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**Follow-up to the political declaration of the third  
high-level meeting of the General Assembly  
on the prevention and control of  
non-communicable diseases**

## ANNEX 7

### **DRAFT INTERSECTORAL GLOBAL ACTION PLAN ON EPILEPSY AND OTHER NEUROLOGICAL DISORDERS 2022–2031**

#### **BACKGROUND**

1. In November 2020, the Seventy-third World Health Assembly adopted resolution WHA73.10 requesting the Director-General of WHO, inter alia, to develop a 10-year intersectoral global action plan on epilepsy and other neurological disorders, in consultation with Member States, in order to promote and support a comprehensive, coordinated response across multiple sectors.
2. The intersectoral global action plan on epilepsy and other neurological disorders 2022–2031 aims to improve access to care and treatment for people living with neurological disorders, while preventing new cases and promoting brain health and development across the life course. It seeks to support the recovery, well-being and participation of people living with neurological conditions, while reducing associated mortality, morbidity and disability, promoting human rights, and addressing stigma and discrimination through interdisciplinary and intersectoral approaches.
3. The intersectoral global action plan on epilepsy and other neurological disorders 2022–2031 builds on previous global resolutions, decisions, reports and commitments, including resolution WHA68.20 on the global burden of epilepsy and the need for coordinated action at the country level to address its health, social and public knowledge implications. A number of preventive, pharmacological and psychosocial approaches are shared by epilepsy and other neurological disorders. This sharing of strategies and approaches (i.e., synergies) can serve as valuable entry points for accelerating and strengthening services and support for epilepsy and other neurological disorders.

#### **OVERVIEW OF THE GLOBAL SITUATION**

4. Disorders of the nervous system are the leading cause of DALYs and the second leading cause of death globally, accounting for 9 million deaths per year. The five largest contributors of neurological DALYs in 2016 were stroke (42.2%), migraine (16.3%), dementia (10.4%), meningitis (7.9%) and epilepsy (4.9%).<sup>1</sup> Globally in 2016, 52.9 million children younger than 5 years had developmental disabilities and 95% of these children lived in low- and middle-income countries.<sup>2</sup>
5. The high burden associated with neurological disorders is compounded by profound health inequities. For example, nearly 80% of the 50 million people with epilepsy live in low- and middle-income countries, where treatment gaps exceed 75% in most low-income countries and exceed 50% in most middle-income countries.<sup>3</sup> Disabilities associated with neurological conditions inordinately

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<sup>1</sup> Global, regional, and national burden of neurological disorders, 1990–2016: a systematic analysis for the Global Burden of Disease Study 2016. *Lancet Neurol.* 2019;18(5):459–480. doi: 10.1016/S1474-4422(18)30499-X. See also Global health estimates 2020: Disease burden by cause, age, sex by country and by region, 2000–2019. Geneva: World Health Organization; 2020.

<sup>2</sup> Developmental disabilities among children younger than 5 years in 195 countries and territories, 1990–2016: a systematic analysis for the Global Burden of Disease Study 2016. *Lancet.* 2018;6(10):E100–E1121. doi: 10.1016/S2214-109X(18)30309-7.

<sup>3</sup> Epilepsy: a public health imperative. Geneva: World Health Organization; 2019.

affect women, older people, those living in poverty, rural or remote areas and other vulnerable populations. Women are also often disproportionately affected by neurological disorders, such as dementia, migraine and multiple sclerosis. Children from underprivileged households, indigenous populations, ethnic minorities and internally displaced or stateless persons, refugees and migrants are also at significantly higher risk of experiencing disability associated with neurological conditions.

6. Neurological disorders lead to increased costs for governments, communities, families and individuals, as well as to loss of productivity for economies. In 2010, brain disorders were estimated to cost € 798 billion in Europe alone.<sup>1</sup> In 2019, the total global societal cost of dementia was estimated at US\$ 1.3 trillion, equivalent to 1.5% of global GDP.<sup>2</sup>

7. Many neurological conditions are preventable, including 25% of the global burden of epilepsy cases.<sup>3</sup> Numerous determinants, including environmental risk factors and protective factors, are known to impact brain development in early life and brain health across the life course. Protective factors for brain development in early life include components such as education, social connection and support, healthy diets, sleep and physical activity.

8. Worldwide, people living with neurological disorders and associated disabilities continue to experience discrimination and human rights violations. For this reason, the intersectoral global action plan on epilepsy and other neurological disorders 2022–2031 is underpinned by a human rights perspective that is grounded in the International Covenant on Civil and Political Rights, the International Covenant on Economic, Social and Cultural Rights, the Convention on the Rights of Persons with Disabilities, the Convention on the Rights of the Child and other relevant international and regional human rights instruments.

9. Supporting the appropriate health system building blocks is particularly important for improving the quality of life of people living with neurological disorders. The implementation of appropriate policy and legislative frameworks is crucial and should aim to promote quality care, provide financial and social protection benefits (including protection from out-of-pocket expenditures) and ensure respect and fulfilment of the rights of people with neurological disorders. Comprehensive responses aimed at tackling neurological disorders should be firmly grounded in a social and economic determinants of health approach.

10. Health systems have not yet adequately responded to the burden of neurological disorders. While approximately 70% of people with neurological disorders live in low- and middle-income countries,<sup>4</sup> their needs are poorly recognized, with only 28% of low-income countries reporting that they have a dedicated policy for neurological disorders.<sup>5</sup> Currently, the number of health workers specialized in neurological health is insufficient to tackle the treatment gaps globally. The median neurological workforce (defined as the total number of adult neurologists, neurosurgeons and child neurologists) in

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<sup>1</sup> J Olesen 1, A Gustavsson, M Svensson, H-U Wittchen, B Jönsson, CDBE2010 study group, et al. The economic cost of brain disorders in Europe. *Eur J Neurol*. 2012; 19(1):155–162. doi: 10.1111/j.1468-1331.2011.03590.x.

<sup>2</sup> Global status report on the public health response to dementia. Geneva: World Health Organization; 2021.

<sup>3</sup> Epilepsy: a public health imperative. Geneva: World Health Organization; 2019.

<sup>4</sup> Feigin VL, Vos T, Nichols E, Owolabi MO, Carroll WM, Dichgans M, et al. The global burden of neurological disorders: translating evidence into policy. *Lancet Neurol*. 2020 Mar;19(3):255-265. doi: 10.1016/S1474-4422(19)30411-9.

<sup>5</sup> ATLAS Country Resources for Neurological Disorders , second edition. Geneva: World Health Organization; 2017.

low-income countries is 0.1 per 100 000 people, compared to 7.1 per 100 000 people in high-income countries.<sup>1</sup>

11. The ongoing COVID-19 pandemic highlights the relevance of neurology to global public health and its significance in broader global health dialogues. Disruption of services, medication inaccessibility, interruption in vaccination programmes and increased mental health issues have added to the burden of those with neurological disorders. More directly, neurological manifestations of COVID-19 infection are present in both the acute stage and the post-COVID-19 condition. Certain underlying neurological conditions represent a risk factor for hospitalization and death due to COVID-19, especially for older adults.<sup>2</sup> The intersectoral global action plan on epilepsy and other neurological disorders 2022–2031 represents an unprecedented opportunity to address the impact of neurological disorders through a comprehensive response throughout and following the pandemic.

## SCOPE

12. The term “neurological disorders” is used to denote conditions of the central and peripheral nervous systems that include epilepsy; headache disorders (including migraine); neurodegenerative disorders (including dementia and Parkinson’s disease); cerebrovascular diseases (including stroke); neuroinfectious/neuroimmunological disorders (including meningitis, HIV, neurocysticercosis, cerebral malaria and multiple sclerosis); neuromuscular disorders (including peripheral neuropathy, muscular dystrophies and myasthenia gravis); neurodevelopmental disorders (including autism spectrum disorder and congenital neurological disorders); traumatic brain and spinal cord injuries; and cancers of the nervous system. While some neurological disorders are rare, they are still responsible for high morbidity and mortality.

13. In line with WHO’s International Classification of Functioning, Disability and Health, functioning and disability are considered the result of interactions between neurological conditions and contextual factors across the life course. For this reason, a holistic approach is required to account for medical, individual, social and environmental influences.

14. Addressing the needs of people with neurological conditions begins with increasing understanding and awareness and addressing stigma and discrimination, which impact well-being and act as barriers to seeking health care. Rather than adopting a disease-specific structure, the intersectoral global action plan on epilepsy and other neurological disorders 2022–2031 uses an integrated, person-centred framework for the prevention, diagnosis, treatment and care of people with neurological disorders. The prevention of neurological disorders rests upon the promotion and development of optimal brain health across the life course. Good brain health is a state in which every individual can learn, realize their potential and optimize their cognitive, psychological, neurophysiological and behavioural responses, while adapting to changing environments.

15. Other relevant areas or disciplines of public health are closely intertwined with and impact neurological disorders, such as mental health, violence, injuries, noncommunicable and infectious diseases, and environmental health. Many neurological conditions are woven into other WHO strategies, action plans or World Health Assembly resolutions. In addition, neurological disorders have strategic links to health systems and UHC, including the full range of essential health services, from health promotion to prevention, treatment, rehabilitation and palliative care. The intersectoral global action

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<sup>1</sup> ATLAS Country Resources for Neurological Disorders, second edition. Geneva: World Health Organization; 2017.

<sup>2</sup> WHO’s Scientific Brief on Neurology and COVID-19 (<https://www.who.int/publications/i/item/WHO-2019-nCoV-Sci-Brief-Neurology-2021.1>, accessed 6 April 2022).

plan on epilepsy and other neurological disorders 2022–2031 is consistent with the 2030 Agenda and the SDGs and takes a life course approach, recognizing that there are strong linkages between maternal, newborn, child and adolescent health, reproductive health and ageing, and brain health and neurological disorders.

16. Linking the intersectoral global action plan on epilepsy and other neurological disorders 2022–2031 with other global commitments<sup>1</sup> reflects WHO’s responsiveness to focusing on the impact on people’s health and working in a cohesive and integrated manner.

17. The intersectoral global action plan on epilepsy and other neurological disorders 2022–2031 provides the vision, goal, guiding principles and strategic objectives with their action areas and targets. It suggests a range of proposed actions for Member States, the WHO Secretariat and international and national partners. While targets are defined for achievement globally, each Member State can be guided by these to set its own national targets, taking into account national circumstances and challenges.<sup>2</sup>

## VISION

18. The vision of the intersectoral global action plan on epilepsy and other neurological disorders 2022–2031 is a world in which:

- brain health is valued, promoted and protected across the life course;
- neurological disorders are prevented, diagnosed and treated, and premature mortality and morbidity are avoided; and
- people affected by neurological disorders and their carers attain the highest possible level of health, with equal rights, opportunities, respect and autonomy.

## GOAL

19. The goal of the intersectoral global action plan on epilepsy and other neurological disorders 2022–2031 is to reduce the stigma, impact and burden of neurological disorders, including their associated mortality, morbidity and disability, and to improve the quality of life of people with neurological disorders, their carers and families.

20. In order to achieve the vision and goal defined above, the prevention, treatment and care of epilepsy and other neurological disorders should be strengthened, wherever possible, utilizing entry points and synergies to achieve the best results for all.

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<sup>1</sup> The list of resolutions and global commitments relevant to neurological disorders is available at <https://www.who.int/news/item/12-01-2022-draft-intersectoral-global-action-plan-on-epilepsy-and-other-neurological-disorders-2022-2031> (accessed 6 April 2022).

<sup>2</sup> A summary of global targets and indicators is available at <https://www.who.int/news/item/12-01-2022-draft-intersectoral-global-action-plan-on-epilepsy-and-other-neurological-disorders-2022-2031> (accessed 28 February 2022).

## STRATEGIC OBJECTIVES

21. The intersectoral global action plan on epilepsy and other neurological disorders 2022–2031 has the following strategic objectives:

- raise policy prioritization and strengthen governance;
- provide effective, timely and responsive diagnosis, treatment and care;
- implement strategies for promotion and prevention;
- foster research and innovation and strengthen information systems; and
- strengthen the public health approach to epilepsy.

## GUIDING PRINCIPLES

22. The intersectoral global action plan on epilepsy and other neurological disorders 2022–2031 relies on the following six guiding principles.

(a) People-centred PHC and UHC

All people with neurological disorders and their families should participate in and have equitable access, without discrimination or risk of financial hardship, to a broad range of promotive, preventive, diagnostic, treatment, rehabilitation, palliative and social care, as well as to essential, effective, safe, affordable and quality medicines and other health products.

(b) Integrated approach to care across the life course

Integrated care for neurological disorders is essential for achieving better promotion, prevention and management outcomes. This is particularly important given the multimorbidity of neurological disorders with one another and with other health conditions, which are often linked by common preventable risk factors. Care for neurological disorders requires close alignment to other existing services and programmes, in line with the Framework on Integrated, People-centred Health Services,<sup>1</sup> as well as consideration of the health and social care needs at all stages of the life course.

(c) Evidence-informed policy and practice

Scientific evidence and/or best practices enable the development of public health policies and interventions for the prevention and management of neurological disorders that are cost-effective, sustainable and affordable. This includes existing knowledge, real-world, practice-based evidence, the preferences of people with neurological disorders and culture-based experience, as well as the translation of new evidence into policy and practice that work towards finding disease-modifying treatments or cures, effective prevention and innovative models of care.

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<sup>1</sup> See document A69/39; see also Framework on integrated people-centred health services (IPCHS) (<https://www.who.int/teams/integrated-health-services/clinical-services-and-systems/service-organizations-and-integration>, accessed 25 April 2022).

(d) Intersectoral action

A comprehensive and coordinated response to neurological disorders requires partnerships and collaboration among all stakeholders. Achieving such collaboration requires leadership at governmental levels; clear delineation of roles and responsibilities among stakeholders; innovative coordination mechanisms, including public–private partnerships; engagement of all relevant sectors, such as health, social services, education, environment, finance, employment, justice and housing; and partnerships with civil society, academia, private sector actors and associations representing those with neurological disorders.

(e) Empowerment and involvement of persons with neurological disorders and their carers

The social, economic and educational needs and freedoms of persons and families affected by neurological disorders should be promoted, prioritized and protected. People with neurological disorders, their carers, local communities and organizations that represent them should be empowered through engagement and consultative mechanisms in care planning and service delivery as well as in policy and legislation development, programme implementation, advocacy, research, monitoring and evaluation.

(f) Gender, equity and human rights

Mainstreaming a gender perspective on a system-wide basis in all efforts to implement public health responses to neurological disorders is central to creating inclusive, equitable and healthy societies. Universal access to interventions for people with neurological disorders and their carers, as well as a focus on reaching the most vulnerable population groups, including migrants, children, women, older people, those living in poverty and those in emergency settings, are crucial to realizing the rights of people with neurological disorders and reducing stigma and discrimination. The implementation of the intersectoral global action plan on epilepsy and other neurological disorders 2022–2031 must explicitly address disparities specific to each national context and reduce inequalities.

## **STRATEGIC OBJECTIVE 1: RAISE POLICY PRIORITIZATION AND STRENGTHEN GOVERNANCE**

23. A broad public health approach grounded in principles of UHC and human rights is needed to improve the care and quality of life of people with neurological disorders. To achieve this, strengthening governance for neurological disorders involves ensuring that strategic policy frameworks are established and supported by effective oversight, regulatory and accountability mechanisms.

24. Lack of knowledge and awareness needs to be addressed at all levels of society, including among government representatives, people with neurological disorders and other stakeholders, in order to change the major structural and attitudinal barriers to achieving positive brain health outcomes, reduce stigma and discrimination, promote the human rights of people with neurological disorders and improve their care and quality of life.

25. Effective advocacy can influence political commitment and mobilize resources to support policy prioritization of neurological disorders, including interlinkages with achieving broader international commitments such as those outlined in the 2030 Agenda and the SDGs and the Convention on the Rights of Persons with Disabilities.

26. The integration and mainstreaming of neurological disorders in relevant evidence-informed national policies, legislation and guidelines within and beyond the health sector, including in education, social protection and employment, is important to meet the multifaceted needs of people with neurological disorders.

27. Health financing is a core function of health systems that can enable progress towards achieving UHC. It involves designing and implementing policies to ensure effective health system governance and service arrangements, including through raising revenue, pooling funds and purchasing services (such as the allocation of resources to health service providers) in order to support access to timely, affordable, resilient and quality services, support and treatment for neurological disorders.

### **Global targets for strategic objective 1**

#### **Global target 1.1**

75% of countries will have adapted or updated existing national policies, strategies, plans or frameworks to include neurological disorders by 2031.

#### **Global target 1.2**

100% of countries will have at least one functioning awareness campaign or advocacy programme for neurological disorders by 2031.

## **1.1 Advocacy**

28. Advocacy represents the first step in raising awareness and better public understanding of brain health and neurological disorders. It is necessary to improve neurological care, reduce stigma and discrimination, prevent violations and promote human rights. Advocacy also includes public and political awareness of the burden and impact of neurological disorders and the dissemination of evidence-based interventions, including the promotion of brain health and the prevention and treatment of neurological disorders.

29. Effective advocacy, including public awareness campaigns, requires tailoring approaches to reflect each country's cultural and social context. In addition, it requires involving people with neurological disorders in the centre of all advocacy efforts to achieve desired health and social outcomes. Public awareness campaigns should include information on the promotion and prevention of neurological disorders and should be designed for people living with neurological disorders.

### **30. Proposed actions for Member States**

(a) Engage all relevant stakeholders, such as advocacy experts, health professionals and people with neurological disorders and their carers, to develop awareness-raising programmes to improve the understanding of neurological disorders, promote brain health and prevent and manage neurological conditions across the life course, including the identification of barriers to health seeking behaviours.

(b) Establish national and regional collaboration, knowledge translation and exchange mechanisms to raise awareness of the burden of disease associated with neurological disorders

and the availability of and access to appropriate evidence-based promotive, preventive, management and care services for people with neurological disorders.

(c) Lead and coordinate intersectoral advocacy strategies for reducing stigma and discrimination and promoting the human rights of people with neurological disorders across the life course, including vulnerable groups. Integrate these within broader health promotion strategies, such as flexible educational and work environments for people with neurological disorders.

### 31. **Actions for the Secretariat**

(a) Engage and include people with neurological disorders, their carers and families in decision-making within WHO's own processes on issues that concern them, through meaningful and structured mechanisms.

(b) Provide technical support and advocacy tools for stigma reduction to help policymakers at national, regional and global levels to recognize the need to prioritise neurological disorders and integrate them into policies and plans.

(c) Provide support and guidance to Member States in meaningfully engaging people with neurological disorders across all age groups by providing a convening platform, generating and leveraging evidence-based information and best practices, and engaging lived experience in decision-making processes.

### 32. **Proposed actions for international and national partners**

(a) In partnership with other stakeholders, advocate for increasing the visibility of neurological disorders in the SDGs and other global commitments, as well as for prioritizing neurological disorders in policy agendas by raising awareness of the social and economic impacts of neurological disorders and the need for an integrated response across the life course and within health care systems.

(b) Support advocacy efforts for protecting the human rights of people with neurological disorders, redressing inequities in access to neurological services for vulnerable populations and reducing stigma and discrimination. Ensure that people with neurological disorders are equally included in activities of the wider community in order to foster cultural, social and civic participation and enhance autonomy.

(c) Provide a platform for dialogue between associations and organizations of people with neurological disorders and their carers, health and social workers, government sectors and other relevant actors at international, regional and national levels, while including young people and older people and ensuring gender-balanced representation. Engage with different sectors, such as the transportation, education, judicial, financial and employment sectors, in advocacy efforts for increasing the independence and autonomy of people with neurological disorders.

## 1.2 **Policy, plans and legislation**

33. The development of comprehensive intersectoral policies, plans and legislation based on scientific evidence and aligned with international human rights standards strengthens governance for neurological

disorders and ensures that the complex needs of people with neurological disorders are addressed within the context of each country.

34. Collaboration between people with neurological disorders, technical experts who generate evidence, policymakers and programme managers who formulate, adapt and implement policies, plans, guidelines and legislation, as well as health professionals who provide care and services to people with neurological disorders, is essential to facilitate the development and implementation of evidence-based policies and plans across sectors.

35. Given the interlinkages between neurological disorders and other public health areas, numerous opportunities exist to integrate neurological disorders into policies and plans for these disciplines, for instance in the areas of noncommunicable and communicable diseases, mental health, maternal, children and adolescent health, ageing and disability.

36. Legislation that impacts the lives of people with neurological disorders, for example people with epilepsy, is frequently outdated and fails to protect and promote their human rights. It is crucial to update all laws relevant to persons with neurological disorders, such as those related to education, employment and women's rights, and ensure that they are more inclusive.

**37. Proposed actions for Member States**

(a) Develop or review, update, strengthen and implement national and/or subnational policies, plans and legislation based on context-specific evidence relating to neurological disorders, whether as separate instruments or by integrating them into other planned intersectoral actions for NCDs, mental health, disability and other relevant areas across the care continuum of all ages. Formulate and implement national policies and legislation in consultation with people with neurological disorders, their carers and other stakeholders in order to promote and protect their rights and prevent stigma and discrimination.

(b) Establish monitoring and accountability mechanisms for resource allocation, including focal points, units or functional divisions responsible for neurological disorders within the health ministry (or equivalent body).

(c) Review disability and other relevant policies and laws to be more inclusive of people with neurological disorders, including by reviewing criteria to access disability benefits; providing funding to support people with disabilities in employment; establishing quota systems for active hiring; making working environments more accessible with employment regulations and labour laws that govern the public and private sectors; and strengthening mechanisms to address claims and complaints related to human rights violations and discrimination against people with neurological disorders through impartial recourse processes.

**38. Actions for the Secretariat:** Offer technical support, tools and guidance to Member States and policymakers to:

(a) share knowledge and evidence-based best practices to inform the development, strengthening, implementation and evaluation of national and/or subnational policies, plans and legislation that are aligned with international human rights standards for an integrated, intersectoral response to neurological disorders;

- (b) strengthen accountability mechanisms and strategies for resolving claims and complaints to address human rights violations and discrimination that are related to people with neurological disorders, for example in employment, access to education, driving, fertility and women's rights;
- (c) adopt legislation to ensure universal access to financial, social and disability benefits for people with neurological disorders and their carers;
- (d) 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; and
- (e) provide ongoing monitoring, guidance and technical support to Member States in implementing the intersectoral global action plan on epilepsy and other neurological disorders 2022–2031, with the help of WHO regional and country offices across all levels.

### 39. **Proposed actions for international and national partners**

- (a) Actively engage stakeholders across sectors to inform the development and implementation of evidence-based policies, plans and legislation, paying explicit attention to the human rights of people with neurological disorders and their carers and preventing stigma and discrimination.
- (b) Support the creation and strengthening of associations and organizations of people with neurological disorders, their families and carers, and foster their collaboration with other organizations as partners in the implementation of policies for neurological disorders.
- (c) Facilitate knowledge exchange and dialogue among associations of people with neurological disorders, their carers and families and their organizations, as well as health and social workers and governments, to ensure that Convention on the Rights of Persons with Disabilities principles such as empowerment, engagement and inclusion are embedded in legislation in order to promote the health of people with disabilities that are associated with neurological disorders.

## 1.3 **Financing**

40. Neurological disorders lead to increased costs for governments, communities, families and individuals, as well as productivity losses for economies, many of which could be remedied by prevention, early detection and timely treatment. People with neurological disorders and their families face significant financial hardship due to health and social care costs, as well as reduced or foregone income. This is compounded by a lack of universal health insurance across all countries, with limited investment and resources to address neurological conditions.

41. Appropriately funded policies and programmes are required in order to ensure access to prevention, diagnosis, treatment and care for people with neurological disorders and their carers and reduce the financial impact of out-of-pocket health and social care costs. This investment will be offset by a reduction in the cost of neurological disability and will ultimately reduce long-term costs for governments.

**42. Proposed actions for Member States**

- (a) Support sustainable funding for policies, plans and programmes for the prevention and management of neurological disorders, based on an integrated response across the life course, through dedicated domestic budgetary allocations, efficient and rational utilization of resources, voluntary innovative financing mechanisms and other means, including multilateral, bilateral, pooled funding and public–private partnerships.
- (b) Produce and/or utilize the most recent data on the epidemiological and economic burden of neurological disorders, as well as the economic evidence base for investment and the projected costs of intervention scale-up in order to make informed decisions on budgets that are proportionate to the scale of the burden in the country and to allocate scarce resources optimally.
- (c) Develop financial and social protection mechanisms, including national health insurance plans and social security benefits, for addressing the direct and indirect costs related to accessing health care (such as transportation costs) and support affordable and accessible care for persons with neurological conditions, their carers and families.

**43. Actions for the Secretariat**

- (a) Promote collaboration and knowledge exchange at international, regional, and national levels to strengthen knowledge on the socioeconomic impact of investment for neurological disorders.
- (b) Offer technical support, tools and guidance to Member States in strengthening their national capacity to engage in intersectoral resource planning, budgeting and expenditure monitoring on neurological disorders.
- (c) Provide guidance for structured approaches to generating national investment for neurological disorders and brain health promotion, care and protection, in line with other existing investment case methods for supporting governments' choices.

**44. Proposed actions for international and national partners**

- (a) Support Member States in mobilizing sustainable financial resources and identifying functional gaps in resource allocation in order to support the implementation, monitoring and evaluation of national and/or subnational policies, programmes and services for neurological disorders.
- (b) Support the participation of people with neurological disorders and their carers in decision-making processes related to international financing mechanisms.
- (c) Support the development of innovative funding models, such as an international assistance fund to subsidize and fund the costs of diagnostics and therapeutics and offset the costs associated with referral, for example for travel and specialist services and interventions.
- (d) Support the accountability and efficiency of resource use in health care systems in order to allocate scarce resources optimally and improve quality and efficiency with minimum wastage of resources.

## **STRATEGIC OBJECTIVE 2: PROVIDE EFFECTIVE, TIMELY AND RESPONSIVE DIAGNOSIS, TREATMENT AND CARE**

45. Neurological disorders are important causes of mortality, morbidity and disability. They require concerted intersectoral efforts to address the needs of people at risk of, or living with, neurological disorders by providing them with equitable access to effective health care and community-based, social, educational and vocational interventions and services.

46. Integrating care for neurological disorders into primary, secondary and tertiary health care levels and providing essential medicines, diagnostics, training and support for health care workers, carers and families of people with neurological disorders are actions consistent with the principles of UHC, the 2030 Agenda and the SDGs.

47. A strong health system that embraces a people-centred and coordinated care approach and is directed towards ensuring effective, timely and responsive diagnosis, treatment and care over sustained periods is needed to improve the well-being and quality of life of people with neurological disorders, as well as to avoid complications, reduce hospitalization and costly interventions and prevent premature death and disability.

### **Global targets for strategic objective 2**

#### **Global target 2.1**

75% of countries will have included neurological disorders in the UHC benefits package by 2031.

#### **Global target 2.2**

80% of countries will provide the essential medicines and basic technologies required to manage neurological disorders in primary care by 2031.

### **2.1 Care pathways**

48. Developing interdisciplinary care for people with neurological disorders requires guidelines that are grounded in evidence-based protocols and practices, organization by stages of care and a life course approach.

49. Services and care pathways, including access to quality emergency care, should be responsive to the needs of people with neurological disorders, their carers and families, who live in both urban and rural areas, and should be inclusive of vulnerable population groups, including socioeconomically disadvantaged individuals, children, older people, people affected by domestic and gender-based violence, prisoners, refugees, displaced populations and migrants, indigenous populations and other groups specific to each national context.

50. A care pathway should be oriented to each stage of the life course, from pregnancy through early childhood to care for older adults. This includes continuing care for children and adolescents with neurological disorders as they adapt to the challenges of transitioning into adulthood.

51. Neurological conditions impact people's functioning and often reduce their mobility, communication, cognitive functioning and self-care, which requires rehabilitation. However, the

rehabilitation needs for people with neurological disorders are largely unmet, with only 16% of countries reporting specialized neurorehabilitation services and only 17% reporting general rehabilitation units that offer neurorehabilitation.<sup>1</sup>

52. Due to the complex needs and high levels of dependency and morbidity of people with neurological disorders, a range of coordinated health and social care is essential, including interventions such as palliative care to provide relief from pain; psychosocial, spiritual and advance care planning support; and interventions to enhance their quality of life.

53. When possible, care pathways should include neurosurgical facilities for the surgical procedures required for the care of neurological conditions such as tumours, epilepsy and acute ischaemic stroke.

54. Continuity of care can be optimized using digital health solutions that foster greater information-sharing between providers, people with neurological disorder and their carers and allow for remote consultation through tele-health.

**55. Proposed actions for Member States**

(a) Develop evidence-based pathways of coordinated health and social services for people with neurological disorders across the life course within UHC in order to enable their access to quality care, when and where required. This includes integration at multiple levels of the health and social care system, use of interdisciplinary care teams, service directories and medical health records, and referral mechanisms. In particular:

- enhance equitable access to quality care for acute (emergency) and chronic neurological conditions;
- strengthen care at primary, secondary and tertiary levels, including medical and surgical facilities;
- develop community-based neurological services, with the involvement of other care providers such as traditional healers, and promote self-care; and
- promote continuity of care between providers and health system levels, including through referral and follow-up, ensuring that primary care services are supported by specialist services in hospitals and community health services with efficient referral and back-referral mechanisms.

(b) Develop strategies to rationalize resources and enhance effective collaboration across public, private and nongovernmental actors through:

- the implementation of context-specific, innovative and integrated models of care, from diagnosis to end-of-life across health and social sectors;
- the promotion, implementation and scaling up of digital health solutions and technologies across health and social care; and

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<sup>1</sup> ATLAS Country Resources for Neurological Disorders , second edition. Geneva: World Health Organization; 2017.

- the creation of interdisciplinary health and social care teams and networks and the capacity-building of health and social care professionals.
- (c) Review existing related services, such as those on mental health, maternal, newborn, child and adolescent health, immunization and other relevant communicable and NCD programmes in order to identify opportunities for the integration of prevention, early diagnosis and the management of neurological disorders and non-neurological comorbidities.
- (d) Promote equitable access to rehabilitation for disabilities associated with neurological conditions by strengthening health systems at all levels, from specialized inpatient settings through to community-delivered rehabilitation.
- (e) Develop new and/or strengthen existing services, guidance and protocols to support the implementation of early palliative care coordination and referral mechanisms, while also ensuring equitable access to palliative care for people with neurological disorders.
- (f) Proactively identify and provide appropriate care and support to population groups at particular risk for neurological disorders or who have poor access to services, such as socioeconomically disadvantaged individuals, older people and other groups specific to each national context, and promote the continuity of integrated care between paediatric and adult providers for adolescents with neurological disorders as they transition into adulthood.
- (g) In partnership with humanitarian actors, integrate support needs into emergency preparedness plans in order to enable access to safe and supportive services for people with pre-existing or emergency-induced neurological disorders such as traumatic injuries.
- (h) Empower people with neurological disorders and their carers to participate in service planning and delivery, and enable them to make informed choices and decisions about care that meets their needs by providing evidence-based, accessible information, including on pathways from detection and diagnosis to treatment (including self-care) and care access.

#### 56. **Actions for the Secretariat**

- (a) Provide guidance and technical support to Member States to identify priority areas for possible intervention and to integrate cost-effective interventions for neurological disorders, their risk factors and comorbidities into health systems and UHC benefit packages.
- (b) Provide technical support to Member States in documenting and sharing best practices of evidence-based standards of care across the life course, including service delivery and interdisciplinary care coordination, emphasizing prevention, diagnosis, treatment (including management of comorbid conditions), rehabilitation and palliative care for people with neurological disorders.
- (c) Offer technical assistance and policy guidance to support emergency preparedness and enable access to safe, supportive services for those with neurological conditions.

#### 57. **Proposed actions for international and national partners**

- (a) Actively engage all relevant stakeholders across sectors, including people with neurological disorders, their carers and families, in order to inform the development and

implementation of intersectoral and interdisciplinary care coordination and integrated neurological care pathways across the continuum, including prevention, diagnosis, treatment, rehabilitation and palliative care.

(b) Facilitate knowledge exchange and dialogue to review and update health service strengthening efforts following humanitarian emergencies, in collaboration with relevant multilateral and regional agencies, organizations representing people with neurological disorders and other civil society organizations.

(c) Generate evidence and develop tools to support programmes for providing access to integrated care for people with neurological disorders.

(d) Facilitate initiatives, in partnership with relevant stakeholders, to support and encourage people with neurological disorders, their families and carers to access neurological care and services through evidence-based, user-friendly, technology-supported information and training tools such as iSupport<sup>1</sup> and/or by establishing national helplines and websites with accessible information.

## 2.2 Medicines, diagnostics and other health products

58. Medicines, diagnostics and other health products, such as assistive technology, biological products, and cell and gene therapy, are essential for prevention, early diagnosis and treatment to reduce mortality and morbidity and improve the quality of life of people with neurological disorders.

59. Essential medicines have a crucial role for both the prevention and treatment of neurological disorders. For example, medicines for multiple sclerosis exist that slow disease progression and improve the quality of life for many people, but their availability and affordability are limited in low- and middle-income countries.

60. The use of medical devices, including imaging and in vitro diagnostics (e.g., neuroimaging, lumbar puncture and microscopy) can reduce morbidity through early detection and by slowing disease progression. Even when effective diagnostic tools are available, they may not be affordable or accessible due to the limited availability of laboratory infrastructure, equipment and trained personnel.

61. Assistive technology enables people to live healthy, productive, independent and dignified lives and reduce the need for formal health and support services, long-term care and the work of carers. Few people in need have access to assistive products due to high costs, lack of awareness, availability, trained personnel, policy and financing. To increase access to assistive products for those who need them the most, they should be available at all levels of health services, especially primary care, and within UHC.

62. The rapid production of new medications and molecules in certain neurological disorders is a model for other neurological or health conditions. Current obstacles to accessing treatment and affordability should be identified in order to pave the way and remove barriers to make future and upcoming medications for neurological conditions available and affordable.

### 63. Proposed actions for Member States

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<sup>1</sup> iSupport for Dementia. Training and support manual for carers of people with dementia. Geneva: World Health Organization; 2019.

- (a) Promote the inclusion, updating and availability of essential, effective, safe, affordable and quality medicines and health products for neurological disorders in national essential medicines lists, as guided by the WHO Model List of Essential Medicines, the WHO List of Priority Medical Devices for Management of Cardiovascular Diseases and Diabetes, the WHO List of Priority Medical Devices for Cancer Management and the WHO Priority Assistive Products List, while including access to controlled medicines and minimizing the risk of misuse. Identify key barriers to access across population groups (including in emergency settings) and strategies to systematically address these.
- (b) Promote the appropriate, transparent and sustainable use of essential medicines for the prevention and management of neurological disorders through measures such as quality assurance, preferential registration procedures, generic and biosimilar substitution, the use of international non-proprietary names and financial incentives, where appropriate. Optimize the training of health professionals, people with neurological disorders and their carers, including by using evidence-based strategies to address the treatment of comorbidities, adverse events and drug interactions such as those due to polypharmacy.
- (c) Enable the availability, access and use of appropriate relevant diagnostics as guided by the WHO Model List of Essential In Vitro Diagnostics, such as microscopy, electrophysiology, genetic testing and neuroimaging technology, for example computed tomography (CT) and magnetic resonance imaging (MRI). Improve infrastructure and train technicians and health care workers in the use of these technologies.
- (d) Establish transparent regulatory frameworks, resources and capacity to ensure that quality, safety and ethical standards are met for health products and diagnostics such as biotherapeutic treatments, genetic testing, pre-implantation genetic testing and assistive products like hearing aids, wheelchairs and prostheses.
- (e) Improve the availability of life-saving medicines and health products for managing neurological disorders during humanitarian emergencies.

#### 64. **Actions for the Secretariat**

- (a) Accelerate action and offer technical support to Member States to increase equitable access to medicines, diagnostics and other health products for people with neurological disorders, including through the setting of norms and standards at a global level; evidence-based, context-specific regulatory guidance; good practices for standards-based procurement and manufacturing; and technical, legislative and regulatory training.
- (b) Update the WHO Model List of Essential Medicines, the WHO Model List of Essential In Vitro Diagnostics, the WHO Lists of Priority Medical Devices, the WHO Priority Assistive Products List and other relevant documents to ensure that they are appropriate for neurological conditions and that pathways are in place for the timely implementation and use of effective treatments and diagnostics.

#### 65. **Proposed actions for international and national partners**

- (a) Encourage all relevant stakeholders to engage in activities to promote efforts for improving access to affordable, safe, effective and quality medicines, diagnostics and other health products, such as neuroimaging.

- (b) Support the global, regional, intergovernmental, national and/or subnational strengthening of regulatory and procurement processes (including through pooled procurement, innovative health financing mechanisms and human resource capacity-building) in order to promote access to and appropriate use of medicines, diagnostics and other health products.
- (c) Encourage the involvement of people with neurological disorders and their carers in research, development and implementation processes for new medicines, diagnostics and other health products.

### **2.3 Health workers' capacity-building, training and support**

66. Achieving improved health outcomes depends greatly on the combination of an adequate neurological workforce (e.g., adult neurologists, child neurologists, neurosurgeons); other health care providers, including but not limited to psychologists, psychiatrists, radiologists, physical therapists, occupational therapists and speech therapists; and competent health workers serving at the PHC level who are trained in identifying and managing neurological disorders.

67. The training and education of an interdisciplinary workforce, including social care workers, rehabilitation specialists trained in neurological conditions, technicians (electrophysiological, imaging, laboratory), pharmacists, biomedical engineers, community health workers, family, carers and traditional healers, where appropriate, is required to support the delivery of person-centred care to people with neurological disorders, reduce their mortality and morbidity and improve their quality of life.

#### **68. Proposed actions for Member States**

- (a) Identify and apply context-appropriate evidence in order to establish:
  - appropriately resourced programmes and policies to address projected health workforce needs for the future in light of demographic changes, increasing ageing populations and the prevalence of diseases such as dementia, stroke and Parkinson's disease; and
  - adequate compensation and incentives for health and social care workers trained in neurological disorders to work in underserved areas and to promote the retention of workers in those areas.
- (b) Strengthen health and social care workforce capacity to rapidly identify and address neurological disorders, including common comorbid and treatable conditions such as infectious diseases, hypoxic ischaemic perinatal brain injury, hypothyroidism, cataracts and NCDs. These initiatives should focus on the enhanced capacity of the existing workforce, both specialist and generalist, including relevant associate health professionals, as appropriate to their roles, and should include:
  - implementing various modes of training programmes (e.g., mental health gap action programme (mhGAP) e-learning course) for general and specialized health and social care workers to deliver evidence-based, culturally appropriate and human rights-oriented neurological care, including by addressing stigma and discrimination for all people across the life course;

- developing career tracks for the neurological workforce by strengthening postgraduate training and working in partnership with medical societies to raise awareness of the appeal of working in brain health;
- expanding existing educational curricula and providing continuing education on the care of people with neurological disorders;
- expanding the role of the neurological workforce to encompass the supervision and support of general health workers in providing neurological interventions;
- harnessing the potential of community health workers and strengthening – collaboration with other informal care providers, such as traditional healers, with effective training, support and supervision; and
- ensuring that people with neurological disorders are involved in the planning, development and delivery of training, as appropriate.

(c) Support health and social care workers to implement and scale-up services using information and communication technologies such as telemedicine and internet/mobile phone technologies in order to expand neurological care to remote and low-resource settings and support home-based services.

**69. Actions for the Secretariat**

(a) Support Member States with adequate tools to incorporate neurological care needs into routine planning for health workers, based on the monitoring and collection of the best available data and following a health labour market approach. Planning considerations should include the identification of service gaps, neurological care training requirements and core competencies for health and social workers in the field, as well as advanced neurological care training.

(b) Support Member States in building health and social care workforce capacity, including informal care providers, by promoting, strengthening and developing guidance and tools and the application of the competency-based training models required for the diagnosis, treatment and care of neurological disorders.

**70. Proposed actions for international and national partners**

(a) Facilitate the exchange of information on best practices and the dissemination of findings in health workers' development and training in order to support national efforts related to the prevention, management and care of people with neurological disorders.

(b) Support the implementation of capacity-building programmes, including training and education, for general and specialized health care workers to identify neurological disorders and provide evidence-based interventions to promote diagnosis, treatment and care for neurological disorders.

(c) Support national authorities in the development of appropriate health care infrastructure and institutional capacity for the training of health personnel in order to strengthen health systems and expand quality services.

## 2.4 Carer support

71. Neurological disorders have a profound impact on individuals, families and communities. Due to their chronic course, people with neurological disorders often require ongoing care that is provided in large part by informal carer providers.

72. Carers can be defined by their relationship to the person with a neurological condition and their care input. Many carers are relatives, but close friends or volunteers can also take on caregiving responsibilities. Carers provide “hands-on” care and support for people with neurological disorders and play a significant role in organizing lifelong care.

73. Challenges for carers include stress, role strain, financial burden, social isolation and bereavement in the event of loss. Roles and challenges may vary depending on the age of the carer and are also different when caring for children, adolescents or older adults.

74. Caring for a person with a neurological disorder may affect the carer’s own health, well-being and social relationships. The global action plan on the public health response to dementia identifies key actions to support carers that are also relevant to other neurological conditions.

### 75. Proposed actions for Member States

(a) Develop mechanisms to involve people with neurological disorders and their carers into care planning, policy-making and legal review and remove barriers to enable their participation, while paying attention to the wishes and preferences of people with neurological disorders and their families.

(b) Provide accessible and evidence-based information on available resources in the community, such as training programmes, respite care, mental health services and other resources that are tailored to the needs of carers of people with neurological disorders.

(c) Within the context of community-based neurological care, provide training programmes, in collaboration with relevant stakeholders, for health and social care staff in the identification and reduction of carer stress.

(d) Develop or strengthen mechanisms to protect carers, such as through the implementation of social and financial benefits (e.g., pension, leave or flexible work hours) and policies and legislation aimed at reducing stigma and discrimination and supporting carers beyond their caregiving role.

### 76. Actions for the Secretariat

(a) Support Member States in developing and evaluating evidence-based information, data, training programmes and respite services for carers of people with neurological disorders through an intersectoral approach that is in line with the Convention on the Rights of Persons with Disabilities.

(b) Facilitate access to affordable, evidence-based resources for carers of people with neurological disorders in order to improve knowledge and skills related to neurological disorders, reduce emotional stress and improve coping, self-efficacy and health, using resources such as

WHO's mhGAP, iSupport, mDementia,<sup>1</sup> the Caregivers Skills Training Programme for Children with Developmental Disorders or Delays and other education, skills training and social support resources.

#### 77. **Proposed actions for international and national partners**

(a) Increase awareness of the impact of caring for people with neurological disorders, including the need to protect carers from discrimination, support their ability to continue to provide care throughout the disease progression and promote their self-advocacy.

(b) Assist in implementing culturally sensitive, context-specific and person-centred training programmes for carers and families in order to promote well-being and enhance knowledge and caregiving skills throughout the progression of neurological disorders, starting with existing resources such as WHO's iSupport and mhGAP.

### **STRATEGIC OBJECTIVE 3: IMPLEMENT STRATEGIES FOR PROMOTION AND PREVENTION**

78. The promotion of brain health and the prevention of neurological disorders involves reducing modifiable risk factors and enhancing protective factors, including during critical periods of brain development.

79. Promoting optimal brain development across the life course starts with preconception, pregnancy, childhood and adolescence, is linked to healthy ageing and encourages healthy behaviour, adequate nutrition, infectious disease control, prevention of head and spinal trauma and reducing exposure to violence and environmental pollutants.

80. UHC represents a key component for promoting brain health and well-being. An important element includes addressing social and economic determinants through a coordinated intersectoral response in a gender-sensitive manner. Collaboration with local populations, including indigenous people, should be undertaken to explore culturally appropriate ways of preventing neurological disorders that respect local customs and values.

81. Incorporating a One Health<sup>2</sup> approach for neurological disorders to design and implement programmes, policies, legislation and research, with communication between multiple sectors, public health, animal and plant health and the environment will contribute towards achieving better health outcomes by preventing neurological disorders.

#### **Global targets for strategic objective 3**

##### **Global target 3.1**

80% of countries will have at least one functioning intersectoral programme for brain health promotion and the prevention of neurological disorders across the life course by 2031.

<sup>1</sup> Be Healthy Be Mobile. A handbook on how to implement mDementia. Geneva: World Health Organization; 2021.

<sup>2</sup> One Health. Q&A. Geneva: World Health Organization; 2017 (<https://www.who.int/news-room/q-a-detail/one-health>, accessed 1 December 2021).

**Global target 3.2**

The global targets relevant for prevention of neurological disorders are achieved, as defined in:

- the NCD-GAP;
- Defeating meningitis by 2030: a global road map; and
- Every newborn: an action plan to end preventable deaths.

**3.1 Promoting healthy behaviour across the life course**

82. Promoting and emphasizing brain health across the life course includes focusing on healthy behaviour. There are strong interrelationships between several neurological disorders, such as dementia and stroke, with NCDs such as hypertension, diabetes, obesity and other related disorders, as well as with behavioural risk factors such as physical inactivity, unbalanced diets, tobacco use and the harmful use of alcohol.

83. An understanding of the risk factors contributing to the neurological burden of disease can inform preventive measures and lead to the development of better disease-modifying strategies.

84. Smoking is a behavioural risk factor associated with neurological disorders such as stroke, dementia and multiple sclerosis. Second-hand tobacco smoke was estimated to account for 4% of the global stroke burden in 2010.<sup>1</sup>

85. The harmful use of alcohol, such as heavy alcohol consumption, can directly affect the nervous system and result in neurological disorders such as cerebellar degeneration, neuropathy, myopathy, delirium tremens and thiamine deficiency leading to Wernicke encephalopathy or Korsakoff syndrome. It also contributes to road traffic crashes, violence, falls and associated brain and spinal cord injuries.

86. Good sleep hygiene is necessary for children's and adults' overall health and well-being. Irregular sleep can be a risk factor for certain neurological disorders and people with neurological disorders often experience sleep disturbances as a consequence of their underlying disorder.<sup>2</sup>

87. Behavioural risk-factor modification can strengthen the capacity to make healthier choices and follow healthy behaviour patterns that foster good brain health and reduce the burden of neurological disorders. For example, exercise and regular physical activity are associated with social, mental and brain health benefits and a better quality of life, improved functioning and lower caregiver burden in people with chronic neurological disorders such as Parkinson's disease.

**88. Proposed actions for Member States**

- (a) Support actions that have been shown to reduce the risk of neurological disorders across the life course by advancing strategies for healthy behaviours, such as promoting the cessation of

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<sup>1</sup> Prüss-Üstün A, Wolf J, Corvalán CF., Bos R, Neira MP. Preventing disease through healthy environments: a global assessment of the burden of disease from environmental risks. 2016; World Health Organization.

<sup>2</sup> Worldwide Project on Sleep and Health. Project Overview. Geneva: World Health Organization; 2018.

tobacco use and excessive alcohol intake, vaccination and increasing physical activity, in line with the NCD-GAP, the global strategy to reduce the harmful use of alcohol, the WHO Guidelines on physical activity and sedentary behaviour and the WHO Guidelines on risk reduction of cognitive decline and dementia. These actions should be undertaken in collaboration with people with neurological disorders, their carers and other relevant stakeholders.

(b) Develop, implement and monitor appropriately resourced, population-wide strategies that promote healthy nutrition and diet, as outlined in the WHO's comprehensive implementation plan on maternal, infant and young child nutrition, the NCD-GAP and the 2030 Agenda.

(c) Encourage urban planning that improves access to sport, education, transport and physical activity in leisure/recreation in order to promote activity and provide alternatives to a sedentary lifestyle.

#### 89. **Actions for the Secretariat**

(a) Provide technical support and strengthen global, regional and national capacities and capabilities to:

- raise awareness of the links between neurological disorders and other NCDs; and
- implement strategies for the reduction and control of modifiable risk factors for neurological disorders by developing evidence-based guidelines for cost-effective, coordinated health care interventions and integrating relevant WHO guidelines into national health planning processes and development agendas.

(b) Strengthen, share and disseminate evidence to support policy interventions for reducing potentially modifiable risk factors for neurological conditions by promoting healthy workplaces, health-promoting schools and other educational institutions, healthy cities initiatives, health-sensitive urban development and social and environmental protection.

#### 90. **Proposed actions for international and national partners**

(a) Promote and mainstream population brain health strategies that are age-inclusive, gender-sensitive and equity-based at national, regional and international levels in order to support healthy behaviour for people with neurological disorders, their carers and families.

(b) Facilitate knowledge exchange on evidence-based best practices to support actions that have been shown to reduce the risk of neurological disorders across the life course, in line with WHO's Framework Convention on Tobacco Control, the global strategy to reduce harmful use of alcohol, the global strategy on diet, physical activity and health and other relevant strategies.

### 3.2 **Infectious disease control**

91. The neurological consequences of infectious diseases such as meningitis, encephalitis, neurocysticercosis, malaria, HIV, toxoplasmosis, polio, enterovirus, syphilis and rabies contribute to global morbidity and mortality, especially among the most vulnerable, marginalized populations and can result in lifelong consequences (e.g., vision and hearing loss, developmental delay, cognitive or motor impairment) that necessitate specialized follow-up care, including rehabilitation. Yet, many of

these neurological consequences are preventable through immunization programmes and infectious disease control.

92. The emergence of neurotropic zoonotic infections can be attributed to several causes, including unsustainable agricultural intensification and the increased use and exploitation of wildlife.<sup>1</sup>

93. Despite advances in global infectious disease control, epidemic infections such as Zika and SARS-CoV-2 have underscored the importance of infectious disease control as a preventive measure for neurological disorders. For example, the COVID-19 pandemic is expected to impact brain health across the life course, with a wide spectrum of associated neurological manifestations in the acute and post-acute stages of illness.

#### 94. **Proposed actions for Member States**

(a) Implement infectious disease management, eradication/elimination/control and immunization programmes based on WHO guidance, such as WHO's road map for neglected tropical diseases 2021–2030, the WHO guidelines on management of *Taenia solium* neurocysticercosis and the global road map on defeating meningitis by 2030. Include approaches for the control of other common and treatable neuroinfectious diseases such as encephalitides and their respective treatments within the health and agricultural sectors, as outlined in WHO's guidance on preventing disease through healthy environments.<sup>2</sup>

(b) Support and promote the availability of rapid and affordable diagnostics for infections of the nervous system (for example lumbar puncture, microscopy, neuroimaging).

(c) Collaborate with all relevant sectors and stakeholders to mitigate the risks of emerging infectious diseases that cause neurological disorders. Close coordination and intersectoral action within and beyond the health sector, including vector control, water and sanitation, animal and environmental health and education, will be needed to maximize synergies.

(d) Create national operational plans to deliver interventions for neurological diseases that are in line with a One Health approach, by developing a coordinated plan that outlines stakeholder accountability for human-, animal-, food- and ecosystem-related actions and by treating animals to prevent the transmission of neuro-infectious pathogens such as mass dog vaccinations for rabies prevention.

(e) Promote vaccination campaigns and sharing knowledge about the usefulness of vaccinations as a method of reducing neurological disabilities.

#### 95. **Actions for the Secretariat**

(a) Offer technical support, tools and guidance to Member States in order to strengthen global, regional and national awareness of infectious disease control and reduce the risk of zoonotic

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<sup>1</sup> United Nations Environment Programme and International Livestock Research Institute. Preventing the Next Pandemic: Zoonotic diseases and how to break the chain of transmission. Nairobi, Kenya; 2017.

<sup>2</sup> Prüss-Üstün A, Wolf J, Corvalán CF, Bos R, Neira MP. Preventing disease through healthy environments: a global assessment of the burden of disease from environmental risks. 2016; World Health Organization.

infections and antimicrobial and insecticide resistance, including by establishing animal or livestock trading and farming policies.

(b) Highlight the neurological consequences of the COVID-19 pandemic and provide guidance on their management in order to strengthen countries' response and improve service delivery at all levels of the health system.

#### 96. **Proposed actions for international and national partners**

(a) Promote multistakeholder collaboration within and beyond the health sector, taking a One Health approach and in line with the 2030 Agenda and the SDGs.

### 3.3 Preventing head/spinal trauma and associated disabilities

97. Traumatic brain and spinal cord injury require complicated and costly medical care. In 2016, there were 27 million new cases of traumatic brain injury and close to 1 million new cases of spinal cord injury globally.<sup>1</sup> Road traffic injuries and falls constitute the highest number of new cases of traumatic brain injury, while other causes such as child abuse and intimate partner violence and sports injuries are also preventable.

98. Each year, 37 million falls are severe enough to require medical attention and mostly affect adults aged 60 years and older, particularly those with comorbidities that impair ambulation such as dementia, Parkinson's disease or multiple sclerosis.<sup>2</sup>

99. Key risk factors for road traffic injuries include speeding; alcohol or drug consumption; non-use of helmets; lack of seat belts and child restraints; inadequate visibility of pedestrians; driver distractions or fatigue; and inadequate enforcement of traffic laws.

100. Many sport-related injuries can also result in traumatic brain and spinal cord injury. Repetitive mild head trauma is associated with chronic traumatic encephalopathy and increases dementia risk. Awareness, laws and policies to educate sports professionals, parents and athletes and the implementation of helmet or protective devices policies are needed to prevent some cases of traumatic brain and spinal cord injury.

101. Despite the high number of head and spinal cord injuries in low- and middle-income countries, there remains a lack of services, capacity and trained specialists in neurosurgery and neurorehabilitation, which are vital in preventing long-term disability and providing follow-up care for survivors of traumatic brain and spinal cord injury.

#### 102. **Proposed actions for Member States**

(a) Implement the recommendations included in the World report on road traffic injury prevention and proposed by the Commission for Global Road Safety.<sup>3</sup> These cover road safety

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<sup>1</sup> Global, regional, and national burden of traumatic brain injury and spinal cord injury, 1990-2016: a systematic analysis for the Global Burden of Disease Study 2016. *Lancet Neurol.*2019;18(1):56-87. doi: 10.1016/S1474-4422(18)30415-0.

<sup>2</sup> Prüss-Üstün A, Wolf J, Corvalán CF, Bos R, Neira MP. Preventing disease through healthy environments: a global assessment of the burden of disease from environmental risks. 2016; World Health Organization.

<sup>3</sup> Make Roads Safe: A New Priority for Sustainable Development. Commission for Global Road Safety; 2006.

management, safer roads and mobility, safer vehicles, safer road users, increased responsiveness to post-crash emergencies and longer-term rehabilitation for victims.

(b) Strengthen information systems to collect data on traumatic brain injury and spinal cord injury in order to improve understanding on the scale of the issue and its implications.

(c) Promote safer contact sports and develop and implement policies and mandatory education for athletes, parents and coaches to inform them about the risks and neurological complications, such as epilepsy, that are associated with traumatic brain and spinal cord injury.

(d) Develop and implement policies, standards and effective interventions to address unsafe home and community environments for older adults, including poor lighting, slippery floors, loose rugs and beds without rails, as outlined in the Global strategy and action plan on ageing and health.

### 103. **Actions for the Secretariat**

(a) Collect and disseminate evidence and best practices to prevent or reduce traumatic brain injury and spinal cord injury, including the prevention of road traffic crashes and falls through the implementation of the Global Plan for the Decade of Action for Road Safety.

(b) Provide guidance, evidence-based practices and technical support for early rehabilitation and support to people affected by the long-term cognitive or physical consequences of traumatic brain and spinal cord injury in order to minimize both physical and psychological impacts and protect against discrimination and stigma.

### 104. **Proposed actions for international and national partners**

(a) Promote multistakeholder collaboration to raise awareness about the inherent safety and protective quality of road networks for the benefit of all road users, especially the most vulnerable (e.g., pedestrians, bicyclists and motorcyclists) in order to prevent traumatic brain and spinal cord injury.

(b) Encourage knowledge-sharing and facilitate the global, regional, intergovernmental and national strengthening of policies for safe driving, sports injuries and the promotion of national efforts for increasing helmet use in accordance with WHO's Helmets: a road safety manual for decision-makers and practitioners.

## 3.4 **Reducing environmental risks**

105. Exposure to environmental and occupational hazards can directly influence brain health. For example, in 2019 approximately 5% of the global stroke burden (in DALYs) was attributable to ambient air pollution.<sup>1</sup> Across the world, vulnerable communities are subject to greater exposure to environmental toxins due to the conditions in which they work and live.

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<sup>1</sup> See GBD Compare.Viz Hub. Institute for Health Metrics and Evaluation; 2021 (<https://vizhub.healthdata.org/gbd-compare/>, accessed 1 December 2021).

106. Toxin-induced encephalopathies, including exposure to heavy metals such as lead,<sup>1</sup> mercury and air pollutants (e.g., carbon monoxide) can cause serious health and nervous system damage in all age groups.<sup>2</sup>

107. Parkinson's disease has been associated with exposure to pesticides in occupational and non-occupational settings.<sup>3</sup> In addition, migraines can be triggered by environmental pollutants such as bright lights, poor air quality and noise.<sup>4</sup>

108. Climate change is one of several concurrent global environmental changes that simultaneously affect human health and neurological conditions, often in an interactive manner. For example, the transmission of vector-borne neurotropic viruses such as Zika, Japanese encephalitis and West Nile disease is jointly affected by climatic conditions, population movement, deforestation, land-use patterns, biodiversity losses, freshwater surface configurations and human population density.<sup>5</sup>

**109. Proposed actions for Member States**

(a) Promote joint collaborations across relevant ministries (e.g., environment, health, water and sanitation) to link brain health promotion and the prevention of neurological disorders with strategies that focus on healthy living, working and environmental conditions, in line with WHO's guidance on preventing disease through healthy environments.<sup>4</sup> In particular:

- accelerate progress towards the global phase-out of lead paint through regulatory and legal measures;
- develop and implement health promotion and protection strategies and programmes across sectors in order to limit exposure to pesticides and other high-priority chemicals, such as trichloroethylene, which have been associated with neurotoxic effects; and
- address the health aspects of exposure to mercury and mercury compounds through collaboration between health authorities, environment authorities and others.

(b) In partnership with nongovernmental organizations, the private sector and other intersectoral stakeholders, integrate environmental determinants that are specific to brain health and neurological disorders into broader mitigation strategies for reducing the impact of climate change, including interventions and policies that promote access to clean air (ambient and

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<sup>1</sup> Global elimination of lead paint: why and how countries should take action: technical brief. Geneva: World Health Organization; 2020.

<sup>2</sup> Chemical safety. Geneva: World Health Organization ([https://www.who.int/health-topics/chemical-safety#tab=tab\\_1](https://www.who.int/health-topics/chemical-safety#tab=tab_1), accessed 1 December 2021).

<sup>3</sup> Ascherio A, Schwarzschild MA. The epidemiology of Parkinson's disease: risk factors and prevention. *Lancet Neurol.* 2016;15(12):1257–1272. doi: 10.1016/S1474-4422(16)30230-7; Ascherio A, Chen H, Weisskopf MG, O'Reilly E, McCullough ML, Calle EE, et al. Pesticide exposure and risk for Parkinson's disease. *Ann Neurol.* 2006;60(2):197–203. doi: 10.1002/ana.20904.

<sup>4</sup> Prüss-Üstün A, Wolf J, Corvalán CF, Bos R, Neira MP. Preventing disease through healthy environments: a global assessment of the burden of disease from environmental risks. 2016; World Health Organization.

<sup>5</sup> Climate change and health. Key facts. Geneva: World Health Organization (<https://www.who.int/news-room/fact-sheets/detail/climate-change-and-health>, accessed 1 December 2021).

household), such as the reduction of fossil fuels and the promotion of cleaner cookstoves and safe water, sanitation, and hygiene.

#### 110. **Actions for the Secretariat**

(a) Provide support to Member States in evaluating and implementing evidence-based options that suit their needs and capacities in order to assess the health impact of public policies, evidence generation and guidance regarding environmental risk such as air pollution, heavy metals, pesticide and industrial solvents for optimal brain health and the prevention of neurological disorders.

#### 111. **Proposed actions for international and national partners**

(a) Promote at national, regional and international levels WHO's guidance on preventing disease through healthy environments and highlight the importance of climate change on brain health, in line with the 2030 Agenda and the SDGs.

(b) Collaborate with stakeholders to support the development of international standards for environmental pollutants (e.g., emissions, second-hand smoke and levels of environmental toxins) to help guide legislation.

(c) Support research to understand the contribution of environmental risk factors to the morbidity and mortality of neurological disorders, especially in low-resource settings.

### **3.5 Promotion of optimal brain development in children and adolescents**

112. The early stages of life, including the fetal stage and birth, present a particularly important opportunity to promote brain health and prevent neurological disorders that can have lifelong consequences as a child's brain develops and adapts rapidly in response to the surrounding environment, nutrition and stimulation.

113. Optimizing brain development in the formative stages involves creating conditions for nurturing care<sup>1</sup> and family and parenting support through public policies, programmes and services. These enable communities and caregivers to attend to children's good health, nutrition and protection from threats.

114. Access to formal education and inclusive education for children with disabilities have also been shown to improve brain health outcomes. All children and adolescents should be able to live, study and socialize in supportive, healthy and safe environments without stigma, discrimination or bullying. Exposure to early life adversity such as maltreatment, neglect, experience of war or conflict, inadequate maternal nutrition (such as lack of folic acid or iron), poor caregiver health, substance use, congenital infections (such as TORCH syndrome – toxoplasmosis, rubella, cytomegalovirus, herpes simplex) or birth complications can have a negative impact on the developing brain and carry lifelong implications for brain health.

115. Certain environmental pollutants are specifically known to affect neurodevelopment. These include air pollution, heavy metals in soil and water, lead in household paint, mercury in seafood and

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<sup>1</sup> Nurturing care for early childhood development: a framework for helping children survive and thrive to transform health and human potential. Geneva: World Health Organization; 2018.

workplace exposure and pesticides.<sup>1</sup> Young children are especially vulnerable to lead toxicity and even low levels of exposure can result in reduced attention span, behavioural problems and reduced educational attainment.

116. Physical activity can confer health benefits for children and adolescents living with neurological conditions, hence limiting sedentary behaviour such as screen-based entertainment (television and computers) and digital communications such as mobile phones is recommended. In addition, adequate sleep regimens maximize health benefits and brain development for children and adolescents.

#### 117. Proposed actions for Member States

- (a) Develop, fund and implement strategies to promote healthy brain development and prevent neurological disorders in childhood and adolescence, focusing on early intervention and rehabilitation.
- (b) Optimize perinatal and child health care, including safe labour and delivery to prevent hypoxic ischaemic brain damage, neonatal intensive care, the use of birth attendants, skin to skin contact (kangaroo mother care), breastfeeding, maternal mental health care, adequate nutrition, immunization, and child development interventions for responsive caregiving and early learning in line with the WHO nurturing care framework. Encourage and strengthen neurodevelopmental assessment in children and adolescents for early diagnosis and intervention.
- (c) In partnership with relevant national regulatory authorities and other stakeholders, develop, strengthen and monitor breastfeeding and national food and nutrition policies and action plans in line with the global strategy for infant and young child feeding, the comprehensive implementation plan on maternal, infant and young child nutrition and WHO's set of recommendations on the marketing of foods and non-alcoholic beverages to children.<sup>2</sup>
- (d) Accelerate the full implementation of the WHO Framework Convention on Tobacco Control in order to reduce fetal exposure, childhood second-hand smoke exposure and adolescent smoking.
- (e) Develop and implement, as appropriate, comprehensive and intersectoral national policies and programmes to reduce the harmful use of alcohol during pregnancy so as to reduce complications such as fetal alcohol spectrum disorder.
- (f) Promote adolescent access to the recommended interventions in the Global Strategy for Women's, Children's and Adolescents' Health, including in humanitarian and fragile settings. Support interventions to promote adolescent brain health and development and establish, as appropriate, adolescent-friendly spaces as a first response to adolescent needs for protection, psychosocial well-being and nonformal education.
- (g) Develop appropriately resourced policies for the improved provision of quality physical education in educational settings, including opportunities for physical activity before, during and after the formal school day. Parks, trees and green areas within urban centres can improve local

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<sup>1</sup> Prüss-Üstün A, Wolf J, Corvalán CF, Bos R, Neira MP. Preventing disease through healthy environments: a global assessment of the burden of disease from environmental risks. 2016; World Health Organization.

<sup>2</sup> Guidance on ending the inappropriate promotion of foods for infants and young children: implementation manual. Geneva: World Health Organization; 2017.

air quality and offer a refuge for children to play. Implement WHO Guidelines on physical activity and sedentary behaviour, including the recommendations on recreational screen time.

(h) Strengthen surveillance mechanisms for the core indicators of brain health and development in children and adolescents, including protective and risk factors.

#### 118. **Actions for the Secretariat**

(a) Offer technical support, tools and guidance to Member States and strengthen national capacity for the promotion of optimal brain development in children and adolescents by:

- enhancing leadership within health ministries and other sectors for the development, strengthening and implementation of evidence-based national and/or subnational strategies and associated intersectoral resource planning to optimize brain development in children and adolescents; and
- compiling and sharing knowledge and best practices related to existing policies that address early childhood and adolescent development, including codes of practice and mechanisms to monitor the protection of human rights.

#### 119. **Proposed actions for international and national partners**

(a) Support the development and implementation of global, regional, national and/or subnational policies and programmes for children and adolescents to address maltreatment, neglect, inadequate maternal nutrition, poor caregiver health, substance use (such as alcohol and smoking), congenital infections, birth complications and environmental pollutants.

### **STRATEGIC OBJECTIVE 4: FOSTER RESEARCH AND INNOVATION AND STRENGTHEN INFORMATION SYSTEMS**

120. Evidence generation through high-quality research is needed to inform policy, planning and programming for neurological disorders. It can provide insight into effective services, care models and treatment options, and foster innovation and equitable access to products such as health technology for prevention, risk reduction, early diagnosis, treatment and the potential for cure or care for neurological disorders.

121. The complexity surrounding brain and neurological research requires improved coordination in the research environment, with multistakeholder involvement and public-private partnerships and allocation of sufficient resources. In this context, cultivating an environment that fosters research collaborations, including data-sharing, is vital to reduce duplication, identify knowledge gaps, fast-track innovation and build capacity in low-income settings.

122. Implementation research, including health systems evaluation, should be prioritized to harness and scale prevention and treatment strategies for neurological disorders. Such an approach will facilitate the monitoring of interventions and allow for the replication and adaptation of successful interventions.

123. Better representation of low- and middle-income countries in the neuroscience research environment should also acknowledge country-specific and local needs so that strategies for diagnosis and management of neurological disorders are tailored to the context.

124. The meaningful engagement of people with neurological disorders, their carers and families to better support and guide the research and development of innovative solutions for neurological disorders is a principal component of the research agenda.

125. Robust, standardized and easily accessible data forms the basis for effective planning and the establishment of targeted interventions. Yet significant data gaps on neurological disorders exist not only in low- and middle-income countries but also in high-income countries.

#### **Global targets for strategic objective 4**

##### **Global target 4.1**

80% of countries routinely collect and report on a core set of indicators for neurological disorders through their national health data and information systems at least every three years by 2031.

##### **Global target 4.2**

The output of global research on neurological disorders doubles by 2031.

#### **4.1 Investment in research**

126. If the incidence of neurological disorders is to be reduced and the lives of people with neurological disorders are to be improved, sustained investment in biomedical, clinical, implementation and translational research is crucial to inform prevention, diagnosis, treatment and care and create the potential to cure more neurological disorders.

127. All research and innovation activities for neurological disorders must be rooted in equity, diversity and inclusiveness, with increased engagement of people with neurological disorders.

128. Investments in neurological research should be accompanied by increased collaboration between Member States and relevant stakeholders, with a particular focus on strengthening global and regional cooperation. Facilitating a global research agenda for neurology will increase the likelihood of effective progress towards better prevention, diagnosis, treatment and care for people with neurological disorders, while reducing redundancies and the duplication of research and costs.

129. Concerted action to build research infrastructure, strengthen human resources in research and development and increase collaboration among the research community, health professionals, people with neurological disorders and the private sector is needed to catalyze neurological research and development, particularly in low- and middle-income countries.

#### **130. Proposed actions for Member States**

- (a) Increase investment and improve research governance as an integral component of the national response to address the burden of neurological disorders. Facilitate the development of new diagnostics, treatments, technology and innovations for people with, and at risk of developing, neurological disorders. Such innovations include, but are not limited to, the use of big data, AI, diagnostics, precision medicine, disease monitoring and assessment tools, assistive technologies, pharmaceuticals and new models of care.

- (b) Support national, regional and international research collaboration on neurological disorders in order to generate new knowledge on the promotion, prevention, diagnosis, treatment and care of neurological disorders and translate existing evidence about neurological disorders into action. Encourage the sharing of, and open access to, research data.
- (c) Build the knowledge and capacity of decision-makers on the need for innovation in the area of brain health and highlight the importance of prioritizing funding for neurological disorders research in national research organizations.
- (d) Strengthen national institutional capacity for research and innovation, such as for the development of new drugs for neurological disorders, including for children, by improving research infrastructure, equipment and supplies.
- (e) Involve and support people with neurological disorders, their carers and the organizations that represent them in actively participating in the research process from planning to implementation.

#### 131. **Actions for the Secretariat**

- (a) Support advocacy efforts for increased investment in research for neurological disorders through research prioritization and agenda-setting in the fields of biomedical, clinical, implementation and translational research at global, regional and national levels.
- (b) Engage WHO collaborating centres, academic institutions, research organizations and alliances to strengthen the capacity for research on neurological disorders.
- (c) Support international coordination mechanisms to facilitate harmonized global research efforts in neurology, and foster regular communication and information exchange between stakeholders to build a globally connected research community.
- (d) Offer guidance and technical support to Member States in developing new diagnostics, treatments and innovative technologies for neurological disorders and mechanisms in order to ensure equitable access and implementation, particularly in low-resource settings.

#### 132. **Proposed actions for international and national partners**

- (a) Promote and mobilize financial support for research in neurological disorders, participate in priority-setting exercises and contribute to the dissemination of research findings in user-friendly language to policymakers, the public, people with neurological disorders, their carers and families.
- (b) Engage the research community, health professionals, policymakers and the private sector in promoting the innovation and development of new tools and treatments for neurological disorders, while ensuring equitable and affordable access of these products in low- and middle-income countries.
- (c) Support national efforts to strengthen capacity for research, development and innovation and knowledge exchange, including institutional capacity-building, research collaborations and the creation of fellowships and scholarships for the prevention, diagnosis, treatment and care of neurological disorders.

- (d) Support implementation research in low- and middle-income countries in order to generate knowledge about barriers to integrating the treatment of neurological disorders into widespread clinical care and about effective strategies to overcome such barriers.

## 4.2 Data and information systems

133. The availability of health and social care data on neurological disorders can support the identification of gaps in service delivery, improve the accessibility to and coordination of care for people with neurological disorders and promote better understanding and detection of population-level changes and trends.

134. Information systems for neurological disorders are often rudimentary or absent, especially in low-income countries, which complicates data acquisition on the availability and utilization of neurological services and the needs of people with neurological disorders and their carers.

135. The systematic integration of data collection into population-level and routine health information systems and the regular monitoring of neurological disorders based on a core set of measures forms the basis of evidence-based actions to improve services and measure progress towards implementing national programmes for neurological disorders and brain health.

### 136. Proposed actions for Member States

- (a) Integrate the monitoring of neurological disorders into routine health information systems and across all levels of care in order to identify, collate and routinely report core data, disaggregated by sex, age and other equity measures, in order to improve neurological care service delivery and promotion and prevention strategies and provide an understanding of the social determinants of neurological disorders.
- (b) Encourage patient registries, surveillance programmes, analysis and publication of data on the availability and evaluation of utilization and the coverage of services and effective treatments for neurological disorders.
- (c) Support data collection and cross-referencing to other monitoring and accountability mechanisms in order to avoid duplication of efforts at country level.

### 137. Actions for the Secretariat

- (a) Offer technical support to Members States to:
- develop and/or improve national data collection systems in order to strengthen data collection for neurological disorders;
  - build national capacity and resources for the systematic collection and analysis of data related to neurological disorders and the facilitation of its use;
  - develop a core set of indicators and targets in line with this and other global action plans and WHO monitoring frameworks in order to monitor outcomes related to neurological disorders.

**138. Proposed actions for international and national partners**

- (a) Provide support to Member States in establishing surveillance, information systems and registries that capture core indicators and patient outcome measures on neurological disorders.
- (b) Advocate for and facilitate the involvement of people with neurological disorders, their families and carers in the collection, analysis and use of data on neurological disorders.
- (c) Support the creation of exchange and dialogue platforms between countries for best practices in collection, management and use of data.

**STRATEGIC OBJECTIVE 5: STRENGTHEN THE PUBLIC HEALTH APPROACH TO EPILEPSY**

139. Epilepsy affects people of all ages, genders, races and income levels. Poor populations and those living in low- and middle-income countries bear a disproportionate disease burden, which poses a threat to public health and economic and social development.

140. In many parts of the world, people with epilepsy and their families suffer from stigmatization and discrimination due to ignorance, misconceptions and negative attitudes surrounding the disease. They often face serious difficulties in education, employment, marriage and reproduction.

141. The risk of premature death in people with epilepsy is three times higher than the general population. Important causes of death and injury include sudden unexpected deaths in epilepsy, status epilepticus, burns, drowning and suicide. Excess mortality is higher in low- and middle-income countries and is associated with lack of access to health facilities, large treatment gaps and a failure to address the potentially preventable causes of epilepsy.

142. Epilepsy often coexists with and can be compounded by other comorbid health conditions, including other neurological disorders, necessitating a synergistic approach to addressing co-existing conditions.

**Global targets for strategic objective 5****Global target 5.1**

By 2031, countries will have increased service coverage for epilepsy by 50% from the current coverage in 2021.

**Global target 5.2**

80% of countries will have developed or updated their legislation with a view to promoting and protecting the human rights of people with epilepsy by 2031.

**5.1 Access to services for epilepsy**

143. Epilepsy is a highly treatable condition and more than 70% of people with epilepsy could live seizure-free lives if they had access to appropriate anti-seizure treatment, the most cost-effective of which are included in the WHO Model List of Essential Medicines. Despite this, the current treatment

gap for epilepsy is estimated at 75% in low-income countries and is substantially higher in rural than in urban areas.<sup>1</sup>

144. Wide treatment gaps may result from a combination of decreased capacity in health care systems, the inequitable distribution of resources and the low priority assigned to epilepsy care. Factors that widen this gap include staff shortage, limited access to anti-seizure medicines, lack of knowledge and confidence of PHC workers in the management of epilepsy, misconceptions and stigma.

145. PHC provides a platform to address the health needs of people with epilepsy through a person-centred approach. With political will and a combination of innovative strategies, epilepsy prevention, diagnosis and treatment can be integrated into primary health services in cost-effective ways, even in low-resource settings.

**146. Proposed actions for Member States**

(a) Develop and strengthen models of care for epilepsy that promote high-quality, people-centred primary care as the core of integrated health services throughout the life course. Strong and functional referral systems with specialist services, as well as care for refractory epilepsy, should be made available. Specialists support the integration of epilepsy care in PHC by, for example, confirming the diagnosis of epilepsy, providing care for refractory epilepsy and assessing the need for resective surgery.

(b) Enhance training and support in epilepsy diagnosis and management of the PHC workforce, including facility-, outreach- and community-based health workers, school staff and emergency care workers, as well as specialist training at secondary and tertiary levels.

(c) Develop strategies for the meaningful engagement of the community in order to increase the demand for epilepsy services.

(d) Implement strategies to make anti-seizure medicines more available, accessible and affordable, considering also the specific needs of children, adolescents and women of childbearing age.

Strategic options include:

- including essential anti-seizure medicines in national essential medicine lists and formularies;
- strengthening supply chains and systems of selection;
- increasing procurement and distribution; and
- improving access to controlled medicines such as phenobarbital.

(e) Improve care to prevent the common causes of epilepsy such as perinatal injury, including hypoxic ischaemic brain injury, central nervous system infections, stroke and traumatic brain injuries, by promoting safe pregnancies and births, preventing head trauma and controlling

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<sup>1</sup> Epilepsy: a public health imperative. Geneva: World Health Organization; 2019.

neuroinfectious diseases such as neurocysticercosis, meningitis, encephalitis and malaria, in line with other global initiatives.

(f) Provide people with epilepsy with information about their disorder to help them understand the importance and benefits of medication adherence, and raise awareness of seizure triggers and monitoring and fundamental strategies for self-management and self-care (e.g., through adequate sleep and regular meals).

(g) Strengthen the monitoring and evaluation of epilepsy services through well-functioning health information systems that generate reliable data and support the use of information for improved decision-making and learning by local, national and global actors. Data should be collected from multiple sources, including registries and disease-specific reporting systems, surveys and administrative and clinical data sets.

#### 147. **Actions for the Secretariat**

(a) Develop and disseminate technical guidance to address key gaps and strengthen actions for epilepsy at global and national levels by addressing key policy, implementation and research considerations.

(b) Provide guidance on strengthening the implementation of the epilepsy component of WHO's mental health gap action programme, including updated recommendations, to provide quality care and evidence-based interventions through PHC and using digital technology.

(c) Offer support to Member States for documenting and sharing best practices of evidence-based epilepsy service delivery and care coordination.

#### 148. **Proposed actions for international and national partners**

(a) Establish community teams to support people with epilepsy, their carers and family in the community and strengthen mechanisms to engage with complementary and alternate medicine providers such as traditional healers.

(b) Advocate for the availability of anti-seizure medicines at affordable prices at all levels of the health care system, especially PHC centres.

(c) Support people with epilepsy and their families and carers to access services, for example by developing evidence-based, user-friendly information and training tools for epilepsy and available services and/or by setting up websites with information and advice at local levels.

(d) Conduct implementation research, including the dissemination of lessons learned to accelerate the scale-up of successful strategies to strengthen epilepsy services.

## 5.2 **Engagement and support for people with epilepsy**

149. People with epilepsy and their families across all resource settings are subjected to stigmatization and discrimination as a result of the misconceptions and negative attitudes that surround epilepsy, including the belief that epilepsy is the result of possession by evil spirits or that it is contagious.

150. Stigmatization leads to human rights violations and social exclusion. In some settings, children with epilepsy may not be allowed to attend school, while adults with the condition may not be able to find suitable employment or to marry.

151. Innovative strategies are needed to strengthen international efforts and national leadership to support policies and laws for people living with epilepsy, improve public attitudes and reduce stigma, while fully respecting the human rights of people living with epilepsy.

152. People with epilepsy, their carers and organizations that represent them should be empowered and involved in advocacy, policy, planning, legislation, service provision, monitoring and research in epilepsy.

**153. Proposed actions for Member States**

(a) Encourage the inclusion of views and needs of people with epilepsy and their families in relevant health policies and all aspects of developing and strengthening services that support their autonomy. Strong attention to gender, diversity and equity is needed to empower the most vulnerable.

(b) Develop or strengthen legislation to promote and protect the rights of people with epilepsy and prohibit discrimination with respect to education, employment, marriage and family planning, obtaining a driving licence and recreation, among others. Improve accountability by setting up mechanisms, using existing independent bodies where possible, to monitor and evaluate the implementation of policies and legislation relevant to epilepsy in order to ensure compliance with the Convention on the Rights of Persons with Disabilities.

(c) Facilitate joint community initiatives, with strong community provider leadership and civil society engagement, as part of scaling up community-owned initiatives on epilepsy.

(d) Enhance access to a range of person-centred, culturally appropriate and responsive services, including liaison with local nongovernmental organizations and other stakeholders, in order to provide information that empowers people with epilepsy to make informed choices and decisions about their care.

**154. Actions for the Secretariat**

(a) Support the active participation of people with epilepsy and their families in the development of relevant technical products, norms and standards.

(b) Support Member States in developing key capacities to effectively engage in participatory processes that involve people with epilepsy and their families and to leverage these results for decision-making.

**155. Proposed actions for international and national partners**

(a) Ensure that people with epilepsy are included in the activities of the wider community and foster cultural, social and civic participation by enhancing their autonomy.

(b) Support advocacy efforts and public education activities related to epilepsy for community health workers, community leaders and people with epilepsy and their families in order to correct

misconceptions, counter negative attitudes towards people with epilepsy and provide knowledge of how to help a person having a seizure.

### 5.3 Epilepsy as an entry point for other neurological disorders

156. Epilepsy can result from genetic or other often unknown causes, but may also be a consequence of other neurological conditions. For example, epilepsy can be secondary to stroke, infections, brain tumours or traumatic brain injury. Epilepsy is also comorbid with other neurological conditions. For example, migraine occurs in about 19% of people with epilepsy and intellectual disability in approximately 26% of adults and 30–40% of children with epilepsy.<sup>1</sup>

157. A seizure can also be a manifestation of other conditions such as infections, metabolic imbalance, brain tumours and neurodegenerative diseases. It can also be a signal of deterioration or change in an underlying neurological condition.

158. Epilepsy and a wide range of other neurological disorders share similar diagnostic and therapeutic technologies, as well as similar research, pharmacological and psychosocial approaches.

159. A well-functioning epilepsy care service can present a good opportunity for strengthening the management of other neurological disorders. Epilepsy can therefore serve as an entry point for accelerating the strengthening of services and support for both epilepsy and other neurological disorders. Other neurological disorders, identified based on national priorities, should be considered concurrently alongside epilepsy treatment and care to achieve the best results for all. This approach may be applicable in some parts of the world, while in others stroke, dementia and neurodegenerative disorders, migraine and other headache disorders may serve as the entry point.

#### 160. Proposed actions for Member States

(a) Orient health systems to expand existing epilepsy prevention, diagnosis, treatment and care to the management of comorbidities as an essential component at all levels of care. For example, good interdisciplinary team care for epilepsy can be transferred to the care of other neurological disorders.

(b) Strengthen the capacity of health workers serving at the PHC level to develop competencies that extend beyond epilepsy care to cut across other neurological disorders, including the treatment of comorbidities, drawing on WHO's mental health gap action programme.<sup>2</sup>

(c) Leverage epilepsy diagnostics such as the electroencephalogram (EEG), neuroimaging technology (including CT and MRI) and specialized referral services (e.g., surgery) to include facilities for diagnosis and management of other neurological disorders.

(d) Expand procurement systems developed for anti-seizure medicines to improve access to effective and quality medicines for other neurological disorders.

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<sup>1</sup> Epilepsy: a public health imperative. Geneva: World Health Organization; 2019.

<sup>2</sup> Mental Health Gap Action Programme (mhGAP). Geneva: World Health Organization (<https://www.who.int/teams/mental-health-and-substance-use/treatment-care/mental-health-gap-action-programme>, accessed 1 December 2021).

**161. Actions for the Secretariat**

- (a) Support Member States to incorporate care for other neurological conditions in routine epilepsy services at primary care levels by providing strategies, processes and tools for countries to apply in order to strengthen the capacity of the health workforce.
- (b) Promote and facilitate the exchange of best practices at international, regional and national levels in order to inform the implementation of integrated care models for epilepsy and other neurological disorders.

**162. Proposed actions for international and national partners**

- (a) Activate national networks and lobby administrators, policymakers and other stakeholders to integrate care for comorbidities (i.e., physical and mental health conditions) as an integral part of epilepsy treatment and care services.

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