

DISCUSSION PAPER FOR 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 WHA 73.10 on **GLOBAL ACTIONS ON EPILEPSY AND OTHER NEUROLOGICAL DISORDERS**, which requested the World Health Organization (WHO) Director-General to develop an intersectoral global action plan on epilepsy and other neurological disorders. The action plan will address the challenges and gaps in providing care and services for people with neurological disorders that exist worldwide and ensure a comprehensive, coordinated response across sectors.

As the first step, the WHO Secretariat has developed the discussion paper for the intersectoral global action plan on epilepsy and other neurological disorders covering the period 2022-2031 following internal consultations with Regional Offices and relevant WHO departments at Headquarters. The discussion paper includes the proposed vision, strategic objectives and a set of recommended actions.

The Secretariat subsequently implemented the following consultation process on the prepared discussion paper of the action plan with 14 Member States, 3 United Nations (UN) agencies and 51 other relevant non-State actors:

- From beginning of March 2021 until mid-April 2021 web-based consultation was carried out to seek comments from Member States, UN agencies and relevant non-State actors on a WHO Discussion Paper.
- The discussion paper was also presented to Member States, UN agencies and relevant non-State actors in a number of virtual meetings and feedback obtained.

In total, feedback on the discussion paper was received from 18 Member States, 3 UN agency and 83 relevant non-State actors. The consolidated comments received from all stakeholders are presented here as: overall feedback; feedback on the scope, vision, goals and guiding principles; and feedback on each strategic objective including on actions for Member States, Secretariat and international partners.

OVERALL FEEDBACK ON THE DISCUSSION PAPER

A number of comments received by all stakeholders were relevant across different sections of the discussion paper. For this reason, these suggestions are listed once below, noting that they are applicable to multiple sections of the discussion paper.

- Overall, the comprehensiveness, multi-stakeholder and multi-sectoral approach to neurological disorders and brain health was appreciated.
- The broad approach of the discussion paper that focuses not only on neurological disorders but also on brain health was welcomed.
- The focus on improving quality of life through a person-centred approach, grounded in the rights of people with neurological disorders, was also welcomed.
- The action plan needs to address discrepancies between the intent of resolution WHA 73.10 and the content of the discussion paper, including the need to address epilepsy as a public health imperative and leverage synergies in the prevention, treatment and care between services for epilepsy and other neurological disorders. The need for a stronger emphasis on epilepsy, was highlighted. Another suggestion was to consistently reference epilepsy and other neurological disorders within the discussion paper across all sections.
- Inclusion of all neurological disorders in the action plan was supported by many and it was suggested that each country can prioritize conditions depend upon the context and challenges they experience. The examples of noncommunicable disorders and mental health where such an integrated approach is used was cited to support this comment.
- The focus on health promotion and disease prevention was welcomed. However, alongside these two, the importance to address key challenges that people living with neurological face, such as stigma, timely access to affordable and optimal treatments and care to reduce the treatment gap was underlined. In the absence of effective treatments for many neurological disorders, increased focus on improving the quality of life and personal outcomes of people living with neurological disorders was also emphasized.
- The discussion paper includes actions for Member States, the Secretariat and international partners. There was a suggestion to include dedicated actions for people with epilepsy and other neurological disorders in the action plan. There is also the need, to involve people living with these conditions more closely in developing the action plan.
- Further details on implementation approaches for the action plan at global / regional / national levels is needed including clearer identification of priority actions and resource mobilization strategies that will meet the needs of vulnerable populations of all ages particularly in low- and middle- income countries (LMIC).
- The setting up of expert groups at global/regional/national levels to provide advice on various issues such as epidemiology, prevention and care, specific needs of children and adolescents, strategies for low resource settings, can be considered.

Additional suggestions included:

- To consider developing ambitious, but achievable, global targets on reducing preventable cases of, and avoidable deaths, resulting from these conditions, strengthening service coverage and access to essential medicines, improving surveillance and critical research and addressing discrimination and stigma.
- To highlight the specific needs of people with different neurological disorders as these may vary across conditions.
- To more strongly identify the value and role of technology, digital infrastructure and tools, including to build capacity across LMICs.

GENERAL COMMENTS ON SCOPE, VISION, GOALS AND GUIDING PRINCIPLES

BACKGROUND AND SCOPE

The life-course approach adopted in the discussion paper was appreciated and welcomed as was the notion that brain health results from both neurological and contextual factors, such as clinical, medical, physical, individual, social and environmental influences. The overarching comment was to include an additional paragraph outlining the history of the resolutions and decisions. A number of additions and modifications to Table 1 on Resolutions and global commitments relevant to neurological disorders were also highlighted, including separate categories for mental health and neurological resolutions and reports. Specific comments included:

- To prioritize the diseases referred to in the scope, beginning with but not limited to epilepsy, and ensure comprehensiveness when listing and referring to neurological disorders. For example, to include reference to neuromuscular diseases, neuromalignancies, paraneoplastic disorders, and rare genetic diseases, amongst others.
- To balance the importance of brain health promotion and prevention of neurological disorders with the need to improve care for people already living with neurological disorders.
- To highlight psychosocial challenges experienced by people living with these neurological conditions, including discrimination and restriction of freedoms and human rights.
- With regards to co-morbidity, suggestions were: to highlight the link between neurological disorders and mental health including for children, adolescents, adults, older adults, carers and family, and care providers; to differentiate between disorders that commonly co-exist because one is a likely sequela of the other and disorders that are comorbid for other reasons.
- To further highlight the neurological impact of COVID-19 with specific actions for different stakeholders within the strategic objectives.
- To include a focus on knowledge sharing and translation as related to innovative solutions and/or strategies aimed at providing treatment and care for people with neurological disorders during the COVID-19 outbreak.
- To indicate gaps in health human resources more broadly, moving beyond the neurological workforce such as primary health care workers, physical, occupational and speech therapists.

VISION

Overarching comments on the vision related to balancing the importance of prevention with disease management, and the fact that not all neurological disorders can be prevented. Additional suggestions included:

- To identify brain health as being valued, promoted and protected as the first element in the vision and to emphasize the need to prioritize brain health in national policies, plans and budgets and strengthen governance for epilepsy and other neurological disorders through national policies, plans and budgets.
- To reference risk reduction and delay of disease onset in addition to prevention.
- To further emphasize the importance of universal health coverage in providing people with epilepsy and other neurological conditions with access to care.
- To indicate the need to reduce avoidable deaths, mortality, morbidity and disability, and improve the quality of life of people with these conditions through access to appropriate, affordable, quality services, essential medicines and ongoing research.
- To outline the need to promote and protect the social, economic, educational and inclusion needs of people with these conditions and their carers, including through legislation.

GOALS

The main comment was to highlight the importance of leveraging epilepsy as an entry point in the goal to improve health and social services and reduce the treatment gap, as well as the quality of life of people of all ages with neurological disorders, while accounting for variations in national contexts, health systems and needs. Specific suggestions to expand the goal were:

- To create a new strategic objective specifically on addressing stigma and discrimination, and the inclusion and promotion of equal opportunities for people with these conditions as this requires more focus. A number of additional suggestions related to stigma and discrimination were received and are summarized under strategic objective 1.
- To add a strategic objective focused on increasing the visibility of brain health and neurological disorders in existing and new policy frameworks.

Additional comments included:

- To reference the need for training and education at all levels of the health care system, and the importance of innovation and technology in improving neurological care.
- To emphasize the importance of integrated interdisciplinary care management across care levels as well as the link between neurological disorders and mental health.
- To highlight the importance of diagnosing and treating these conditions at primary care level, including through improving access to essential/ cost-effective medicines.
- To enhance the focus on carers and post-diagnostic support, as well as on public awareness of these conditions, especially prevention and treatment.

GUIDING PRINCIPLES

The comments received were in general agreement with, and supported, the seven guiding principles stated in the discussion paper. While gender and equity are included as a guiding principle, the need to more consistently reference these concepts throughout the discussion paper was identified. It was also suggested that an eighth guiding principle be added, referencing the need to protect access to, and delivery of, services and care for people with these conditions during emergencies and times of crisis. Based on this principle, relevant actions should be strengthened across strategic objectives.

Additional suggestions were:

- To refer to the socio-economic implications of disability associated with these conditions, especially in young people.
- To identify the value of interdisciplinary care teams.
- To consider how the guiding principles can be tailored and applied based on regional and country needs.

Comments related to specific guiding principles included:

- People-centered primary healthcare and universal health coverage:
 - To include the concept of participation in this guiding principle.
- Integrated approach to care:
 - To consider combining this guiding principle with the one related to life-course approach.
 - To include palliative care in the integrated approach to care guiding principle.
- Evidence-based practice:
 - To refer to real-world evidence, patient preferences and the development of treatments aimed at improving the quality of life of people with neurological disorders
- Life-course approach:

- To highlight in greater details the specific needs of children and adolescents including challenges of transitioning into adulthood
- While the action plan includes actions on children, the needs of older adults should be better reflected
- Intersectoral action:
 - It was suggested to more clearly outline recommendations for multistakeholder collaboration and coordination, including the role of public-private partnerships.
- Empowerment of persons with neurological disorders:
 - To define the involvement of people with epilepsy and other neurological disorders
- Gender, equity and human rights:
 - Further focus of the action plan on low resource settings is required to decrease inequities
 - To include a reference to carers in this guiding principle.

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

GENERAL COMMENTS

There was appreciation for the comprehensive and broad focus of the discussion paper with integrated and multisectoral approach for neurological disorders, which is critical for achieving the Sustainable Development Goals (SDGs) and other global commitments.

Additional comments include:

- To draw attention to advocacy for increasing the visibility of neurological disorders in SDGs and other existing as well as new global commitments.
- To consider reformulating strategic objective 1 to focus on national plans and financing
- To consider providing supporting arguments to the need to prioritize epilepsy and other neurological disorders in government agendas, e.g., burden of disease, cost of illness as well as return of investment data
- To emphasize the importance of integration and mainstreaming of neurological disorders within other national and local policies such as palliative care.
- To highlight the importance to include education, vocational training and employment within other relevant policies, legislation and health and social care programmes to meet the needs of people with these conditions.
- To clarify what is meant by strengthening governance.

1.1 ADVOCACY

GENERAL COMMENTS

Many comments emphasized the importance and value of this action area. Specific comments included:

- To highlight the importance of advocacy of neurological conditions and associated co-morbidity in leading to more robust policy and legislation.
- To emphasize advocacy on the importance of providing psycho education and social emotional learning for better brain health and child development.
- To further stress the importance of addressing stigma and discrimination which can be emphasized having a specific strategic objective as suggested earlier or consider creating a sub-section for addressing stigma and discrimination for people with these conditions as well as their families within this action area. Include information on the need for outreach to communities where stigmatization is most prevalent.
- To include in public education - hygiene, safe food practices, sanitation, and preventing open-air defecation to prevent the most common brain infections (e.g., neurocysticercosis and scrub typhus) that could result in epilepsy.
- To advocate for the availability of medicines at pricing that is affordable at all levels of health system including primary health care centres to ensure accessible health care that is person-centred.
- To emphasize the need to raise awareness among the public that there are existing effective medicines for many neurological conditions, appropriate health seeking practices and the need for adherence to often long duration of treatment
- To underscore the importance of early diagnosis and screening for neurological disorders to enable effective and timely interventions.

- To highlight the importance of clarifying and streamlining care pathways from detection to diagnosis to treatment within the health education programmes to empower people with neurological disorders and their carers.
- To consider including research as a higher priority as one of the advocacy objectives.
- To highlight the need to reflect country's cultural context for effective advocacy and public awareness campaigns.

ACTIONS FOR MEMBER STATES

- To highlight the importance of developing processes to empower people with neurological disorders in close consultation with civil society organizations which represent people with neurological disorders and their families.
- To utilize economic data such as data on burden of disease, cost of illness and return on investment for prioritization and development of policy frameworks that address neurological disorders
- To highlight the importance of Member States collaborating with civil society organizations to support capacity building initiatives to strengthen skills and knowledge in self-care of people with neurological disorders.
- To highlight the importance of addressing the needs of family members and carers as in many settings, stigma may not only affect the person with neurological disorders but also their families.
- To stress that Member States should work together to tackle issues such as stigma and discrimination.
- To consider providing detailed actions on what a Member State should do to raise the prioritization of brain health.

ACTIONS FOR SECRETARIAT

- To consider identifying neurological conditions as a distinct public health priority area in policies at global, regional and local levels to disentangle it from other issues such as mental health, substance use and noncommunicable diseases.
- To highlight that within global noncommunicable diseases (NCDs) strategy, neurological disorders can be a distinct category like cancers and mental health and not subsumed under mental health.
- To define a framework of good practice for disease-awareness campaigns.
- To highlight the importance of engaging and including people with neurological disorders, their carers and organizations that represent them in decision-making within WHO's own processes on issues that concern them. Ways need to be found to provide more meaningful and structured engagement mechanisms especially for people from under-represented regions.
- To consider supporting those people living with neurological disorders and relevant service user organizations that do not always have sufficient capacity and resources to be formally engaged with WHO through mechanisms like non-state actors.
- To emphasize that given the reclassification of stroke as a neurological disorder in ICD11, efforts should be accelerated for better integration of stroke into neurological health.

ACTIONS FOR INTERNATIONAL PARTNERS

- To highlight the importance of raising awareness among policy makers about the impact of neurological disorders on lifetime functioning and costs for society, and about the impact of effective treatment.
- To consider establishing relevant 'Working Committees' and platform of dialogue with international, regional and national structures with experts including youth and ensuring gender-balanced representation.
- To emphasize the need to develop concrete guidelines and standards of care to be adopted.
- To highlight sectors such as transportation, mobility, education and employment sectors where more advocacy for increasing functioning of people with neurological disorders should be done.
- To highlight the importance of international exchange and cooperation in advocacy efforts for better impact.

1.2 POLICY, PLANS AND LEGISLATION

GENERAL COMMENTS

The comments supported the importance of policies, plans and legislation, for people with neurological disorders needing inclusion, especially those with comorbidities and disability or functional impairment.

- To highlight the importance of developing policies, plans and programs based on scientific evidence and social experiences while ensuring they are comprehensive and multisectoral so that the complex needs of people with neurological disorders are addressed within the context of each country.
- To highlight the importance of listening to the voices of people living with neurological disorders when developing any policy.
- To consider establishing an environment that allows for multi-stakeholders including civil society to engage in continuous discussions on relevant policies.
- To highlight the need for inclusive education policies to cater to children and adolescents with disabilities associated with neurological conditions.
- To emphasize the importance of addressing discriminatory laws, where they exist, but where there are no such laws add the “development of inclusive legislation” to protect people with these conditions from discrimination and human rights violations.

ACTIONS FOR MEMBER STATES:

- To highlight that Member States review their disability policy and laws to make it more inclusive for people with neurological disabilities including epilepsy. This also applies to the employment regulations and labour laws governing both public and private sector for specific regulations to accommodate for people with neurological disabilities.
- While there is a specific call to strengthen and/or implement policies, plans and legislation, to reduce discrimination and ensure universal access to financial, social and disability benefits for carers, these actions also need to be elaborated with the same degree of specificity for people living with neurological conditions.
- To emphasize the need to include the private sector perspective in collaborative efforts to develop comprehensive policies, plans and legislation that enable public-private collaboration.
- To consider improving regulatory and fiscal measures with reference to products such as tobacco, alcohol, and sugar-sweetened beverages.
- To highlight the importance of formulating and implementing national policies and legislation in consultation with relevant stakeholders to promote and protect the rights of people with epilepsy and prohibit discrimination.

ACTIONS FOR SECRETARIAT

- To highlight the importance of supporting Member States to strengthen the strategies to resolve claims and complaints about human rights violations and discrimination as related to people with neurological disorders.
- To consider providing a ranking of actions at policies, systems, services level as a minimum set which can be adapted i.e., define exactly what countries have to have in their national health plan so as to be sure that at least a common starting point is shared between countries.
- To consider mentioning specific rights for people with neurological disorders, for e.g.: employment, driving, access to education, fertility and women's rights.

ACTIONS FOR INTERNATIONAL PARTNERS

- To emphasize the importance of facilitating international structure of donors and funding agencies to support global policies in line with human rights for a better integration and inclusiveness at the level of Member States.
- To facilitate exchange and dialogue among stakeholders (associations of people with neurological disorders, their carers and families, health and social workers).
- To highlight the importance of international policies, where people with neurological disorders, their families and representatives from service user organizations can play effective and proactive role.

1.3 FINANCING

GENERAL COMMENTS

The inclusion of financing and consideration of costs associated with neurological care for governments, communities, families and individuals in the action plan was appreciated. People with neurological disorders and their families face significant financial hardship due to health and social care costs as well as reduced income. Specific comments included:

- To highlight the availability of limited investment and resources to address neurological conditions.
- To focus on the need for resource mobilization strategies and approaches for neurological conditions.
- To reference the need for financial and social protection to address out-of-pocket expenditures experienced by people with neurological disorders, their carers and families.
- To highlight the importance for increasing investment in different areas including early interventions, new technologies, diagnostic methods and training.
- To emphasize the importance of funding for the training of specialists in neurology in LMIC.
- To underscore the need to provide evidence of economic impact of proactive interventions to avoid a focus purely on costs, which can be a major barrier to governments. This includes emphasizing that appropriately funded policies and programmes may reduce costs for governments and communities by reducing wastage and achieving better (less costly) outcomes.
- To highlight the importance of a better understanding of, not only of the costs of treatment, but equally, the costs of non-action.
- To highlight the lack of universal health insurance across both LMICs and high-income countries (HICs) and the impact on people living with these conditions.

ACTIONS FOR MEMBER STATES

- To carry out and utilize the cost-benefit analysis to decide where to concentrate financial efforts.
- To emphasize the need for countries to be better aware about the most recent data on the burden of neurological disorders in order to make informed decisions on budgets that are proportionate to the scale of the burden.
- To acknowledge that at present there is great disparity on access to treatment and care across countries and settings and to encourage the development of an international assistance fund, which helps to fund treatment and offset costs related to referrals including travel and specialist services and interventions.
- To highlight the importance of collaboration amongst Member States about medicine pricing and treatment cost options.
- To emphasize the need to encourage and incentivize private sector investment in innovative solutions to neurological disorders and to adopt innovative pricing models that help de-risk investment and enable both innovation and broad access.

- To highlight the importance of securing sufficient budget to reimburse new treatments, medicines for rare illnesses, medicines which limits or delays progression to illnesses and second- or third-line treatment to make these readily available and affordable for patients.
- To call for more overseas assistance particularly for LMICs due to growing NCD burden, including neurological disorders, coupled with increasing international support for domestic financing.

ACTIONS FOR SECRETARIAT

- To highlight the importance of promoting collaboration and evidence exchange to strengthen the knowledge about the economic impact of investment for neurological disorders, to support resource management.
- To provide guidance on ‘fair pricing’ of medicines and diagnostics and consider the importance of price transparency.
- Considering the high burden due to neurological disorders/brain health, to highlight the need to follow the model of other disease areas such as HIV, TB and malaria and develop a global fund for brain health/neurological disorders that countries can draw on.

ACTIONS FOR INTERNATIONAL PARTNERS

- To consider substantially increasing the funding for NCDs plans, including neurological disorders.
- To support people affected by neurological disorders and other NCDs to have secured seats at the decision-making tables of international financing mechanisms.
- To highlight that less than 3% of global health donor’s financing goes to NCDs, including neurological disorders, and less than 1% of health-related funding goes to prevention of diseases, including neurological disorders which should be substantially increased.
- To highlight the need to identify functional gaps in resource allocation in integration of neurological disorders.
- To emphasize the importance for the pharmaceutical companies to map out access pathways and consider how to ensure fair pricing for existing and new vaccines, medicines and diagnostics in different national settings to ensure a sustainable and affordable supply of health products and to ensure that ground-breaking new health products reach the people that need them without delay.
- To support the development of an international assistance fund, which helps to fund treatment and offset costs associated with referral such as for travel and specialist services and interventions.
- To facilitate knowledge exchange to identify functional gaps in resource allocation and help to mobilize economic resources for rehabilitation of neurological disorders.
- To consider employing available evidence-based models which supports pooled funding models, where funding from multiple groups is combined for a specific investment.
- To highlight the evidence that supports the viability of international transactions taxes or levies placed on specific transactions to fund investments in drug procurement and supply, and of the front-loading of development aid through bond sales, particularly to stabilize funding and subsidize drug procurement.

1.4 INTEGRATED RESPONSE WITHIN HEALTH AND SOCIAL CARE SYSTEMS

GENERAL COMMENTS

- To highlight the importance of functioning and quality of life of people with neurological disorders in health and social planning. Specifically, functionality and quality of life, environmental modification, psychotherapies and psychoeducation, should be integrated in occupational, social, labor policies.
- To highlight the need for health systems to embrace a people-centred and coordinated care approach that commits to raise care quality, improve outcomes and enable better resource allocation.

- To highlight the importance of multidisciplinary networks linking health and social care over sustained periods due to long-term and transversal nature of care and treatment for neurological disorders.
- To highlight the need to strengthen two essential pillars of care for people with neurological disorders – a highly specialized and targeted care at one level, and integrated, people-centred response on the other. Examples can include: the management of common conditions in the community by a provider network, using a tiered approach; improved acute neurology services at a secondary care level led by neurologists.
- To consider establishing a national clinical director (or clinical leadership) within health systems for neurological disorders-
- To consider orienting health systems to expand the prevention, management and care of neurological disorders building on existing epilepsy services as an entry point for expansion and to optimize synergies.
- To highlight the importance of comprehensive health systems providing specialized services in all public health hospitals so that people with epilepsy and families can receive timely treatment including specialist support.

ACTIONS FOR MEMBER STATES

- To highlight that primary health care provides a platform where the health needs of people with neurological disorders, including promotion, prevention, management and care can be effectively addressed through a people-centred approach. This platform needs to be linked with a general neurology service including emergency neurological service, and, where possible, disease oriented multidisciplinary care.
- To highlight the need to ensure data exchange within the different sectors i.e., health and social services with a role in preventing and managing neurological disorders.
- To consider clarifying how digital health fits in provision of care for people with neurological disorders.
- To consider raising the importance of palliative care at all stages in progressive neurological disorders, and particularly at the end of life.
- To consider development of programmes that help with people with neurological disorders in navigating the health and social care system.
- To reinforce the importance of collaboration with civil society and other partners to develop a tri-sector partnership (civil society including, youth organizations and media, government and private sector).

ACTIONS FOR SECRETARIAT

- To highlight the importance of a biopsychosocial approach to improve the quality of life of people with neurological disorders.
- Neurological disorders impact education, employment, pensions systems. All these sectors might play a role and should be mentioned as possible facilitators or barriers so that Member States can also gain a broader perspective in caring for people with neurological disorders.
- Consider providing guidance and technical support to Member States in integrating cost-effective interventions for neurological disorders, their risk factors, and comorbidities into health systems, including essential primary health care packages and how to utilize strengthened epilepsy services as an entry point.

ACTIONS FOR INTERNATIONAL PARTNERS

- To emphasize that neurorehabilitation can provide intervention programmes tailored to the individual, their capacity and performance.
- To highlight the importance of inclusion of palliative care in the development of multidisciplinary care networks.

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. Focused care involving neurorehabilitation using assistive devices and palliative care were emphasized as were the high out of pocket expenses for medicines and diagnostics and the importance of closing the treatment gap by ensuring access to essential diagnostics, medicines, and treatment, particularly for LMICs. Addressing the many challenges and lack of sufficient data for carers was also appreciated. Additional suggestions included:

- To highlight the focus on reducing the unacceptable, global treatment gap for all neurological disorders using epilepsy as an example for which effective treatments are available at very low cost, but which are still out of reach for over 70% of the affected population.
- To include diseases other than epilepsy that can also provide examples of the importance of adopting a synergistic approach to addressing co-existing conditions. For example, Alzheimer's disease often presents with other neurological symptoms, including sleep disorders, hallucinations, migraines, seizures and Parkinson's disease.
- To further highlight that effective, timely and responsive diagnosis, treatment and care with early intervention at the onset of the disease is essential to modifying the course of progression for many neurological disorders. This is true for many neurological disorders such as multiple sclerosis, epilepsy, Alzheimer's disease, normal pressure hydrocephalus and Parkinson's disease.
- To consider incorporating sleep medicine as an area in the action plan since sleep medicine is a growing area within the context of neurological disorders.

2.1 CARE PATHWAYS

GENERAL COMMENTS

The discussion paper's section on Care Pathways was well received with overarching themes of recognizing the importance of early intervention, palliative care and further strengthening of multi-disciplinary neurorehabilitation. Highlighting the gaps in the healthcare workforce (trained primary care and neurology specialists), treatment in under-resourced areas and access to cost-effective medicines and diagnostics were all emphasized. Leading priority is closing the treatment gap by ensuring access to essential medicines, diagnostics, and treatment. Specific suggestions included:

- To further highlight the importance of primary care and outline the role of WHO's mental health Gap Action Programme (mhGAP) in addressing epilepsy and dementia and to expand it for other neurological disorders.
- To consider inclusion of role of neurosurgical interventions such as mechanical thrombectomy or other neurosurgical treatments for acute ischemic stroke or urgent spinal surgery for cord compression related to Pott's disease which can avoid disability.
- To emphasize the need for evidence-based guidelines for cost-effective, coordinated healthcare interventions in order to develop better prevention and timely treatment for neurological disorders.
- To strengthen the role of neurorehabilitation for traumatic brain and spinal cord injuries which has become progressively more complicated due to the increased incidence of severe cases with disorders of consciousness that require long term interventions and assistance.

ACTIONS FOR MEMBER STATES

- To underscore the need for health education programmes to provide guidance on the care pathway from detection and diagnosis to treatment and care in order to improve the diagnostic journey for people with neurologic disorders.
- To address the barriers to seeking help and obstacles to optimal treatment (missed diagnosis, delayed or inadequate treatment, non-adherence, no access to care, unaffordability, over-use or under-use) in cases of acute neurological disease such as suspected brain infection or uncontrolled epilepsy. These include healthcare workers' awareness of available diagnostics and therapies.

ACTIONS FOR SECRETARIAT

- To devise a set of minimum standards of care, across the life course covering all possible neurological disorders.

ACTIONS FOR INTERNATIONAL PARTNERS

- To strengthen collaboration with palliative care organizations at international, and national level.

2.2 MEDICINES, DIAGNOSTICS AND OTHER HEALTH PRODUCTS

GENERAL COMMENTS

Many comments were provided on the importance of this action area including the value and role of essential medicines, diagnostic tests such as lumbar puncture and accessibility and affordability of imaging modalities such as MRI and CT. Specific comments included:

- To strengthen linkages with the WHO essential medicine list (EML) area of work, in particular the area of essential medicines and fair pricing while recognizing that essential medicines for neurological conditions are poorly represented on the WHO EML.
- To recognize that even low-cost medicines, such as anticoagulants and anti-epileptics can have limited accessibility in LMICs due to affordability and supply chain obstacles. To highlight the need for consistent updating of the best pharmacological and non-pharmacological therapeutic options including new therapies, protocols and guidelines.
- To highlight that lumbar puncture is an essential tool in the diagnosis and treatment of many neurological disorders therefore providing training and equipment to perform this vital neurological procedure as well as the associated microscopy is important.
- To consider including diagnostics for common and treatable infections, such as scrub typhus, Japanese encephalitis, Herpes simplex and tuberculosis, as well as appropriate medication for these disorders (i.e., doxycycline, acyclovir and anti-tubercular agents).
- To consider including widely available, internationally endorsed and free to use technology-based solutions for delaying or preventing neurological diseases such as stroke and dementia for the promotion of brain health.

ACTION FOR MEMBER STATES

- To focus attention on the implementation of mhGAP guidelines for management of epilepsy and dementia in primary care settings

- To highlight the need for sustainable supplies of medicines. Challenges include maintaining consistent medicine supply for chronic conditions due to irregular supply of medicines, affordability and bureaucratic systems to prove eligibility.
- To foster transparency of essential medicines regulatory submissions and assessment and decisions to ensure public trust for all medicinal products manufactured or imported to the country.
- To encourage construction and development of MRI and CT machines as well as governmental guidelines on when these imaging modalities are indicated. Collaborate with governments to improve transportation from rural areas to larger areas with diagnostic imaging modalities.
- To encourage involvement of people with neurologic disorders and their carers in the regulatory and reimbursement processes of new technologies so that decision on access to care are person-centred.
- To emphasize the importance of recognizing that neurological disease can vary from person to person and hence decisions on best treatment regimen should be evidence-based and agreed-upon with both people with neurologic disorders and their physicians. Access to appropriate medications which have the potential to improve quality of life should not be based on economic savings.

ACTIONS FOR SECRETARIAT

- To underscore that equitable access should address affordability for both the health systems and individuals. WHO Secretariat can help by reviewing WHO EML, WHO medicine formulary, essential diagnostics and other relevant documents provided by WHO to ensure they include medications for neurological disorders that are up-to-date, contain the newest and most effective treatments and diagnostics.
- To provide technical support and guidance for ensuring up-to-date, evidence-based regional/national/resource-stratified diagnostic and treatment guidelines are in place.

ACTIONS FOR INTERNATIONAL PARTNERS

- To highlight that cost and equity of access to diagnostics and treatment are important issues. International commitment to providing treatment at low cost, and access to an international fund to subsidize and fund costs of therapeutics and diagnostics would be progress in addressing these important barriers.
- To encourage pharmaceutical companies to provide vaccines, medicines and diagnostics at a fair price to ensure sustainable affordability for health systems and individuals.
- To include the need to promote international and national efforts for affordable, safe, effective and quality medicines, diagnostics and other health products (including neuroimaging and assistive products for autonomy) coupled with infrastructural investments for imaging devices.
- To support philanthropic efforts to fund more MRI/CT/EEG machines.

2.3 HEALTH WORKERS' CAPACITY BUILDING, TRAINING AND SUPPORT

The focus on shifting toward community-based integrated neurological care complemented by increasing specialist neurological workforce training and capacity building outlined in the action area was well received.

GENERAL COMMENTS

- While expanding neurological specialties is needed as a long-term strategic goal, to emphasize that the short-term strategy should be training and capacity building on primary care physicians and non-medical clinical officers as they are providing the majority of neurological care in LMICs at the moment.
- To consider addition of training and capacity building of laboratory staff as they are vital members of the healthcare team for diagnostics in microscopy.

- To emphasize the need to adequately train medical and community staff in particular areas such as child development, palliative care and neurorehabilitation.
- To highlight the need to build telemedicine capacity that is critical to improve access to services both during normal times and during crises.
- Introduce the importance of e-learning to support health worker training.
- To underscore the importance of providing updated medical training to general practitioners to rapidly identify symptoms without delay as neurological symptoms are often dismissed and deemed irrational, in some population groups such as women and ethnic minorities. This would ensure that those who need help are provided care.

ACTIONS FOR MEMBER STATES

- To support healthcare and social care workers to use information and communication technologies such as telemedicine, internet/mobile phone technologies in order to scale up remote neurology services and thus expand neurological care to remote and low-resource settings and support home-based services.
- To focus on creating comprehensive strategies and capacity building by investing in data infrastructure and the use of digital tools through policy actions and investment and encourage innovation through the recognition of the benefits of data sharing.
- To strengthen the need for all healthcare professionals' abilities to detect neurological disorders in a timely manner considering that the entry point in healthcare is not always disease specific and is generally available and able to treat many different health conditions.
- To incorporate representatives from relevant civil society organizations into the development and delivery of training to healthcare workers across all specialties including primary care and nurses.

ACTIONS FOR SECRETARIAT

- To benchmark the number of hours medical and nursing students spend training/learning about neurological disorders and the number of hospital beds available per 100,000 patients in comparison to other chronic diseases as this would be helpful data to identify gaps.

ACTIONS FOR INTERNATIONAL PARTNERS

- To point out that international organizations can provide support in developing the educational curriculum for neurological disorders including neurorehabilitation and palliative care and develop neurology-focused guidelines that are adapted for training health staff in non-specialized health settings, and humanitarian emergencies.

2.4 CARER SUPPORT

Overall, there was agreement that this is an important action area. Feedback included the value of expanding existing WHO tools such as mhGAP and iSupport to carers of other neurological disorders, the importance of generating more data related to carer burden, psychological morbidity, social isolation, financial hardship and the stigma and discrimination suffered by carers themselves.

GENERAL COMMENTS

- To stress the need to support carers by providing carer training education and support them in using information and communication technologies such as telemedicine, internet/mobile phone technologies.

- To point out that carers may also take on a 'therapist' role, adding further carer burden, particularly when caring for children or adolescents with neurological disorders. The role of carers should be better clarified with respect to children and older adults.
- To draw attention that bereavement support for carers is crucial for those who have cared for someone through a progressive illness and then suffered a sudden unexpected death – such as from stroke.
- To recognize that often carers are abandoned and women, in particular, are left alone with the burden of caring.

ACTIONS FOR MEMBER STATES

- To support the development of internationally funded respite centres, including volunteers from relevant nongovernmental organizations (NGOs), to provide practical and financial support to carers.
- To consider that financial benefits to carers themselves might be costly for states and that economic and social benefits are generally given to the persons with neurological disorders and disabilities, thus indirectly benefiting the family.
- To promote programmes to enable the identification of carers and apply special support schemes, detaxation and allowances within the employment sector. Reference that carers may not self-identify as carers.
- To consider that additional provisions for carers could include the development of carer guides to navigate the healthcare system and fostering an inclusive environment in the workforce by providing support and flexible work arrangements.

ACTIONS FOR SECRETARIAT

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

ACTIONS FOR INTERNATIONAL PARTNERS

- To highlight that existing action plans (for example, the global action plan for the public health response to dementia) can be disseminated and provide a common ground for developing support for carers.

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

Overall comments for this action area were appreciation for key principles while demonstrating some of the gaps to be addressed, in particular the needs of children and people who live in low resource settings and an emphasis on population-wide prevention strategies considering the links between NCDs and neurological disorders.

GENERAL COMMENTS

- Whilst neurological conditions share some risk factors with other NCDs, there is still much to be discovered about the full range of preventable causes of neurological conditions. Therefore, strategies to prevent neurological conditions must run alongside actions taken to manage the effects that people who are living with these conditions experience.
- Strategic objective 3 (prevention) might be better placed as objective 2.
- Include reference to the challenges of adolescents transitioning into adulthood and how this can be managed

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 children living in low resource settings, particularly during prenatal, birth care and postnatal period.

GENERAL COMMENTS

- To underscore the importance of quality antenatal, intrapartum and postnatal care for promotion of optimal brain development in children
- To consider inclusion of prevention of intrapartum hypoxic-ischemic encephalopathy which is common in emergency settings especially in LMICs due to lack of resources such as skilled healthcare workers.

ACTION FOR MEMBER STATES

- To recognize the importance of strengthening healthy schools including special education systems especially for children with sensory impairment such as blindness and deafness.
- To highlight the role of early intervention and programmes starting at an early age to prevent neurological conditions later in life. For example, healthy behaviours such as physical activity throughout the life course can reduce the risk of developing dementia later in life.

ACTIONS FOR INTERNATIONAL PARTNERS

- To draw attention to the important role of relevant NGOs in promoting optimal brain development.

3.2 PROMOTING HEALTHY BEHAVIOUR ACROSS THE LIFECOURSE

In general, the actions included in this area were well received. The importance of regular physical and mental exercise and sleep which contribute to slowing age-related brain deterioration and maintain cognitive abilities was emphasized.

GENERAL COMMENTS

- To highlight the need for more investment in prevention such as public awareness, healthy lifestyles and addressing modifiable risk factors to strengthen capacity to make healthier choices.
- To highlight or include a separate section on specific populations such as children/adolescents as well as older adults.
- To reiterate the fact that a host of neurological disorders share similar risk factors with other major NCDs, and that effective risk factor modification is required to reduce morbidity and mortality across the lifespan.

ACTIONS FOR MEMBER STATES

- To emphasize that for the promotion of brain health in the public and lay audiences it is important to have clear definition of what this includes
- To support the availability and accessibility of treatment and care that targets modifiable risk factors and diseases such as cardiovascular disease as part of preventative programs

3.3 INFECTIOUS DISEASE CONTROL

Many comments were provided on the importance and value of this action area with an emphasis on vaccinations against infections and highlighting certain preventable neurological conditions such as encephalitis buttressed by the importance of including lumbar puncture and microscopy in the diagnosis of many neurological diseases. The COVID-19 pandemic was emphasized as an opportunity to further develop neurological services in LMICs.

GENERAL COMMENTS

- To emphasize that the global burden from encephalitis is considerable with some progress in disease control through WHO initiatives (e.g.: Japanese encephalitis). Further work in this area should be a key part of this action plan and common and treatable infectious causes of encephalitis and meningitis (scrub typhus, Japanese encephalitis, yellow fever, dengue and chikungunya) should be included as they are readily amenable to public health interventions.
- To specifically highlight both microscopy and lumbar puncture as essential tools for diagnosing infections of the brain as well as a focusing on training and equipment to perform these important neurological procedures.
- To stress the importance of vaccination against infections in general, most importantly for parasites and viruses in LMICs (e.g., malaria, neurocysticercosis)

ACTIONS FOR MEMBER STATES

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

- To support and promote the availability of rapid and affordable diagnostics for infections of the nervous system (e.g.: lumbar puncture, microscopy, imaging).

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 and targeting certain areas such as safer contact sports, preventing physical abuse and strengthening policies for safe behaviours in the workplace and on the roads.

GENERAL COMMENTS

- To include reference to injuries due to burns and drowning in people with epilepsy and importance of preventing these injuries.
- To draw attention to infant physical abuse that can lead to TBI and highlight intervention strategies such as support for new mothers, identification of distress and targeted new parent education linked to Justice, Protection and Child Protection sectors.

ACTIONS FOR MEMBER STATES

- To facilitate collaboration with Ministry of Sports so that education for athletes and coaches incorporates awareness on different aspects of traumatic neurological disorders including severe consequences of TBI such as epilepsy.

3.5 REDUCING ENVIRONMENTAL RISKS

The focus on environmental risks related to brain health was appreciated by many with a range of diseases mentioned including the effect of the environment on diseases such as Alzheimer's, Parkinson's and toxic encephalopathies. The observation was made that marginalized communities are subject to exposure to environmental toxins at a much higher level through toxins in the home and workplace and through unclean water.

GENERAL COMMENTS

- To highlight that, as with children, exposure to heavy metals such as lead and mercury can have serious neurological consequences for all ages with exposure due to artisanal and small-scale gold mining (ASGM). Therefore, the safe disposal of mercury waste is critical to preventing direct nervous system damage.
- To emphasize the fact that the role of environmental factors in brain development and neurological disorders is vastly understated and urgent action is needed. For example, the industrial solvent trichloroethylene (TCE) increases the risk of Parkinson's disease by 500% and is a class I carcinogen linked to numerous cancers. These chemicals, pesticides and TCE, are increasingly used in LMIC.
- Reference should be made of the toxic encephalopathies that can result from environmental factors (e.g., the report of acute encephalitis syndrome and lychees).
- Highlight the need to bridge the gender and race data gap regarding the effect of environmental toxins on marginalized communities and the subsequent development of neurological disorders.

ACTIONS FOR MEMBER STATES

- Underline the importance of clean and adequate use of water sources and disposition of waste in preventing neurological conditions.

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

OVERALL COMMENTS

Appreciation of the attention to research for neurological disorders was expressed by many.

- To divide strategic objective 4 into two: (i) fostering research and innovation related to epilepsy and other neurological disorders, and (ii) strengthening information systems for epilepsy and other neurological disorders.
- To appreciate that brain research is extremely complex, consequently, there is a need for an increased international collaboration through setting up of knowledge hubs i.e., common research platforms to share data, consolidating fragmented research and to consider coordinating multicenter research studies. The COVID-19 unprecedented research cooperation can provide a roadmap for neuroscience research.
- To highlight that there are significant gaps in data on neurological conditions in higher income countries as well as in LMICs and to support the strengthening of research and information systems since better data and understanding of the situation relating to neurological conditions in countries is the basis for effective advocacy to promote collaboration, research grants and support for research across a diverse range of countries.
- To consider promoting digital innovations to champion and support better diagnosis and management of neurological conditions.
- To prioritize implementation research at the healthcare level and conduct health systems evaluation and when an intervention has demonstrated impact this can be replicated in similar settings
- To highlight the importance of exploring policy and regulatory changes that might increase private-sector investment in R&D innovation that fills unmet medical needs for neurological disorders.
- To encourage involvement of people with neurological disorders to better support and guide the research and development of innovative solutions for neurological disorders on every level. To engage people with neurological disorders, their families and carers in order to have genuine and meaningful impact on the research output.

4.1 INVESTMENT IN RESEARCH

GENERAL COMMENTS

- To highlight the need for more funding and research grants for neurological disorders.
- To emphasize the importance of investing in evidence generation studies about the burden of disease, patient preferences, and the return on investment for prevention and treatment of neurological disorders.
- To highlight the need for investment in new technologies including precision medicine.
- To highlight the current challenges faced in R&D in brain health and neurological disorders. For example, clinical trial guidelines within neuroscience are sometimes outdated which interferes with meaningful clinical trials for neurological disorders.
- To draw attention to what people with neurological disorders value in terms of treatment outcomes and innovative treatments when planning research.
- To emphasize the importance of generating more evidence on the socio-economic burden of neurological disorders.
- To reiterate that it is important to continue investing in both disease modifying treatments and in treatments addressing symptom reduction.
- To foster international collaboration, Public private Partnerships (e.g., need for close collaboration between academia and industry), and data sharing.
- To highlight the challenge that innovation reward models tend to discriminate against incremental innovation, which are often the preferred treatment outcomes for people with neurological disorders.
- To promote balance between investments in basic, translational and implementation research.

ACTIONS FOR MEMBER STATES

- To highlight the importance to build knowledge and capacities of decision-makers on need for innovation within brain health.
- To underscore the importance to incentivize the involvement of people with neurological disorders in research planning and funding.
- To highlight the importance of neurological disorders in the priority research funding of the country, or national research councils.
- To encourage a more patient-centric mindset in drug development initiatives

ACTIONS FOR SECRETARIAT

- To consider developing cost-effective, high-impact interventions for a larger number of neurological disorders which could be scaled up.
- To consider establishment of an international coordinating structure for research and development with experts, technicians, professionals, and civil society representatives.
- To highlight the need to monitor Member States' research funding dedicated to brain research generally and to neurology specifically.

ACTIONS FOR INTERNATIONAL PARTNERS

- To underscore that industries producing medicines and diagnostics should take responsibility in planning and developing methodologies to ensure equitable and affordable access of these products in LMIC.

4.2 RESEARCH CAPACITY BUILDING

GENERAL COMMENTS

- To highlight the need for development of an international research centre and international collaboration on priority research areas.
- To emphasize that research infrastructure is needed for research into care provision, including rehabilitation and palliative care
- To contextualize the research to address the needs of people living in LMICs where risk factors, disease prevalence and resources differs considerably from those in high resource setting.
- To highlight the need for capacity building for leading edge technology such as genetic analysis and precision medicine approaches for neurological disorders.
- To emphasize the need for collaboration between researchers from different countries for exchange and transfer of knowledge and skills.

ACTIONS FOR MEMBER STATES

- To highlight the importance of strengthening national institutional capacity, through strategic alliances; enhancing research infrastructure, equipment and supplies in research institutions, and harnessing the use of big data and artificial intelligence.
- To support initiatives that integrate LMICs researchers in research efforts.
- To involve all stakeholders engaged in the care of people with neurological disease to collaborate as this is important in developing research strategy.

ACTIONS FOR SECRETARIAT

- To highlight the need to determine how evidence-based practices from HICs can be applied effectively and sustainably in LMICs where there are limited numbers of health professionals, including how to effectively utilize task-shifting approaches.
- To engage WHO collaborating centres, academic institutions, research organizations and alliances to strengthen capacity for research on neurological disorders at the country level.
- To encourage NGOs working in the area of neurological disorders to participate in health research trainings.

ACTIONS FOR INTERNATIONAL PARTNERS

- To involve international palliative care organisations to help in developing research and participate in existing research networks
- To highlight the importance of research that is contextually and culturally appropriate.

4.3 DATA AND INFORMATION SYSTEMS

GENERAL COMMENTS

Many comments reflected the fact that systematic collection of population-level and routine health data provides the basis to guide evidence-based actions to improve services. Further specific comments include:

- To highlight the importance of integrating monitoring of neurological disorders into routine information systems, across all levels of care and identify, collate, routinely report and use core data, disaggregated by sex, age and other equity measures in order to improve service delivery.
- To highlight the need to provide technical support and expertise to countries to develop safe and robust data collection systems.
- To highlight the need to install a computerized and modern information system to facilitate exchanges and surveillance of neurological diseases by Member States.
- To appreciate that the development of patient outcome measures including for symptoms and quality of life will allow palliative care, rehabilitation and other issues that are important to patients and their families to be monitored and appropriate management put in place.
- To emphasize that it is not sufficient to collect and interpret data. Policy makers need to take note of data, understand it and utilize it.

ACTIONS FOR MEMBER STATES

- To work with the neurological community to establish common reporting mechanisms on process and outcome measures, which support the provision, analysis and evaluation of effective treatment and care.
- To support international collaborations that will deliver on interoperability of data, which will accelerate brain research.
- To use established and robust vital statistics and demographic surveillance sites for establishing the burden and trends of neurological disorders.

ACTIONS FOR SECRETARIAT

- To highlight the importance of collecting routine information including details of symptoms / place of care and place of death – to allow monitoring of palliative care and other issues that are important to patients and their families.
- To consider including development of specific actions and indicators to address epidemiology and service information gaps.
- To support the clarification and evidence generation of the global figures on disease burden of neurological conditions and projected figures by 2030.
- To support efforts that are building new data-sharing techniques that drive better disease understanding.
- To emphasize the importance of setting up reporting and monitoring mechanisms with data based and evidence for information sharing among Member States.

ACTIONS FOR INTERNATIONAL PARTNERS

- To highlight the importance of involvement of people with neurological disorders, their families and carers in the collection of data.
- To highlight the importance of working with the neurological community to establish common reporting mechanism which support the provision, analysis and evaluation of effective treatment and care.
- To emphasize the support for international collaborations that will deliver on interoperability of data, which will accelerate brain research.