open defecation is practiced, basic sanitation is deficient, and health education is absent or limited. Improving sanitation, pig husbandry, community health education, hygiene and food safety would prevent many cases of epilepsy.
- Support the development, funding, and enhancement of local policies regarding healthy environment with natural resources, in order to stop water exploitation, air pollutants, and deforestation that can impact brain health.

ACTIONS FOR THE SECRETARIAT

- To work with international partners to set and publish standards for safe levels of environmental pollutants to produce a publication of environmental standards important for optimal brain health.
- To collaborate with international organizations to emphasize a need for evidence generation for the environmental effects on neurological diseases.

ACTIONS FOR INTERNATIONAL AND NATIONAL PARTNERS

- No comments

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

OVERALL COMMENTS

Appreciation for supporting the involvement and engagement of people with neurological disorders in the development of research priorities and research projects was expressed by many.

- To highlight the importance of sociocultural and religious sensitivities and gender differences in research and development activities.
- To emphasize that it is the immense complexity of the brain which makes the progress in this field slow and costly, and to call for allocating more resources to neuroscience research.
- To emphasize that research and development into medicines and technology should be promoted and enhanced.
- To emphasize the importance of reducing duplications, identifying emerging knowledge gaps, and fast-tracking research innovation.
- To highlight the importance of research in generating context-specific knowledge to inform policy, planning and programming for neurological disorders.
- To highlight the importance of research in children with neurological disorders, especially for effective early diagnosis and interventions.
- To underscore the importance of cost-effectiveness studies to include benefit-risk considerations and long-term consequences of drug intake into analysis, to favour drugs with less adverse and long-term effects on health. This is relevant for chronic neurological conditions such as epilepsy.
- To emphasize the need for equitable access to innovation and research products.
- To include monitoring mechanism for collection, evaluation, and reporting of data on neurological conditions across the life course.
- To emphasize the importance of identifying and addressing barriers to reliable data collection.

4.1 INVESTMENT IN RESEARCH

GENERAL COMMENTS

- To consider adding an action on the creation of a common research fund for neurological research.
- To highlight the importance of building infrastructure and capacity for neurological research, especially in LMICs. This would require provision of adequate data, information systems and digital health monitoring solutions, to enable studies to transition from HICs to LMICs and also enable reverse innovation.
- To emphasize the importance of investment in basic science, along with biomedical, clinical, implementation and translational research in neurology.

ACTIONS FOR MEMBER STATES

- To emphasize the importance of collaboration of all involved in the care of people with neurological disorders in developing a research strategy.
- To underscore the importance of clinical trials for developing new drugs for children with neurological disorders in the early stages of disease.
- To consider developing a research registry to develop synergies, efficiencies and lower financial cost linked to neurological research.
- To highlight the importance of involving patient organizations in the research process for neurological disorders.

ACTIONS FOR SECRETARIAT

- To consider providing support for collection, compilation, dissemination of relevant information and creation of a platform to enable stakeholders to share research experiences, recommendations and data for neurological disorders.
- To provide guidance to Member States and research organizations about how each country can be connected and share the outcomes of neurological research.

ACTIONS FOR INTERNATIONAL PARTNERS

- No comments

4.2 DATA AND INFORMATION SYSTEMS

GENERAL COMMENTS

- To consider adding a key point recommending intersectoral coordination related to neurology data collection (for example, mental health teams may also report on epilepsy).
- To highlight that information systems for neurological disorders can be rudimentary or absent also in HICs.
- To highlight the importance of training medical personnel in reporting and information systems for neurological disorders so they understand the process and its utility.

ACTIONS FOR MEMBER STATES

- To consider cross referencing to the WHO Defeating meningitis by 2030 global road map and other instruments to avoid duplication of efforts at data collection and reporting at country level.

ACTIONS FOR SECRETARIAT

- To emphasize that the development of data information systems that can be shared internationally should be a priority.
- To provide guidance to countries in the development of data sharing programmes.

ACTIONS FOR INTERNATIONAL PARTNERS

- To highlight the importance of supporting national and international registries to generate collaboration and evidence to raise awareness of neurological problems.

- To underscore the importance of inclusion of patient outcome measures to ensure the care of patients and families are truly represented.
- To create platform for dialogue for the exchange of best practices and findings in research and data between experts in the field.

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

OVERALL COMMENTS

Appreciation of the addition of this strategic objective was expressed by many. Overall comments included:

- To highlight the importance of epilepsy as an entry point by some countries where neurological care is minimal, serving as a model as to how to organize prevention, care, rehabilitation and social support. In countries where no other neurological healthcare exists, healthcare for children and adults with epilepsy could be started as a minimum neurological care. Following this approach, other neurological disorders could be selected by each country based on identified priorities. It is important to emphasize that this approach can be applicable in some parts of the world and not necessarily relevant in some others where stroke, dementia and neurodegenerative disorders, migraine and other headache disorders may serve as the entry point.
- To provide further explanatory paragraph(s) on the synergies between epilepsy and other neurological disorders and why epilepsy is best suited to serve as an entry point for other neurological disorders.
- To highlight the importance of primary care and the role of WHO's mental health Gap Action Programme (mhGAP) for general practitioners in addressing epilepsy and to expand it for other neurological disorders.
- To include advocacy for the availability of anti-epileptic medicines at affordable prices at all levels of the healthcare system especially the primary health care centres.
- To further highlight issues related to children with epilepsy in all action areas.
- To address the need for bereavement support as a role in supporting carers and families coping with sudden death due to epilepsy.
- To consider changing the title of the objective to: "To strengthen the public health approach to neurological disorders, including epilepsy", or "To strengthen the public health approach to epilepsy and neurological disorders", or "To strengthen the public health approach to epilepsy and other neurological disorders and promote synergies between all neurological disorders."

5.1 ACCESS TO SERVICES FOR EPILEPSY

GENERAL COMMENTS

- To highlight the importance of early diagnosis and screening for epilepsy to enable effective and timely interventions. This is particularly relevant to children and adolescents, where schools can play an important role.
- To provide further description on what the role of the specialist would be in supporting integration of epilepsy care in primary health care. For example, the specialist role can be redefined to: Confirm the diagnosis of epilepsy; provide care for refractory epilepsies; and assess the need for resective surgery.

- To include the creation of refractory epilepsy study centres for people who can benefit from resective surgery.
- To draw attention to the engagement of traditional healers as this is critical for both influencing community perceptions and appropriately managing epilepsy in some LMICs.

ACTIONS FOR MEMBER STATES

- To underscore the need for enhanced training in epilepsy diagnosis and management is needed at all levels – community, primary, secondary, and tertiary health care. While the focus for initial recognition and ongoing support and sustainable care should be at primary and community level, enhancing specialist knowledge and training at secondary and tertiary level is also needed.
- To include emergency care workers as a cadre to be trained to provide epilepsy services.
- To add the need to make widely available anti-seizure medicines that are safe in pregnancy.
- To emphasize the importance of integrating views and needs of people living with epilepsy in the healthcare system
- To consider establishing specialized epilepsy referral centres equipped with sufficient neurodiagnostic investigations and managed by highly qualified epilepsy teams in collaboration with stakeholders to share their expertise.

ACTIONS FOR SECRETARIAT

- To develop technical briefs on epilepsy that provide more detail around diagnosis and treatment, including management of refractory epilepsy and neuropsychological manifestations.
- To update and disseminate accurate information on the management and multi-disciplinary care of all those affected by epilepsy.

ACTIONS FOR INTERNATIONAL AND NATIONAL PARTNERS

- To address the importance of medicine adherence in the treatment of epilepsy.
- To consider using epilepsy as a case study and as public health success story.

5.2 ENGAGEMENT AND SUPPORT FOR PEOPLE WITH EPILEPSY

GENERAL COMMENTS

- To encourage activities such as an international day for epilepsy to improve community awareness about epilepsy.
- To emphasize the understanding and addressing stigma in epilepsy is important.
- To provide guidance for increasing the knowledge of the general population about epilepsy, including addressing myths and misconceptions and what to do when someone is having a seizure. This can be done by providing information materials such as brochures or pamphlets and collaboration with media.

ACTIONS FOR MEMBER STATES

- To review laws that prevent people with epilepsy from having a driving license and to make these laws less restrictive.

ACTIONS FOR SECRETARIAT

- To ensure recruitment, hiring procedures and accommodations for the needs of people with epilepsy (and any other disability) which are mainstreamed across workplaces.

ACTIONS FOR INTERNATIONAL AND NATIONAL PARTNERS

- No comments

5.3 EPILEPSY AS AN ENTRY POINT FOR OTHER NEUROLOGICAL DISORDERS

GENERAL COMMENTS

- To highlight that good multidisciplinary team care for epilepsy can be transferred to the care of other neurological disorders, with evidence of improvement in quality and length of life.
- To include the importance to integrate programs (epilepsy with other neurological, mental and chronic noncommunicable diseases).
- To emphasize that epilepsy care should be joined with specialties, encouraging working across the primary/secondary care interface, and moving epilepsy treatment more into the area of physicians and primary care to reduce stigma.
- To highlight that the public health systems should be expanded based on the epilepsy model to accommodate other neurological disorders.
- To include the opportunity of strengthened information systems for epilepsy that can then be used to facilitate better data collections for other neurological disorders.

ACTIONS FOR MEMBER STATES

- To emphasize that epilepsy can be chosen as a starting point for the development of a national plan to promote brain health and treat neurological disorders.
- To underscore that countries should identify national priorities for brain health and neurological disorders while keeping an integrated approach in mind. For some countries this could be epilepsy, for others stroke and its consequences, for others dementia and neurodegenerative disorders, for others still migraine and other headache disorders.
- To include details of the causes of epilepsy and the prevention measures since management will differ based on different causes.

ACTIONS FOR SECRETARIAT

- No comment

ACTIONS FOR INTERNATIONAL AND NATIONAL PARTNERS

- To highlight that national partners should be aware of epidemiology of neurological disorders at the national level as this can help in setting national neurological priorities.
- To emphasize the importance of neurorehabilitation services for people with epilepsy.

GLOBAL TARGETS AND INDICATORS

GENERAL COMMENTS

Many comments received reflected support and appreciation for the nine global targets that have been described in the draft action plan. While some suggested having more aspirational targets, caution was advised by others to keep the targets and indicators realistic and to consider feasibility of measurement and reporting burden on countries. Additional targets/indicators were also suggested, and these have been described in the sections below. Further comments included:

- To consider that in terms of reporting, a longer reporting cycle (e.g. every 5 years) may be more achievable than every 2 years in the current context.
- To include a separate section on how progress towards the global targets will be measured and monitored – both globally and regionally – and when they will be publicly reported on. It will also be important to set more intermediate targets that country can report on.
- Add ‘epilepsy’ to all global targets.
- An explanatory statement can be added to describe the rationale and source of the targets and indicators.
- To consider including some targets as ‘mandatory targets’ that countries will need to report on.
- To describe the method by which the global targets can be adapted to regional and country targets.
- To consider defining benchmarks that can be used for availability of neurological services.

GLOBAL TARGET 1.1

- To triangulate self-reporting with review of policies in terms of their existence and operationalization.
- To add an indicator that 75% countries have an identifiable budget line dedicated to neurology.
- To revise the target to provide more flexibility with respect to stand-alone/condition/disorder-specific strategies that Member States may already have in place.
- To consider including in the target evidence-informed guidelines on diverse neurological disorders.
- To include infectious diseases as an example in the indicator description.
- To add an additional indicator on having a clear identification of neurological problems at country level in the national health plan.

GLOBAL TARGET 1.2

- To specify the advocacy/awareness campaign needs at the national level.
- To specify that the campaign must address cross-cutting issues and more than one neurological disorder, as opposed to having a campaign on stigma or one neurological disorder only.

GLOBAL TARGET 2.1

- To add additional targets/indicators on increasing neurological workforce across the whole care pathway. E.g. increase specialization in neurology by x% every 2 year and another one on improving training in brain health and neurology to primary healthcare providers. Other additional targets/indicators suggested include: Integration of neurology into NCD-related global programmes; a target on rehabilitation; a palliative care target; a target on improving quality of life of patients and carers. It was also suggested to add a key indicator: countries choose at least one neurological disorder that is epidemiologically relevant for the country and identify the proportion of people who use the services identified for that neurological disorder.
- To include reference to neurological disorders across the life course in the description of this target.

GLOBAL TARGET 2.2

- To consider splitting the global target into separate needs for medicines, technologies and workforce for (a) primary and (b) specialist/secondary care, or this target should be expanded to include specialist care.
- To define what is meant by ‘technologies’ and add specific mention of essential assistive products.

GLOBAL TARGET 3.1

- To include the concept of using a One Health approach in the description of this target.

GLOBAL TARGET 3.2

- To add more documents to the list of the ones already presented: UN General Assembly adopted resolution 74/299 “Improving global road safety”, proclaiming the Decade of Action for Road Safety 2021-2030; Road Map for Neglected Tropical Diseases 2021-2030; the upcoming WHO Mental Health Action Plan.
- To consider aligning further with other WHO publications to ensure key modifiable risk factors are addressed in a consistent manner, particularly for alcohol and tobacco consumption.
- To include central nervous system infections as they cause a range of otherwise preventable neurological complications.
- To refer to the immunization agenda 2030, as measles, mumps and others are important causes of brain disease and epilepsy.

GLOBAL TARGET 4.1

- To include place of death and consider patient outcome measures in the core set of indicators.
- To highlight that efforts are required to develop a core set of indicators that are relevant across the life course. This is particularly important for those conditions where research and surveillance efforts typically focus on children and youth such as neurodevelopmental disorders, given that these disorders are chronic in nature.
- To consider that global target 4.1, “50% of countries routinely collect and report on a core set of indicators for neurological disorders through their national health data and information systems every two years by

2031,” may be better suited with the target for strategic objective 5 as the statement seems more relevant to public health than research.

- To add an additional indicator suggested – patient involvement in publicly funded research and development, regulation reimbursement.

GLOBAL TARGET 4.2

- No comment

GLOBAL TARGET 5

- To expand the indicator set in global target 5 (increased service coverage for epilepsy by 20% by 2031) to cover all neurological disorders and potentially make a corresponding adjustment of the indicator in relation to the suggested expansion to cover all neurological disorders.
- To consider adding an indicator on incorporating into national plans, at the tertiary level, at least one national reference centre for epilepsy surgery per country.
- To consider replacing service coverage with reducing the treatment gap and, given that anti-seizure medicines are both highly effective and inexpensive, give consideration to increase the target to reducing current treatment gap by half by 2031.
- To reformulate Target 5.1 to be more aspirational as well as more concrete. A cascade target is proposed: Epilepsy 90-80-70 (1) 90% of all people with epilepsy aware of their diagnosis as a treatable brain disorder and (2) 80% of people diagnosed with epilepsy with access to appropriate, affordable, safe anti-seizure medicines and (3) 70% of those treated achieve adequate seizure control.
- To add an additional target for all countries to review and amend existing discriminatory legislation particularly in the areas of education, driving, employment, marriage, and fertility for people with epilepsy and other neurological disorders.