Intersectoral Global Action Plan on Epilepsy and Other Neurological Disorders

2022 - 2031

Discussion paper 05/03/2021

In November 2020, the Seventy-third World Health Assembly (WHA) adopted resolution WHA 73.10 requesting the Director-General, inter alia, to develop an Intersectoral global action plan on epilepsy and other neurological disorders in consultation with Member States to ensure a comprehensive, coordinated response across multiple sectors.

The World Health Organization (WHO) Secretariat will follow a clear process to develop a global action plan on epilepsy and other neurological disorders. The first step of the process is for the WHO Secretariat to publish a discussion paper on the Intersectoral global action plan on epilepsy and other neurological disorders.

The steps in the process to develop the action plan will be:

• Member States, United Nations (UN) Agencies and relevant non-State actors will be invited to share their comments in response to the discussion paper through virtual and web-based consultations from beginning of March until mid-April 2021.

• The WHO Secretariat will publish online the consolidated comments received on the discussion paper through the web-based and virtual consultations at the end of April 2021.

• The first draft of the Intersectoral global action plan for epilepsy and other neurological disorder will be available for online consultation by mid-June 2021.

• Member States, UN agencies and relevant non-State actors will be invited to submit their comments in response to the first draft through web-based and virtual consultations until the first week of August 2021.

• At the end of August 2021, a summary of all comments received from Member States, UN agencies and relevant non-State actors during the consultation process will be posted on the website.

• The outcomes of the consultation will serve as input for the WHO Secretariat to prepare a revised draft of the Intersectoral global action plan on epilepsy and other neurological disorders that will be submitted for review at the 150th session of the Executive Board.

• Considering any guidance provided by the 150th session of the WHO Executive Board, the Seventy-fifth World Health Assembly may be invited to consider the Intersectoral global action plan for epilepsy and other neurological disorders.

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BACKGROUND

- 1. The Intersectoral global action plan on epilepsy and other neurological disorders aims to set out clear objectives and actions to ensure a coordinated, intersectoral response by Member States, the Secretariat and international, regional, national and subnational partners. While context-dependent, these partners include but are not limited to: development, regional and subregional intergovernmental agencies; academic and research institutions; civil society; professional associations; people with neurological disorders and the organizations that represent them; the private sector; and, the media.
- 2. This action plan aims to improve care, recovery, well-being and participation of people living with neurological disorders across the life-course, while reducing associated mortality, morbidity and disability associated with neurological conditions. An emphasis is set on preventing neurological disorders and promoting brain health and development through multidisciplinary and multisectoral approaches. A comprehensive approach to addressing the burden of neurological conditions must include the following: promotion of healthy brain development in early life and optimization of brain health across the life course, prevention of avoidable neurological conditions, and a continuum of care for neurological conditions including diagnosis, treatment, rehabilitation and palliative care.
- 3. Worldwide, people living with neurological disorders and disabilities associated with neurological conditions continue to experience discrimination and human rights violations. For this reason, a human rights perspective grounded in the International Covenant on Civil and Political Rights¹, the International Covenant on Economic, Social and Cultural Rights², the UN Convention on the Rights of Persons with Disabilities (CRPD)³, the Convention on the Rights of the Child⁴ and other relevant international and regional human rights instruments underpins this action plan.
- 4. Addressing social and economic determinants of health including housing, education, income and social protection, access to safe environments, clean water and air, food security, is central to promoting brain health, reducing risk factors for neurological disorders and providing access to care and services.
- 5. In adults, disorders of the nervous system are the leading cause of disability adjusted life years (DALYs) and the second leading cause of death globally, accounting for 9 million deaths per year. The four largest contributors of neurological DALYs in 2016 were stroke (42·2%), migraine (16·3%), dementia (10·4%) and meningitis (7·9%). Epilepsy (5%) ranks fifth with idiopathic epilepsy being the second most common cause of neurological disorders in certain low-income countries⁵. Headache disorders, such as migraine, are the most prevalent neurological disorders⁶. Parkinson's disease, propelled by an increasingly large ageing population, is the fastest growing neurological disorder⁷.
- 6. In children and adolescents, headache disorders are among the top ten causes of global DALYs, and within the top three causes in girls 10-24 years old in 2019⁸. Meningitis is also among the top ten causes of global DALYs in children below 10⁹ in 2019. Globally, in 2016, 52·9 million children younger than 5 years had developmental disabilities and 95% of these children live in low- and middle-income countries (LMICs)¹⁰.
- 7. The high burden associated with neurological disorders is met by profound inequities. Nearly 80% of people with epilepsy live in LMICs, where treatment gaps exceed 75% in most LMICs and 50% in most middle-income countries¹¹. Disabilities associated with neurological conditions disproportionately affect women, older people, those living in poverty and rural or remote areas, and other vulnerable populations. Children from underprivileged households, indigenous populations and ethnic minorities are also at significantly higher risk of experiencing disability associated with neurological conditions. Internally displaced or stateless persons, refugees and migrants also experience particular challenges in accessing services for neurological disorders.

¹ International Covenant on Civil and Political Rights. <u>https://www.ohchr.org/en/professionalinterest/pages/ccpr.aspx</u>

² International Covenant on Economic, Social and Cultural Rights <u>https://www.ohchr.org/EN/ProfessionalInterest/Pages/CESCR.aspx</u>

³ United Nations (UN) Convention on the Rights of Persons with Disabilities. <u>https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html</u>

⁴ Convention on the Rights of the Child. <u>https://www.ohchr.org/en/professionalinterest/pages/crc.aspx</u>

⁵ https://www.thelancet.com/journals/laneur/article/PIIS1474-4422(18)30499-X/fulltext

⁶ https://www.thelancet.com/journals/laneur/article/PIIS1474-4422(18)30322-3/fulltext

⁷ https://www.thelancet.com/journals/laneur/article/PIIS1474-4422(18)30295-3/fulltext

⁸ https://www.thelancet.com/journals/lancet/article/PIIS0140-6736(20)30925-9/fulltext

⁹ https://www.thelancet.com/journals/lancet/article/PIIS0140-6736(20)30925-9/fulltext

¹⁰ https://www.thelancet.com/journals/langlo/article/PIIS2214-109X(18)30309-7/fulltext

¹¹ Epilepsy: A public health imperative. Geneva: World Health Organization; 2019. https://apps.who.int/iris/handle/10665/325293

- 8. Many neurological conditions are preventable, including 25% of epilepsy cases, and numerous determinants, including risk 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 in particular include all components of nurturing care such as access to education, social connection and support, healthy diets, sleep, and physical activity. Risk factors such as premature birth, low birth weight and birth trauma are known to negatively impact brain development in childhood. In addition, neuro-infections (such as rabies, tetanus, meningitis, HIVassociated neurological disorders and malaria), traumatic injuries (for example due to accidents, violence or exposure to environmental pollutants with neurotoxic effects) and behavioural risk factors (such as tobacco use and as hypertension, diabetes and obesity) negatively affect brain health across the life course and can be prevented.
- The ongoing COVID-19 pandemic highlights the relevance of neurology to global public health and its significance within broader global health security dialogues. Headache, impaired sense of smell and taste, agitation, delirium, stroke and meningo-encephalitis all represent neurological manifestations associated with COVID-19. Long term manifestations such as cognitive impairment might also be associated with the post-COVID condition. Underlying neurological conditions represent a risk factor for hospitalization due to COVID-19, especially for older adults¹². The Intersectoral global action plan on epilepsy and other neurological disorders represents an unprecedented opportunity to address the impact of neurological disorders through a comprehensive response throughout and following the pandemic.
- 10. Health systems have not yet adequately responded to the burden of neurological disorders across the life course. While approximately 70% of people with neurological disorders live in LMICs, this need is poorly recognized with only 28% of low-income countries having a dedicated policy for neurological disorders¹³. Worldwide, public health system expenditure on neurological disorders also remains low. WHO's Neurology Atlas 2017 highlights an imbalance in health system supply and demand with only 12% of countries surveyed reporting a separate budget line for neurological disorders¹⁴.
- 11. Currently, the number of health workers specialized in neurological health is insufficient. In fact, the median neurological workforce (defined as the total number of adult neurologists, neurosurgeons and child neurologists) in LMICs is 1.4 per 100,000 compared to 7.1 per 100,000 people in high-income countries.
- 12. Ensuring that appropriate health system building blocks are in place is particularly important to improving the quality of life of people living with neurological disorders. With only 24% of countries reporting stand-alone neurological health policies¹⁵, the implementation of appropriate policy and legislative frameworks is crucial and should aim to ensure quality care, the provision of financial and social protection benefits and the protection, promotion and safeguarding of rights of persons with neurological disorders. Comprehensive responses aimed at tackling neurological disorders should be firmly grounded in a social and economic determinants of health approach.

SCOPE

13. The term "neurological disorders" is used to denote a range of conditions affecting the central and peripheral nervous system that cause a high burden of disease such as cerebrovascular disease including stroke; headache disorders including migraine; neurodegenerative disorders including dementia and Parkinson's disease; neuroinfectious/neuroimmunological disorders including meningitis, HIV, cerebral malaria, and multiple sclerosis; epilepsy; neurodevelopmental disorders; cerebral palsy, and traumatic brain and spinal cord injuries.

¹²Favas TT, Dev P, Chaurasia RN, et al. Neurological manifestations of COVID-19: a systematic review and meta-analysis of proportions. Neurological Sciences. 2020.

Abdullahi A, Candan SA, Abba MA, et al. Neurological and musculoskeletal features of COVID-19: a systematic review and meta-analysis. Frontiers in Neurology. 2020.

https://www.who.int/mental_health/neurology/epidemiology/en/#:~:text=The%20Neurology%20Atlas%20is%20an,disposing%20of%20extremel y%20meagre%20resources.

https://www.who.int/mental health/neurology/epidemiology/en/#:~:text=The%20Neurology%20Atlas%20is%20an,disposing%20of%20extremel <u>v%20meagre%20resources.</u>
 ¹⁵ Atlas: country resources for neurological disorders – 2nd ed. Geneva: World Health Organization; 2017. Licence: CC BY-NC-SA 3.0 IGO.

- 14. In line with WHO's International Classification of Functioning, Disability and Health (ICF)¹⁶, functioning and disability need to be considered as the result of interactions between neurological conditions and contextual factors. For this reason, a holistic approach is adopted to account for medical, individual, social, and environmental influences.
- 15. Rather than adopting a disease-specific structure, the Intersectoral global action plan on epilepsy and other neurological disorders uses an integrated, person-centered framework for the prevention, diagnosis, treatment, rehabilitation and palliative care of people with neurological disorders, as many of these conditions share risk factors and/or require a similar systems-based approach.
- 16. 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 behavioral responses while adapting to changing environments.
- 17. Enhancing epilepsy prevention, treatment and care represents an important entry point for, and foundation to other neurological disorders.
- 18. 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 thus interwoven in other WHO strategies, action plans or World Health Assembly (WHA) resolutions. In addition, neurological disorders have strategic links with universal health coverage including the full range of essential health services, from health promotion to prevention, treatment, rehabilitation and palliative care. The action plan also takes a life-course approach as there are strong linkages with maternal, newborn, child and adolescent health, reproductive health and ageing with brain health and neurological disorders.
- 19. Linking the Intersectoral global action plan on epilepsy and other neurological with those frameworks reflects WHO's responsiveness to focusing on impact on people's health and working in a cohesive and integrated manner (see Table 1).

Table 1: Resolutions and global commitments relevant to neurological disorders.		
Health systems	• UN Political declaration on universal health coverage (2019) ¹⁷	
2	Declaration of Astana on primary health care (2018) ¹⁸	
	• WHA 67.22 Resolution on access to essential medicine (2014) ¹⁹	
	• Global strategy on human resources for health: workforce (2030) ²⁰	
	• WHA 71.8 Resolution on Improving Access Assistive Technology (2018) ²¹	
	• WHA 60.29 Resolution on Health technologies (2007) ²²	
Mental health	• Comprehensive mental health action plan 2013–2030 ²³	
	• Global action plan on the public health response to dementia $2017-2025^{24}$	
	• Global strategy to reduce the harmful use of alcohol $(2010)^{25}$	
	• EB146(14) Accelerating action to reduce the harmful use of alcohol (2020) ²⁶	
	• WHA 68.20 Resolution to address the global burden of epilepsy (2015) ²⁷	
	• WHA 67.8 Resolution on the management of autism spectrum disorders (2014) ²⁸	
	• EB148(3) Promoting mental health preparedness and response for public health (2021) ²⁹	
Noncommunicable	• Global action plan for the prevention and control of noncommunicable diseases 2013-2030 ³⁰	
diseases		

¹⁶ International Classification of Functioning, Disability and Health. <u>https://www.who.int/standards/classifications/international-classification-of-functioning-disability-and-health</u>

¹⁹ https://apps.who.int/gb/ebwha/pdf_files/WHA67-REC1/A67_2014_REC1-en.pdf

¹⁷ https://www.un.org/pga/73/wp-content/uploads/sites/53/2019/07/FINAL-draft-UHC-Political-Declaration.pdf

¹⁸ https://www.who.int/docs/default-source/primary-health/declaration/gcphc-declaration.pdf

²⁰ https://www.who.int/hrh/resources/pub_globstrathrh-

^{2030/}en/#:~:text=The%20Global%20Strategy%20on%20Human.employers%2C%20professional%20associations%2C%20education%20and ²¹ https://apps.who.int/gb/ebwha/pdf_files/WHA71/A71_R8-en.pdf_

²² https://www.who.int/healthsystems/WHA60_29.pdf

²³ https://www.who.int/publications/i/item/9789241506021

²⁴ https://www.who.int/mental health/neurology/dementia/action plan 2017 2025/en/

²⁵ https://www.who.int/substance_abuse/activities/gsrhua/en/

²⁶ https://www.who.int/news/item/28-03-2020-who-to-accelerate-action-to-reduce-the-harmful-use-of-alcohol

²⁷ https://www.who.int/mental_health/neurology/epilepsy/resolution_68_20/en/

²⁸ <u>https://www.who.int/mental_health/maternal-child/WHA67.8_resolution_autism.pdf</u>
²⁹ <u>https://apps.who.int/gb/ebwha/pdf_files/EB148/B148_CONF5-en.pdf</u>

^{111105://}apps.wilo.iii/gb/ebwila/pdi_iies/Eb146/b146_CON

³⁰ https://www.who.int/publications/i/item/9789241506236

	• Global disability action plan 2014–2021 ³¹
	• UN Political Declaration on noncommunicable diseases (2018) ³²
	• WHO's rehabilitation 2030 initiative ³³
Infectious diseases	• Global health sector strategy on HIV 2016–2021: towards ending AIDS ³⁴
	• Global technical strategy for malaria 2016-2030 ³⁵
	Global strategy and targets for tuberculosis prevention, care and control after 2015 ³⁶
	• Decision EB146(6) on meningitis prevention and control (2020) ³⁷
Neglected tropical	
diseases	• Decision EB146(14) on neglected tropical diseases (2020) ³⁸
discuses	• Ending the neglect to attain the Sustainable Development Goals: a road map for neglected tropical diseases
	2021–2030 ³⁹
Family and Child	• Global strategy for women's, children's and adolescent's health $2016-2030^{40}$
Health	• Nurturing Care Framework (2018) ⁴¹
	• Global accelerated action for the health of adolescents (AA-HA!): guidance to support country
	implementation (2017) ⁴²
	• INSPIRE: Seven strategies for Ending Violence Against Children (2016) ⁴³
	• Multisectoral action for a life course approach to ageing: Global strategy and action plan on ageing and
	health (2016-2020) ⁴⁴
Ageing and Health	• Global strategy (2016-2030) and action plan on ageing and health (2016-2020) ⁴⁵
0 0	• The Decade of Healthy Ageing (2021-2030) ⁴⁶
Environment and	Preventing disease through healthy environments: a global assessment of the burden of disease from
climate change	environmental risks (2016) ⁴⁷
ennate enange	• Climate change and human health: risks and responses (2003) ⁴⁸
Social	• EB148.R2 on social determinants of health (2021) ⁴⁹
determinants of	
health	

VISION

20. The vision of the action plan is a world in which:

- neurological disorders are prevented; i.
- ii. people affected by neurological disorders fulfil their potential with equal rights, opportunities, dignity, respect and autonomy; and
- iii. brain health is valued, promoted and protected.

³¹ <u>https://apps.who.int/iris/handle/10665/19</u>9544

³² <u>https://digitallibrary.un.org/record/1648984?ln=en</u>

³³ https://www.who.int/rehabilitation/rehab-2030-call-for-action/en/

³⁴ https://www.who.int/hiv/strategy2016-2021/ghss-hiv/en/

https://www.who.int/malaria/publications/atoz/9789241564991/en/ 36 https://www.who.int/tb/post2015_TBstrategy.pdf?ua=1

³⁷ https://apps.who.int/gb//ebwha/pdf_files/EB146/B146(6)-en.pdf

³⁸ https://apps.who.int/gb/ebwha/pdf_files/EB146/B146_14-en.pdf

³⁹ https://www.who.int/neglected_diseases/resources/who-ucn-ntd-2020.01/en/

⁴⁰ https://www.who.int/life-course/partners/global-strategy/en/

⁴¹ https://www.who.int/maternal_child_adolescent/child/nurturing-care-framework/en/

⁴² https://www.who.int/maternal_child_adolescent/topics/adolescence/framework-accelerated-action/en/

 ⁴³ https://www.who.int/publications/i/item/inspire-seven-strategies-for-ending-violence-against-children
 ⁴⁴ https://www.who.int/ageing/global-strategy/en/

⁴⁵ <u>https://www.who.int/ageing/global-strategy/en/</u>

⁴⁶ <u>https://www.who.int/initiatives/decade-of-healthy-</u> ageing#:~:text=The%20United%20Nations%20Decade%20of.of%20older%20people%2C%20their%20families%2C

⁴⁷ <u>https://www.who.int/ageing/global-strategy/en/</u>

⁴⁸ https://www.who.int/globalchange/publications/cchhsummary/en/

⁴⁹ https://apps.who.int/gb/ebwha/pdf_files/EB148/B148_R2-en.pdf

GOAL

21. To reduce the impact and burden of neurological disorders, including associated mortality, morbidity and disability, and improve the quality of life of persons of all ages with neurological disorders.

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

STRATEGIC OBJECTIVES

- 22. To raise the prioritization and strengthen governance for neurological disorders.
- 23. To provide effective, timely and responsive diagnosis, treatment and care for neurological disorders.
- 24. To implement strategies to promote brain health and development and prevent neurological disorders.
- 25. To foster research and innovation and strengthen information systems for neurological disorders.

GUIDING PRINCIPLES

- 26. The action plan relies on the following seven guiding principles that are universally applicable and relevant to each of the goals and strategic objectives described in this document.
 - i. People-centered primary healthcare and universal health coverage

All people with neurological disorders and their families should 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, safe, affordable, effective and quality medicines and other health products.

ii. Integrated approach to care

Care for neurological disorders requires an integrated approach with closely alignment with other existing services and programmes. These include (but not limited to) communicable and noncommunicable diseases, environmental health, immunization, maternal, newborn, child and adolescent health, mental health, disability, healthy ageing and social care. Spanning across different sectors, integrated care is essential for achieving promotion, prevention, treatment and care goals. This is particularly important given the multimorbidity of neurological disorders with one another, and with other health conditions, and often linked by common risk factors that can be prevented.

iii. Evidence-based practice

Scientific evidence and/or best practice enable the development of public health policies and interventions for prevention and management of neurological disorders that are people-centred, cost-effective, sustainable and affordable. This includes taking into account existing knowledge and culturally-based experience as well as the generation of new evidence towards finding disease-modifying treatments or cure, effective prevention and innovative models of care.

iv. Life-course approach

Policies, programmes and services for the prevention and management of neurological disorders need to take account of health and social needs at all stages of the life course. This includes promotion of maternal health (including preconception, antenatal and postnatal care, and maternal nutrition), healthy growth and development of children, adolescents and youth, promotion of a healthy working life, and healthy ageing.

v. Intersectoral action

A comprehensive and coordinated response to neurological disorders requires partnerships and collaboration among all stakeholders. Achieving such collaboration requires leadership at

governmental level and engagement of all relevant sectors, such as health, social services, education, environment, finance, employment, justice, and housing, as well as partnerships with civil society and private sector actors.

vi. Empowerment of persons with neurological disorders

People with neurological disorders, their carers, local communities and organizations that represent them should be empowered and involved in the prevention and management of neurological disorders, including in advocacy, policy, planning, legislation, service provision, research, and monitoring and evaluation.

vii. Gender, equity and human rights

Mainstreaming a gender perspective on a systems-wide basis in all efforts to implement public health responses to neurological disorders is central to creating inclusive, equitable, economically productive and healthy societies. Equitable and universal access to high-impact interventions and a focus on reaching the most vulnerable population groups, including migrants, children, women, older people and those living in poverty and emergency settings, are crucial to realizing the rights of people with neurological disorders. Implementation of the action plan must explicitly address disparities specific to each national context including related to age, gender, disability associated with neurological conditions, socioeconomic status, and geography and reduce inequalities, consistent with the 2030 Agenda for Sustainable Development and the Sustainable Development Goals (SDGS)⁵⁰, the UN CRPD⁵¹ and other international and regional human rights instruments.

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

- 27. A broad public health approach grounded in principles of universal health coverage and human rights-based health and social care is needed to improve the care and quality of life of people with neurological disorders. To achieve this, government leadership, involvement of relevant stakeholders including people with neurological disorders, and strengthening of evidence-based and appropriately resourced policies, plans and legislation are needed.
- 28. The integration and mainstreaming of neurological disorders within other relevant policies, legislation and health and social care programmes are important to meet the needs of people with neurological disorders.
- 29. Epilepsy co-exists with many neurological disorders; thus, the development of epilepsy services as an entry point for broader neurological care should be targeted.

1.1 ADVOCACY

- 30. Awareness raising is central to improving understanding of neurological disorders and their risk factors, improving access to promotion, prevention, management and care services, decreasing stigma and discrimination and protecting the human rights of people with neurological disorders.
- 31. Effective advocacy including public awareness campaigns require tailoring to reflect each country's cultural context and close involvement of people with neurological disorders in order to achieve health and social outcomes and improve the quality of life of people with neurological disorders, their carers and the broader community within which they live.

Actions for Member States

32. Engage all relevant stakeholders, including people with neurological disorders, to develop advocacy programmes to reduce stigma and discrimination, to promote brain health and prevent and manage neurological disorders across the life course.

⁵⁰ UN Sustainable Development agenda. <u>https://www.un.org/sustainabledevelopment/development-agenda/</u>

⁵¹ United Nations (UN) Convention on the Rights of Persons with Disabilities. <u>https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html</u>

- 33. Establish national and regional collaboration and knowledge exchange mechanisms to raise awareness of the burden of disease associated with neurological disorders and the availability of effective interventions as well as to facilitate access to appropriate, evidence-based promotive, preventive, management and care services for people with neurological disorders.
- 34. Develop processes to empower people with neurological disorders to seek early detection and more effectively manage their own condition, including through health education and tools for self-care and self-management.

Actions for the Secretariat

- 35. Engage and include people with neurological disorders, their carers and organizations that represent them in decision-making within WHO's own processes on issues that concern them.
- 36. Promote best practices for awareness-raising and reducing stigma and discrimination including enhancing interlinkages between neurological disorders, existing WHO strategies and their accountability frameworks and sustainable development commitments, including the UN 2030 Agenda for Sustainable Development and the SDGs⁵², the UN Development Assistance Framework⁵³ and others.

Actions for international partners

- 37. Encourage all stakeholders to:
 - i. raise awareness of the magnitude of the social and economic impact of neurological disorders;
 - ii. advocate for the prioritization of neurological disorders on policy agendas;
 - iii. protect and promote human rights of people with neurological disorders and support their carers and their families;
 - iv. redress inequities in access to neurological services for vulnerable populations.
- 38. Support advocacy efforts aimed at ensuring people with neurological disorders are included in activities of the wider community and foster cultural, social and civic participation by enhancing their autonomy.
- 39. Support associations and organizations of people with neurological disorders and their carers and their integration into existing networks, services and supports by providing a platform for dialogue between organizations, health and social workers, government sectors and other relevant actors.

1.2 POLICY, PLANS and LEGISLATION

- 40. The development of comprehensive, multisectoral policies, plans and legislation supports the prioritization of neurological disorders and ensures the complex needs of people with neurological disorders are addressed within the context of each country.
- 41. Legislation impacting the lives of people with neurological disorders (for example for people living with epilepsy) are frequently outdated and fail to protect and promote their human rights. This leads to barriers in accessing appropriate and affordable health and social care.
- 42. Collaboration between technical experts who generate evidence, policy makers and programme managers who formulate and implement policy/plan and legislation, and health care professionals who provide care and services to people with neurological disorders and their carers, is important to ensuring evidence-based programmes and care across sectors.

Actions for Member States

43. Develop, strengthen and implement national and/or subnational policies, plans and legislation relating to neurological disorders, whether as separate instruments or integrated into other planned multisectoral actions for noncommunicable diseases, mental health, disability and other relevant areas. These undertakings should be developed across all relevant sectors and in consultation with people with neurological disorders and other stakeholders.

⁵² Convention on the Rights of Persons with Disabilities (CRPD) (adopted by the United Nations General Assembly in resolution 61/106, December 2006

⁵³ UNITED NATIONS DEVELOPMENT ASSISTANCE FRAMEWORK GUIDANCE was produced by the UN Development Operations Coordination Office.

- 44. Strengthen accountability mechanisms to address claims and complaints related to human rights violations and discrimination against people with neurological disorders through impartial recourse processes.
- 45. Develop or strengthen carer protection by strengthening and/or implementing policies, plans and legislation, to reduce discrimination and ensure universal access to financial, social and disability benefits.

Actions for the Secretariat

46. Offer technical support, tools and guidance to Member States to:

- i. share knowledge and evidence-based best practices to inform the development, strengthening and implementation of national and/or subnational policies, plans and legislation for an integrated, multisectoral response to neurological disorders;
- ii. strengthen accountability mechanisms to address human rights violations and discrimination as related to people with neurological disorders;
- iii. adopt legislation to ensure universal access to financial, social and disability benefits for carers of people with neurological disorders.

Actions for international partners

- 47. Actively engage stakeholders across sectors to inform the development and implementation of evidence-based legislation, paying explicit attention to human rights of people with neurological disorders and their carers.
- 48. Facilitate knowledge exchange and dialogue among associations of people with neurological disorders, their carers and families, health and social workers and government to ensure UN CRPD principles such as empowerment, engagement and inclusion are embedded in legislation to promote the health of people with disabilities associated with neurological disorders⁵⁴.

1.3 FINANCING

- 49. Neurological disorders lead to increased costs for governments, communities, families and individuals, and loss in productivity for economies. People with neurological disorders and their families face significant financial hardship due to health and social care costs as well as reduced or forgone income.
- 50. Appropriately funded policies and programmes are required to ensure access to prevention, diagnosis, treatment and care for people with neurological disorders and their carers and to reduce the financial impact of out-of-pocket health and social care costs.

Actions for Member States

- 51. Ensure sustainable funding for policies, plans and programmes for prevention and management of neurological disorders through dedicated domestic budgetary allocations, efficient and rational utilization of resources, voluntary innovative financing mechanisms and other means including multilateral, bilateral and pooled funding. Funding allocations should be based on assessment and planning of resource needs.
- 52. Monitor resource allocation and establish accountability by setting up a focal point, unit or functional division responsible for neurological disorders or a coordination mechanism within the health ministry (or equivalent body).
- 53. Implement funding mechanisms including national health insurance plans and social security benefits to address direct and indirect costs related to accessing health care (such as transportation costs) and ensure affordable and accessible care for persons with neurological conditions.

Actions for the Secretariat

- 54. Promote collaboration and knowledge exchange at international, regional and national levels to strengthen countries' financial accountability mechanisms and support the rational use of existing domestic resources for neurological disorders.
- 55. Offer technical support, tools and guidance to Member States to strengthen national capacity to engage in multisectoral resource planning, budgeting and expenditure monitoring on neurological disorders.

⁵⁴ Convention on the Rights of Persons with Disabilities (CRPD) (adopted by the United Nations General Assembly in resolution 61/106, December 2006

56. Create guidance to inform the development of funding mechanisms that address the direct and indirect health care costs for persons with neurological disorders, in line with universal health coverage principles.

Actions for international partners

- 57. Support Member States in mobilizing sustainable financial resources to support the implementation, monitoring and evaluation of national and/or subnational policies, programmes and services for neurological disorders.
- 58. Facilitate knowledge exchange to identify functional gaps in resource allocation and strengthen health financing mechanisms for neurological disorders.

1.4 INTEGRATED RESPONSE WITHIN HEALTH AND SOCIAL CARE SYSTEMS

- 59. Neurological disorders are often associated with complex needs and high levels of dependency and morbidity, requiring a range of health and social care services.
- 60. Neurological disorders often co-exist with one another and with other health conditions. For example, roughly 50% of adults with epilepsy have one or more co-existing physical or mental health condition such as depression,

anxiety, migraine and heart disease.⁵⁵ People with neurological disorders are also less likely to be diagnosed for comorbid health conditions, which, when left untreated, can lead to poorer health outcomes and an increased risk of premature mortality. Health and social care system integration is essential for the management of neurological disorders and its co-morbidities.

61. The Framework on Integrated, People-centred Health Services (IPCHS)⁵⁶ emphasizes the importance of integrated services at the different levels and sites of care. Primary health care provides a platform where the health needs of people with neurological disorders, including promotion, prevention, management and care can be effectively addressed through a people-centred approach.

Actions for Member States

- 62. Orient health systems to expand the prevention, management and care of neurological disorders across the lifecourse with a focus on strengthening integrated health and social care in community-based, primary health care settings. This includes:
 - i. reviewing existing neurological and related services and programmes, such as those on mental health, dementia, maternal, newborn, child and adolescent health, immunization and other relevant communicable (e.g. meningitis, neurocysticercosis, HIV/AIDS) and noncommunicable disease programmes to identify opportunities for integration with prevention, early diagnosis and management of neurological disorders;
 - ii. expanding existing epilepsy prevention, diagnosis, treatment and care to provide access to services for other co-morbid neurological disorders.
- 63. Develop strategies to rationalize resources and enhance effective collaboration across public, private and nongovernmental actors, including through:
 - i. the implementation of context-specific, innovative, and integrated models of care, from diagnosis to end-of-life across health and social sectors;
 - ii. the promotion, implementation and scaling of digital health solutions and technologies across health and social care system actors and system levels;
 - iii. the creation of multidisciplinary health and social care teams and networks and capacity building of health and social care professionals and volunteers.

Actions for the Secretariat

⁵⁵ Epilepsy: a public health imperative. Geneva: World Health Organization; 2019.

⁵⁶ Framework on integrated, people-centred health services, WHA69/39 (2016) <u>https://apps.who.int/gb/ebwha/pdf_files/WHA69/A69_39-en.pdf?ua=1&ua=1</u>

- 64. Promote and facilitate the exchange of best practices at international, regional and national levels to inform the implementation of integrated, community-based care models and multidisciplinary care networks for neurological disorders.
- 65. Provide guidance and technical support to Member States in integrating cost-effective interventions for neurological disorders, their risk factors, and comorbidities into health systems, including essential primary health care packages.
- 66. Support the promotion, implementation and scaling of digital health solutions and technologies to improve coordination between sectors, actors and system levels and within multidisciplinary care teams.

Actions for international partners

- 67. Support the inclusion of neurological disorders into existing health services and programmes, including the expansion of existing epilepsy interventions.
- 68. Promote the creation, identification and scaling of community-based, multidisciplinary care networks and models for neurological disorders.
- 69. Foster the development of multistakeholder and multisectoral partnerships to implement and integrate digital health solutions and technologies across health and social care system levels.

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

- 70. Neurological disorders are important causes of morbidity and mortality requiring concerted intersectoral efforts to address the needs of people at risk of, or living with, neurological disorders through equitable access to effective health care interventions.
- 71. Integrating neurological care including rehabilitation and palliative care in primary health care, essential medicines, diagnostics and other health products, health workers' training, and support for carers and families of people with neurological disorders are actions consistent with the principles of universal health coverage⁵⁷ and the 2030 Agenda for Sustainable Development and its goals⁵⁸.
- 72. A strong health system directed towards ensuring effective, timely and responsive diagnosis, treatment and care for neurological disorders is needed to improve the well-being and quality of life of people with neurological disorders, as well as avoiding complications, reducing hospitalization and costly interventions, and preventing premature death and disability. This should include availability and provision of quality, affordable and appropriate assistive products.
- 73. Neurological disorders such as epilepsy and stroke often co-exist and can be compounded by other comorbid health conditions necessitating a synergistic approach to addressing co-existing conditions. For example, a well-functioning epilepsy care service could present a good opportunity to strengthen the management of other co-existing neurological disorders.

2.1 CARE PATHWAYS

- 74. Developing multi-disciplinary health and social care for people with neurological disorders requires evidencebased protocols and practices, organization by stages of care, incorporation of human rights principles and taking a life-course approach.
- 75. A number of essential elements are needed to enhance equitable access to quality and timely neurological care for both acute and chronic conditions. These include community-based neurological services, integration of neurological care and treatment into primary care, strengthening delivery of both emergency and chronic care,

⁵⁷ https://www.un.org/pga/73/wp-content/uploads/sites/53/2019/07/FINAL-draft-UHC-Political-Declaration.pdf

⁵⁸ UN Sustainable Development agenda. <u>https://www.un.org/sustainabledevelopment/development-agenda/</u>

continuity of care between providers and health system levels including referral and follow-up, effective collaboration between formal and informal care providers(such as traditional healers), and promotion of self-care.

- 76. Services and care pathways need to be responsive to the needs of people with neurological disorders, their carers and families, and inclusive of vulnerable population groups, including socioeconomically disadvantaged individuals, women and children, older people, people affected by domestic and gender-based violence, prisoners, refugees, displaced populations and migrants, indigenous populations, and others specific to each national context.
- 77. Neurological conditions impact peoples' functioning and commonly reduce their mobility, communication and self-care. People with neurological disorders require rehabilitation through the acute, sub-acute and long-term phases of their condition and often have complex needs. However, the rehabilitation needs for people with neurological disorders are profoundly unmet with only 16% of countries reporting specialized neurorehabilitation services and only 17% reporting general rehabilitation units that offer neurological rehabilitation.⁵⁹
- 78. Neurological disorders because of complex needs and high levels of dependency and morbidity in later stages of disease, require a range of coordinated health and social care including long-term and palliative care to provide relief from pain, physical, psychosocial and spiritual support and to enhance the quality of life, including support with advance care planning.

Actions for Member States

- 79. Develop an evidence-based pathway of coordinated health and social services for people with neurological disorders across the life course to ensure access to quality care when and where required. This includes integration at multiple levels of the health and social care system for example through multidisciplinary care teams, service directories, medical health records and referral mechanisms.
- 80. Review and update existing legislation, policies, plans and financing schemes to ensure effective coordination across the care continuum, including prevention, diagnosis, treatment, rehabilitation and palliative care
- 81. Ensure equitable access to rehabilitation for disabilities associated with neurological conditions by strengthening health systems at all levels from highly specialized in-patient settings through to community delivered rehabilitation,
- 82. Develop new and/or strengthen existing services, guidance and protocols to support the implementation of palliative care coordination and referral mechanisms as well as ensuring equitable access to palliative care for people with neurological disorders.
- 83. Proactively identify and provide appropriate care and support to population groups at particular risk of neurological disorders or who have poor access to services, such as socioeconomically disadvantaged individuals, older people and others specific to each national context. In partnership with humanitarian actors, integrate support needs into emergency preparedness plans to enable access to safe and supportive services, for persons with pre-existing or emergency-induced neurological disorders such as traumatic injuries.
- 84. Empower people with neurological disorders to participate in service planning and delivery and make informed choices and decisions about care that meets their needs by providing evidence-based, accessible information.

Actions for the Secretariat

- 85. Provide technical support to Member States to document and share best practices of evidence-based service delivery and multidisciplinary care coordination, emphasizing prevention, diagnosis, treatment, rehabilitation and palliative care for people with neurological conditions.
- 86. Provide technical support to Member States to update and strengthen rehabilitation policies and develop mechanisms for rehabilitation financing and utilize the WHO Rehabilitation Guide for Action⁶⁰ for development of national strategic plans and monitoring frameworks that include neurological conditions.
- 87. Develop guidance and provide technical support to Member States to improve the effectiveness and quality of palliative care and develop palliative care pathways for neurological disorders in line with the principle of universal health coverage.

⁵⁹ Atlas: country resources for neurological disorders – 2nd ed. Geneva: World Health Organization; 2017.

⁶⁰ https://www.who.int/rehabilitation/rehabilitation-guide-for-action/en/

- 88. In partnership with international multilateral agencies, regional agencies, subnational intergovernmental and nongovernmental organizations, offer technical support and policy guidance to inform community-based health services reconstruction efforts for people with neurological disorders during and following humanitarian emergencies.
- 89. Provide guidance on engaging people with neurological disorders, their families and carers in service planning and treatment decisions.

Actions for international partners

- 90. Actively engage all relevant stakeholders across sectors to inform the development and implementation of multisectoral and multidisciplinary care coordination and integrated neurological care pathways across the continuum, including prevention, diagnosis, treatment, rehabilitation and palliative care.
- 91. Facilitate knowledge exchange and dialogue to review and update rehabilitation and palliative care policies and plans in collaboration with relevant international multilateral agencies, regional agencies, intergovernmental agencies, and organizations representing people with neurological disorders and other civil society organizations.
- 92. In partnership with international multilateral agencies and national agencies, support the piloting and scaling of programmes aimed at accessing integrated care (including rehabilitation and palliative care) for people with neurological disorders.
- 93. Support coordinated efforts to ensure inclusion of neurological disorders in essential health services and packages implemented during emergencies by humanitarian health actors including identification of individuals requiring neurological care, health and social human resource capacity building and development of supportive plans and policies.
- 94. Facilitate civil society 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 information and training tools and/or by establishing national helplines and websites with accessible information.

2.2 MEDICINES, DIAGNOSTICS AND OTHER HEALTH PRODUCTS

- 95. Medicines, diagnostics and other health products such as assistive technology, biological products, cell and gene therapy are essential for prevention, diagnosis, treatment, rehabilitation and palliative care to reduce the mortality and morbidity of, and improve the quality of life of people with neurological disorders.
- 96. Appropriate use of diagnostics can reduce morbidity through early and rapid detection of neurological disorders or risk factors at early disease stages. Diagnostics further support disease monitoring and inform the development of targeted, cost-effective interventions that can slow disease progression, and reduce complications and disability.
- 97. Even when effective diagnostic tools are available, they may not be affordable or accessible with limited laboratory infrastructure, equipment and trained personnel. For example, neuroimaging and microscopy are widely used methods for diagnosing neurological disorders but they require appropriately trained personnel for maintaining and using the devices.
- 98. Essential medicines have a crucial role for both prevention and treatment of neurological disorders. For instance, vitamin K antagonists and oral direct anticoagulants can prevent a large number of ischaemic strokes. Antibiotics, for example are a life saving treatment for meningitis, however often shortages prevent access of first choice WHO recommended antibiotics in many countries. Medicines for multiple sclerosis exist that slow disease progression and improve quality of life for many people, however their availability is limited in LMICs. Controlled medicines are needed for the treatment of pain and palliative care and when not accessible, can cause needless suffering.
- 99. Many chronic neurological disorders can be treated through cost-effective medicines. For example, a cost-effectiveness analysis of epilepsy treatment in nine WHO subregions found that first-line medications, such as phenobarbital, represent a highly cost-effective use of resources for health⁶¹.

⁶¹ Chisholm D. Cost-effectiveness of first-line antiepileptic drug treatments in the developing world: a population-level analysis. Epilepsia. PMID: 15857443

100. Assistive technology enables people to live healthy, productive, independent, and dignified lives. Assistive technology reduces the need for formal health and support services, long-term care and the work of cares. Few people in need have access to assistive technology due to high costs and a lack of awareness, availability, trained personnel, policy, and financing.

Actions for Member States

- 101.Ensure availability, access and use of appropriate relevant diagnostics such as microscopy, electroencephalogram (EEG) and neuroimaging technology (including Computed Tomography (CT), Magnetic Resonance Imaging (MRI) by training technicians and health care workers in the use of these technologies.
- 102. Ensure that essential, safe, affordable, effective and quality medicines and health products for neurological disorders are available through appropriate policy, legislative, regulatory and procurement systems including access to controlled medicines while minimizing the risk of diversion and misuse. Identify key barriers to accessing essential, safe, affordable, effective and quality medicines and health products across population groups and strategies to systematically address these.
- 103.Promote the appropriate use of essential medicines, including generics, for the prevention and management of neurological disorders through measures such as quality assurance of medical products, preferential or accelerated registration procedures, generic substitution, preferential use of the international non-proprietary names, financial incentives where appropriate and training of prescribers and consumers. Include strategies to systematically address these using the four components of access (rational selection, availability, affordability, and appropriate use). ⁶²
- 104. Address the treatment of co-morbidities and drug interactions for appropriate medicine use across the life course. For example, train healthcare workers in the safety, clinical and economic implications for appropriate polypharmacy management, particularly in older people⁶⁴.
- 105. Establish regulatory frameworks, resources, and capacity to ensure quality, safety and ethical standards are met for medical products, such as biotherapeutic treatments and assistive devices such as hearing aids, wheelchairs, spectacles and prostheses.
- 106. In partnership with international multilateral agencies, regional agencies, subnational intergovernmental, nongovernmental organizations and the private sector, improve the availability of life-saving technologies and essential medicines for managing neurological disorders during humanitarian emergencies.

Actions for the Secretariat

- 107.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 global level, evidence-based context-specific regulatory guidance, good practices for standards-based procurement and manufacturing, and technical, legislative and regulatory training.
- 108. Provide targeted support to Member States to achieve global and national health objectives related to access to medicines for people with neurological disorders, including by strengthening national regulatory and procurement systems, developing innovative health financing mechanisms and facilitating collaboration between regional agencies, intergovernmental agencies, national and/or subnational health authorities and the private sector, including pharmaceutical, diagnostics and other health product companies.

Actions for international partners

- 109. Encourage all relevant stakeholders to engage in activities to promote national efforts aimed at improving access to affordable, safe, effective and quality medicines, diagnostics and other health products, such as neuroimaging.
- 110.Support global, regional, intergovernmental, national and/or subnational strengthening of regulatory and procurement processes (including through pooled procurement, innovative health financing mechanisms health

⁶² https://www.who.int/mental health/management/improving access medicines mental disorders/en/

⁶³ https://www.who.int/mental_health/neurology/epilepsy/report_2019/en/

⁶⁴ Medication Safety in Polypharmacy. Geneva: World Health Organization; 2019 (WHO/UHC/SDS/2019.11).

human resource capacity building) to ensure access to and appropriate use of medicines, diagnostics and other health products.

2.3 HEALTH WORKERS' CAPACITY BUILDING, TRAINING AND SUPPORT

- 111. The combination of adequate neurological workforce (adult neurologists, child neurologists, neurosurgeons) as well as other health-care providers including psychologists, neuroradiologists, EEG technicians, physical therapists, occupational therapists and speech therapists) and competent primary health care workers who are trained in identifying and managing neurological disorders is central to achieving improved health outcomes. Building primary health care capacity provides an important opportunity to improve prevention, diagnosis, treatment, care, rehabilitation and palliative care for people with neurological disorders and promote brain health across the life course.
- 112. Training and education of a multidisciplinary workforce including general and specialized health care professionals, social care workers, rehabilitation specialists trained in neurological conditions, pharmacists, biomedical engineers, community health workers, family carers, and traditional healers, where appropriate, is required to ensure the appropriate use of available medicines and diagnostics, leverage existing resources and enhance health outcomes, particularly in LMICs⁶⁵.

Actions for Member States

- 113.Build health and social care worker capacity by expanding existing educational curricula and providing continuing education in the area of palliative care for people with neurological disorder
- 114. Identify and apply existing and emerging context-appropriate evidence to establish:
 - i. appropriately resourced programmes and policies to address projected health workforce needs for the future in light of demographic changes and the prevalence of diseases such as dementia and Parkinson's disease due to increased population ageing.
 - ii. adequate compensation and incentives for health and social care workers trained in neurological disorders to work in underserved areas and promote the retention of these workers in those areas.
 - iii. Protect health workers and ensure that their rights are being upheld.
- 115.Strengthen health and social care workforce capacity to address neurological disorders, including common comorbid conditions such as infectious diseases and noncommunicable diseases. These initiatives should focus on enhanced capacity of the existing workforce, both specialist as well as primary healthcare workers. This includes:
 - i. implementing training programmes for general and specialized health and social care workers to deliver evidence-based, culturally appropriate and human rights-oriented neurological care for all people across the life course;
 - ii. developing career tracks for adult neurologists, child neurologists and neurosurgeons by strengthening postgraduate training.
 - iii. expanding the role of the neurological workforce to encompass supervision and support of general health workers in providing neurological interventions.
 - iv. harnessing the potential of community health workers and strengthen collaboration with other informal care providers such as traditional healers with effective training, support and supervision.
 - v. Ensuring that people with neurological disorders are involved in the development and delivery of training, as appropriate.
- 116.Support health and social care workers to implement and scale up remote neurology services using information and communication technologies such as telemedicine, internet/mobile phone technologies to expand the neurological care to remote and low-resource settings and to support home-based services.

Actions for the Secretariat

117.Support Member States with adequate tools to incorporate neurological care needs in the routine planning for health workers. Such planning approaches should be based on best available data and follow a rigorous health

⁶⁵ WHO Global strategy on human resources for health: workforce 2030.

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 for advanced neurological care training.

- 118.Support Member States to build health and social care workforce capacity as well as for informal care providers by promoting, strengthening and developing guidance, tools and the application of competency-based training models required for the diagnosis, treatment and care of neurological disorders.
- 119. Facilitate exchange and disseminate evidence-based best practices (including the use of digital health technologies) on structured integrated care programmes, service delivery planning, implementation, and monitoring for neurological disorders in partnership with national and subnational agencies, academic institutions and research agencies, professional associations and patient organizations.

Actions for international partners

- 120. Facilitate the exchange of information on best practices and dissemination of findings in health workers' development and training to support national efforts related to the prevention and management of neurological disorders.
- 121.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 conditions.
- 122.Support national authorities in strengthening health systems and expanding quality services including through the development of appropriate health care infrastructure and institutional capacity for training of health personnel.

2.4 CARER SUPPORT

- 123.Neurological disorders have a profound impact on individuals, their families and communities. Due to their chronic course, people with neurological disorders often require ongoing care provided in large part by informal carers.
- 124. Carers can be defined by their relationship to the person with a neurological condition and their care input. Many carers are relatives or extended family members, but close friends, neighbours and paid lay persons 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 life-long care delivered by others.
- 125.Challenges for carers include stress, role strain, financial burden, and social isolation and may vary depending upon the age of the carer and the person affected.
- 126. 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 2017-2025⁶⁶ identifies key actions to support carers that are also relevant to neurological conditions, which will be expanded upon and implemented as part of this action plan.

Actions for Member States

- 127.Provide accessible and evidence-based information on available resources in the community, training programmes, respite services and other resources tailored to the needs of carers of people with neurological disorders to enable people with neurological disorders to live in the community and to prevent carer stress and health problems.
- 128. Within the context of community-based neurological care, provide training programmes for health care and social care staff for the identification and reduction of carer stress.
- 129.Develop or strengthen mechanisms to protect carers of people with neurological disorders, such as through the implementation of social and disability benefits, (such as pension or leave) and policies and legislation aimed at reducing discrimination and supporting carers beyond their caregiving role across all settings.

⁶⁶ Global action plan on the public health response to dementia 2017–2025

130.Develop mechanisms to involve carers in care planning, with attention being given to the wishes and preferences of people with neurological disorders and their families.

Actions for the Secretariat

- 131.Support Member States in developing and evaluating evidence-based information, training programmes and respite services for carers of people with neurological disorders through a multisectoral approach.
- 132. Facilitate access to affordable, evidence-based resources for carers of people with neurological disorders to improve knowledge and skills related to neurological disorders, reduce emotional stress and improve coping, self-efficacy and health, including through the use of information and communication technologies such as WHO's mental health Gap Action Programme (mhGAP⁶⁷), iSupport⁶⁸, mDementia⁶⁹, Caregivers skills training package (CST) for children with developmental disorders ⁷⁰ and other education, skills training and social support.

Actions for international partners

- 133.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 through disease progression, and empower them to develop self-advocacy skills.
- 134. Assist in implementing culturally-sensitive, context-specific and person-centred training programmes for carers and families to promote well-being and enhance knowledge and caregiving skills across the progression of neurological disorders.

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

- 135. The promotion of brain health and the prevention of neurological disorders across the life course involves reducing modifiable risk factors and enhancing protective factors during critical periods of brain development.
- 136. The overall strategy entails promoting optimal brain development in children and adolescents, encouraging healthy behaviour, infectious disease control, implementing interventions to prevent head and spinal trauma and preventing exposure to environmental pollutants.
- 137. The interventions to promote brain health require taking a life-course linking with healthy ageing which is about creating the environments and opportunities that enable people to be and do what they value throughout their lives.
- 138. Universal health coverage represents a key component to promoting brain health and well-being and extending life expectancy for all. An important component includes addressing social and economic determinants through a coordinated multi-sectoral response.

3.1 PROMOTION OF OPTIMAL BRAIN DEVELOPMENT IN CHILDREN AND ADOLESCENTS

⁶⁷ https://www.who.int/teams/mental-health-and-substance-use/mental-health-gap-action-programme

⁶⁸ <u>https://www.who.int/mental_health/neurology/dementia/isupport/en/</u>

⁶⁹ https://apps.who.int/iris/bitstream/handle/10665/339846/9789240019966-eng.pdf

⁷⁰ https://www.who.int/mental_health/maternal-child/PST/en/

- 139. The early stages of life present a particularly important opportunity to promote brain health and prevent neurological disorders. In early life, a child's brain develops and adapts rapidly in response to the surrounding environment, nutrition, and stimulation.
- 140. Optimizing brain development in the formative stages involves creating conditions for nurturing care⁷¹ and family cohesion through public policies, programmes and services. These enable communities and caregivers to ensure children's good health, nutrition and protect them from threats.
- 141. Access to formal education has also been shown to improve brain health outcomes. All children and adolescents should be able to live, study, work and socialize in supportive, healthy, and safe environments that promote and protect their health and reduce their engagement in risk behaviours.
- 142.Exposure to early life adversity such as maltreatment, neglect, inadequate maternal nutrition, poor caregiver health, substance use (including alcohol and smoking), congenital infections or birth complications can have a negative impact on the developing brain and carry life-long implications for brain health. Preventing child maltreatment, neglect or sexual violence requires robust child protection laws, policies and services.
- 143.Certain environmental pollutants are specifically known to affect neurodevelopment. These include, but are not limited to, air pollution, heavy metals in soil and water, lead in household paint, mercury in seafood as well as various products and workplace exposure and pesticides⁷². Young children are especially vulnerable to lead toxicity, and even low levels of exposure can result in reduced attention span, behaviour problems and reduced educational attainment.
- 144. Physical activity can confer health benefits for children and adolescents living with neurological conditions, thus limiting sedentary behaviours, particularly for recreation, such as screen-based entertainment (television and computers) and digital communications, such as mobile phones is recommended.

Actions for Member States

- 145.Develop, fund and implement strategies to promote healthy brain development and prevent neurological disorders in childhood and adolescence, focusing on early intervention. Health policies and programmes should address risk factors as well as enhance protective factors to both optimize brain development, such as access to formal education, and prevent the development of neurological disorders.
- 146. Accelerate the full implementation of the WHO Framework Convention on Tobacco Control (FCTC)⁷³ to reduce foetal exposure, childhood secondhand smoke exposure and adolescent smoking.
- 147.Develop and implement, as appropriate, comprehensive and multisectoral national policies and programmes to reduce the harmful use of alcohol⁷⁴, particularly during pregnancy.
- 148. Integrate maternal mental health interventions into broader health services, optimize perinatal and child health care including safe labor and delivery, the use of birth attendants, skin to skin contact (kangaroo mother care), breastfeeding, adequate nutrition, immunization, and child development interventions for responsive caregiving and early learning.
- 149. In partnership with relevant national regulatory authorities and private sector actors, develop, strengthen and monitor national food and nutrition policies and action plans in line with the global strategy for infant and young child feeding⁷⁵, 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 children⁷⁶.

⁷¹ WHO Nurturing care framework for early childhood development launched at the 71st World Health Assembly:

https://www.who.int/maternal_child_adolescent/child/nurturing-care-framework/en/

⁷² WHO Preventing disease through healthy environments: https://apps.who.int/iris/handle/10665/204585

⁷³ WHO Framework Convention on Tobacco Control:

https://www.who.int/fctc/text_download/en/#:~:text=The%20WHO%20Framework%20Convention%20on,the%20highest%20standard%20of%2 Ohealth

⁷⁴ WHO Global strategy to reduce the harmful use of alcohol:

https://apps.who.int/iris/bitstream/handle/10665/44395/9789241599931 eng.pdf?sequence=1

⁷⁵ WHO factsheet: <u>https://www.who.int/news-room/fact-sheets/detail/infant-and-young-child-feeding</u>

⁷⁶ WHO guideline on inappropriate promotion of foods for infants and children, 2017: https://www.who.int/publications/i/item/9789241513470

- 150.Ensure that every adolescent has access to the recommended interventions in the Global strategy for women's, children's and adolescents' health⁷⁷, 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.
- 151.Develop appropriately resourced policies for improved provision of quality physical education in educational settings from infant years to tertiary level, including opportunities for physical activity before, during and after the formal school day. Parks, trees and green areas within urban centres can improve local air quality as well as offer a refuge for children to play. Implement WHO guidelines on physical activity and sedentary behaviour including recommendations on recreational screen time.⁷⁸
- 152.Strengthen surveillance mechanisms for core indicators of brain health and development in children and adolescents.

Actions for the Secretariat

- 153.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:
 - i. enhancing leadership within health ministries and other relevant sectors for the development, strengthening and implementation of evidence-based national and/or subnational strategies or plans and associated multisectoral resource planning to optimize brain development in children and adolescents.
 - **ii.** compiling and sharing knowledge and best practices related to existing policies addressing early childhood and adolescent development, including codes of practice and mechanisms to monitor the protection of human rights.

Actions for international partners

154. Facilitate global, regional, intergovernmental, national and/or subnational strengthening of policies for children and adolescents addressing maltreatment, neglect, inadequate maternal nutrition, poor caregiver health, substance use (such as alcohol and smoking), congenital infections, birth complications and environmental pollutants.

3.2 PROMOTING HEALTHY BEHAVIOUR ACROSS THE LIFECOURSE

- 155.Promoting brain health across the life course includes focusing on healthy behaviour. Growing evidence suggests an interrelationship between many neurological disorders, such as dementia and stroke with noncommunicable diseases such as hypertension, diabetes and other related risk factors. These risk factors include physical inactivity, obesity, unbalanced diets, tobacco use, and harmful use of alcohol.
- 156. Addressing potentially modifiable risk factors can strengthen capacity to make healthier choices and follow healthy behavior patterns that foster good brain health. An understanding of the risk factors contributing to the neurological burden of disease can also inform preventative measures.
- 157.Effective urban planning and increased access to sports facilities can increase physical activity at population levels, resulting in improved educational achievement, social, mental and brain health benefits, improved air quality, reduced environmental pollution, and lowering the risk of various neurological disorders including dementia and stroke. Exercise and regular physical activity are associated with better quality of life, better physical function, and lower caregiver burden in people with chronic neurological disorders such as Parkinson's disease.

⁷⁷ WHO global strategy for women's, children's and adolescents' health (2016-2030): <u>https://www.who.int/life-course/partners/global-strategy/globalstrategyreport2016-2030-lowres.pdf</u>

⁷⁸ WHO guidelines on physical activity and sedentary behavior: <u>https://www.who.int/publications/i/item/9789240015128</u>

- 158.Smoking is a risk factor associated with neurological disorders such as stroke, dementia and multiple sclerosis. Second-hand tobacco smoke was estimated to account for 4% of global stroke burden in 2010.⁷⁹
- 159. Alcohol directly affects the nervous system and can result in neurological disorders such as cerebellar degeneration, neuropathy, myopathy, delirium tremens, and thiamine deficiency leading to Wernicke's encephalopathy or Korsakoff syndrome. It also contributes to road traffic accidents, falls and associated brain and spinal cord injuries.

Actions for Member States

- 160.Support actions shown to reduce the risk of neurological disorders across the life course by advancing strategies for the cessation of tobacco use and the harmful use of alcohol in line with the Global action plan for the prevention and control of noncommunicable diseases⁸⁰ and the Global strategy to reduce the harmful use of alcohol⁸¹.
- 161.Develop and implement appropriately resourced policies and national strategies on physical activity and sedentary behaviours for health in line with the WHO Guidelines on physical activity and sedentary behaviour⁸² and in consultation with relevant intergovernmental agencies, academic institutions and research centres, nongovernmental organizations, and people with neurological disorders, their families and carers.
- 162. Develop, implement and monitor appropriately resourced, population-wide strategies that promote healthy nutrition and diet as outlined in the WHO Comprehensive implementation plan on maternal, infant and young child nutrition⁸³ and the Global action plan for the prevention and control of noncommunicable diseases action plan and 2030 agenda⁸⁴.
- 163.Collate and disseminate guidance and tools to inform the implementation and evaluation of national/subnational interventions aimed at reducing the prevalence of tobacco use, decreasing the harmful use of alcohol and promoting a healthy diet and physical activity.

Actions for the Secretariat

164. Provide technical support and strengthen global, regional and national capacities and capabilities to:

- i. raise awareness of the links between neurological disorders and other noncommunicable diseases,
 - ii. integrate the reduction and control of modifiable risk factors by implementing the WHO FCTC and integrating its guidelines into national health planning processes and development agendas; and
 - iii. support the formulation and implementation of evidence-based, multisectoral interventions for promoting brain health and reducing the risk of neurological disorders across the life course.
- 165.Strengthen, share and disseminate evidence to support policy interventions aimed at reducing potentially modifiable risk factors for neurological conditions by promoting healthy workplace initiatives, health-promoting schools and other educational institutions, healthy-cities initiatives, health-sensitive urban development and social and environmental protection initiatives.

Actions for international partners

166. Promote and mainstream population brain health strategies that are age-inclusive, gender-sensitive and equitybased at national, regional and international levels in order to support socially and physically active healthy behaviours for people with neurological disorders, their carers and families.

https://www.who.int/publications/i/item/9789241506236

https://www.who.int/nutrition/publications/CIP_document/en/

⁸⁴ Global action plan for the prevention and control of noncommunicable diseases action plan. https://www.who.int/publications/i/item/9789241506236

⁷⁹WHO Preventing disease through healthy environments: https://apps.who.int/iris/handle/10665/204585

⁸⁰ Global action plan for the prevention and control of noncommunicable diseases action plan.

⁸¹ WHO Global strategy to reduce the harmful use of alcohol: https://apps.who.int/iris/bitstream/handle/10665/44395/9789241599931_eng.pdf?sequence=1

⁸² WHO guidelines on physical activity and sedentary behavior: <u>https://www.who.int/publications/i/item/9789240015128</u>

⁸³ WHO Comprehensive implementation plan on maternal, infant and young child nutrition.

167. Facilitate the exchange of knowledge and evidence-based best practices to support actions shown to reduce the risk of neurological disorders across the life course, in line with WHO's Framework Convention on Tobacco Control (FCTC)⁸⁵, the Global strategy to reduce harmful use of alcohol⁸⁶, the Global strategy on diet, physical activity and health⁸⁷ and other relevant strategies.

3.3 INFECTIOUS DISEASE CONTROL

- 168. The neurological consequences of infectious diseases such as meningitis, neurocysticercosis, cerebral malaria, HIV, toxoplasmosis and rabies contribute to global morbidity and mortality among the most vulnerable, marginalized populations and can result in lifelong sequelae.
- 169.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 preventative 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.
- 170. The emergence of neurotropic zoonotic infections can be attributed to several causes including unsustainable agricultural intensification and increased use and exploitation of wildlife⁸⁸.

Actions for Member States

- 171.Implement infectious disease management, eradication and immunization programmes based on WHO guidance, such as WHO's Road map for neglected tropical disease 2021–2030⁸⁹, the Defeating meningitis by 2030 global road map⁹⁰. Include approaches for control of other neuroinfectious diseases within the health and agricultural sectors as outlined in WHO's Preventing disease through healthy environments⁹¹.
- 172. Collaborate with all relevant sectors and stakeholders, including climate change groups and migration authorities, to mitigate risks of emerging infectious diseases that cause neurological disorders. Close coordination and multisectoral action within and beyond health, including vector control, water and sanitation, animal and environmental health and education, will be needed to maximize synergies.
- 173. Create national operational plans to deliver interventions for neurological diseases in line with a One Health⁹² approach by developing a coordinated plan outlining stakeholder accountability for humans-, animal-, food- and ecosystem-related actions, and treating animals to prevent transmission of neuro-infectious pathogens such as mass dog vaccinations for rabies prevention.

Actions for the Secretariat

174.Offer technical support, tools and guidance to Member States to strengthen global, regional and national awareness of infectious disease control including reducing the risk of zoonotic infections, antimicrobial and insecticide resistance and animal or livestock trading and farming policies.

⁸⁵ WHO Framework Convention on Tobacco Control:

https://www.who.int/fctc/text_download/en/#:~:text=The%20WHO%20Framework%20Convention%20on,the%20highest%20standard%20of%20health

⁸⁶ WHO Global strategy to reduce the harmful use of alcohol:

https://apps.who.int/iris/bitstream/handle/10665/44395/9789241599931_eng.pdf?sequence=1

⁸⁷ WHO Global strategy on diet, physical activity and health.

https://www.who.int/dietphysicalactivity/strategy/eb11344/strategy_english_web.pdf

⁸⁸ United Nations Environment Programme and International Livestock Research Institute (2020). Preventing the Next Pandemic: Zoonotic diseases and how to break the chain of transmission. Nairobi, Kenya. <u>https://digitallibrary.un.org/record/3872023?ln=en</u>

⁸⁹ WHO's Road map for neglected tropical disease 2021–2030. <u>https://www.who.int/neglected_diseases/Ending-the-neglect-to-attain-the-SDGs--</u> <u>NTD-Roadmap.pdf</u>

⁹⁰ WHO's Defeating meningitis by 2030 global road map. <u>https://www.who.int/initiatives/defeating-meningitis-by-2030</u>

⁹¹ WHO Preventing disease through healthy environments: https://apps.who.int/iris/handle/10665/204585

⁹² https://www.who.int/news-room/q-a-detail/one-health

Actions for international partners

175.Promote multi-stakeholder collaboration within and beyond the health sector, notably for environmental and veterinary health in line with the 2030 Agenda for Sustainable Development and its Sustainable Development Goals⁹³.

3.4 PREVENTING HEAD/SPINAL TRAUMA AND OTHER INJURIES

- 176. Traumatic brain injury (TBI) and spinal cord injury (SCI) require complicated and costly medical care. In 2016, there were 27 million new cases of TBI and close to one million new cases of SCI globally⁹⁴. Road traffic injuries and falls constitute the highest number of these new cases and many are preventable.
- 177.Key risk factors for road traffic injuries include speeding, alcohol impairment, non-use of helmets, non-use of seat belts and child restraints, inadequate visibility of pedestrians and other road users and inadequate enforcement of traffic laws. Many sport-related injuries can also result in traumatic brain and spinal cord injury.
- 178. Awareness, laws and policies to educate sports professionals, parents and athletes and implementation of helmet or protective devices policies are needed to prevent TBI and SCI.⁹⁵.
- 179.Each year, 37 million falls are severe enough to seek 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.

Actions for Member States

- 180.Implement the recommendations included in the World report on road traffic injury prevention and proposed by the Commission for Global Road Safety⁹⁶. These include road safety management, safer roads and mobility, safer vehicles, safer road users and increased responsiveness to post-crash emergencies and longer-term rehabilitation for victims.
- 181.Strengthening information systems to collect data on TBI and SCI arising from road traffic collisions in order to improve understanding on the scale of the issue and its implications.
- 182.Develop and implement policies, standards and effective interventions to address unsafe home and community environments including poor lighting, slippery floors, loose rugs, and beds without rails as outlined in the Global strategy and action plan on ageing and health⁹⁷.
- 183.Develop and implement policies and mandatory education for athletes, parents, and coaches to inform about the risks associated with TBI and SCI in sports.

Actions for the Secretariat

- 184.Collect and disseminate evidence and best practices to prevent or reduce TBI and SCI including the prevention of road traffic accidents and falls through implementation of the Global plan for the decade of action for road safety. ⁹⁸
- 185.Provide guidance, evidence-based practices and technical support for early rehabilitation and support to people with TBI and SCI to minimize both physical and psychological impact.

Actions for international partners

⁹³ UN Sustainable Development agenda. https://www.un.org/sustainabledevelopment/development-agenda/

⁹⁴ 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 Jan;18(1):56-87

⁹⁵ Opportunities for Prevention of Concussion and Repetitive Head Impact Exposure in College Football Players: A Concussion Assessment, Research, and Education (CARE) Consortium Study. JAMA Neurol. 2021 Feb 1;e205193

⁹⁶ Commission for Global Road Safety. https://www.who.int/management/programme/health_promotion/MakeRoadsSafe.pdf

⁹⁷ https://www.who.int/ageing/global-strategy/en/

⁹⁸ https://www.who.int/roadsafety/decade_of_action/plan/en/

- 186.Promote multi-stakeholder 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) to prevent TBI and SCI
- 187. Encourage all relevant stakeholders to engage in activities to promote national efforts for increasing helmet use in accordance with WHO's *Helmets: a road safety manual for decision-makers and practitioners.*⁹⁹

3.5 REDUCING ENVIRONMENTAL RISKS

- 188. Exposure to environmental and occupational hazards can directly influence brain health. For example, in older people, exposure to household and ambient air pollution has been strongly linked with Alzheimer's and Parkinson's diseases and is considered a potentially modifiable risk factor for the development of dementia.
- 189. As with children, exposure to heavy metals such as lead¹⁰⁰ and mercury can cause serious health and nervous system damage in all age groups. Significant mercury exposure is associated with artisanal and small-scale gold mining (ASGM) and mercury products. Safe disposal and long-term storage of mercury waste is a global challenge with direct impacts on human health and the environment¹⁰¹.
- 190.In 2019, 5.65% of the global stroke burden (in DALYs) was attributable to ambient air pollution¹⁰² and has been associated with increased hospital admissions and deaths from stroke.
- 191.Parkinson's disease has been associated with exposure to pesticides and the industrial solvent trichloroethylene (TCE) in occupational and non-occupational settings¹⁰³. Additionally, migraines can be triggered by environmental pollutants such as bright lights, poor air quality and noise¹⁰⁴.
- 192.Climate change is one of several concurrent global environmental changes that simultaneously affect human health and neurological conditions, often in an interactive manner. As an example, the transmission of vectorborne neurotropic viruses such as Zika, Japanese encephalitis and West Nile is jointly affected by climatic conditions, population movement, deforestation, land-use patterns, biodiversity losses, freshwater surface configurations, and human population density¹⁰⁵.

Actions for Member States

- 193.Link brain health promotion and the prevention of neurological disorders with strategies that focus on promoting healthy living, working and environmental conditions, in line with WHO's guidance Preventing disease through healthy environments¹⁰⁶
- 194. Accelerate progress towards the global phase out of lead paint through regulatory and legal measures¹⁰⁷.
- 195.Develop and implement health promotion and protection strategies and programmes across sectors to limit exposure to pesticides and other high-priority chemicals, such as TCE, which have been associated with neurotoxic effects;
- 196.Ratify and implement the Minamata Convention on Mercury and address the health aspects of exposure to mercury and mercury compounds through collaboration between health authorities, environment authorities, and others, in line with resolution WHA67.11¹⁰⁸.

¹⁰⁶ WHO Preventing disease through healthy environments: https://apps.who.int/iris/handle/10665/20458
 ¹⁰⁷ <u>https://www.who.int/ipcs/assessment/public_health/gaelp/en/</u>

⁹⁹ WHO Helmets: a road safety manual for decision-makers and practitioners.<u>https://www.who.int/mediacentre/news/releases/2006/pr44/en/</u>
¹⁰⁰ World Health Organization. (2020). Global elimination of lead paint: why and how countries should take action: technical brief. World Health Organization. <u>https://apps.who.int/iris/handle/10665/333840</u>. License: CC BY-NC-SA 3.0 IGO

¹⁰¹ International programme on chemical safety. <u>https://www.who.int/ipcs/assessment/public_health/mercury/en/</u>

¹⁰² https://vizhub.healthdata.org/gbd-compare/

¹⁰³ Ascherio A, Schwarzschild MA. The epidemiology of Parkinson's disease: risk factors and prevention. Lancet Neurol. 2016;15(12):1257-72. 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.

¹⁰⁴ WHO Preventing disease through healthy environments: https://apps.who.int/iris/handle/10665/204585

¹⁰⁵ WHO Climate Change and health. <u>https://www.who.int/news-room/fact-sheets/detail/climate-change-and-health</u>

¹⁰⁸ WHA67.11. https://apps.who.int/gb/ebwha/pdf_files/WHA67-REC1/A67_2014_REC1-en.pdf

- 197.In partnership with the private sector, nongovernmental organizations and other multisectoral stakeholders, integrate environmental determinants specific to brain health and neurological disorders into broader mitigation strategies aimed at reducing the impact of climate change, including through interventions and policies that:
 - i. promote access to clean air (ambient and household) such as reducing the use of fossil fuels and promoting the use of cleaner cook stoves;
 - ii. Promote access to adequate and equitable sanitation, hygiene and safe water;

Actions for the Secretariat

198. Provide support to countries in evaluating and implementing evidence-based options that suit their needs and capacities and in assessing the health impact of public policies regarding air pollution, heavy metals, pesticide and industrial solvents for the prevention of neurological disorders across programmes for environmental health.

Actions for international partners

199.Promote at national, regional and international levels, WHO's guidance on Preventing disease through healthy environments¹⁰⁹ and highlight the importance of climate change¹¹⁰ on brain health, in line with the 2030 Agenda for Sustainable Development and its Sustainable Development Goals¹¹¹.

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

- 200. Information, evidence and the generation of new knowledge are needed to inform policy, planning and programming for neurological disorders. Together, they provide insight into effective health services, care models, and disease-modifying treatment options, and foster innovation such as innovative health technologies in prevention, risk reduction, early diagnosis, treatment, care and support related to neurological disorders. When translated into daily practice, research plays an important role in informing evidence-based policies, programmes and services for people with neurological disorders.
- 201. Currently, most neurology research is conducted by high-income countries. For example, while significant investments in epilepsy research have been made in high-income countries, funding for epilepsy only represents a small proportion of overall funding. This research imbalance needs to be improved to ensure that LMICs have cost-effective strategies to respond to neurological disorders, tailored to local resource settings.
- 202.Systematic monitoring and reporting of a core set of indicators on neurological disorders provides the data needed to guide evidence-based actions to improve services, evaluate programmes and measure progress towards implementation of national policies.
- 203.Information systems for neurological disorders in most LMICs are rudimentary or absent, making it difficult to understand the needs of people with neurological disorders, their families and carers, availability, capacity and utilization of services and to rationalize programmes and resources accordingly.

¹⁰⁹ WHO Preventing disease through healthy environments: https://apps.who.int/iris/handle/10665/204585

¹¹⁰ Watts.Net al (2018) The 2018 report of the Lancet Countdown on health and climate change: shaping the health of nations for centuries to come, The Lancet

¹¹¹ UN Sustainable Development agenda. <u>https://www.un.org/sustainabledevelopment/development-agenda/</u>

4.1 INVESTMENT IN RESEARCH

- 204. If the incidence of neurological disorders is to be reduced and the lives of people with neurological disorders are to be improved, investment in biomedical, clinical, implementation and translational research are crucial to inform prevention, risk reduction, diagnosis, treatment and care.
- 205.All research and development activities must be rooted in equity, diversity, and inclusiveness with increased engagement and consultation with end-users to ensure that technologies and innovation are prioritized according to real demand and added value. Strategies are required to facilitate the transfer of technologies and sharing of associated information, while acknowledging and respecting intellectual property rights.
- 206. Collaboration between Member States and relevant stakeholders, with a particular focus on strengthening North–South, South–South and triangular cooperation, to promote 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, duplication of research and costs.

Actions for Member States

- 207.Increase investment in research and improve research governance as an integral component of the national response to the burden of neurological disorders.
- 208. Support national, regional and international research collaborations for neurological disorders to enhance sharing of, and open access to, research data, generate new knowledge on neurological disorders promotion, prevention, diagnosis, treatment and care, and translate existing evidence about neurological disorders into action.
- 209. Incentivize the development of new diagnostics, treatments and innovations that respond to the needs of people with neurological disorders, their families and carers and people at risk of developing neurological disorders. These innovations include but are not limited to use of big data, artificial intelligence, diagnostics including use of automated diagnostic algorithms, precision medicine, disease monitoring and assessment tools, assistive technologies, pharmaceuticals and new models of care.

Actions for the Secretariat

- 210. Advocate for increased investment in research for neurological disorders, through research prioritization, agenda setting in the fields of biomedical, clinical, implementation and translational research at global, regional and national level.
- 211.Promote intercountry exchange of expertise to enhance regional and international research collaborations, especially in LMICs, including through the systematic mapping of national investments in research and outputs of research for neurological disorders.
- 212.Offer guidance and technical support to Member States:
 - i. in developing new diagnostics, treatments and innovative technologies for neurological disorders, particularly in low-resource settings.
 - ii. in developing mechanisms to ensure equitable access to and the implementation of potential new diagnostics, treatments, and innovative technologies for neurological disorders within countries, especially in LMICs.
 - iii. in ethical considerations in the development of new treatments and innovations and the involvement of people with neurological disorders in research efforts.

Actions for international partners

- 213.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 policy-makers, the public, people with neurological disorders, their families their carers.
- 214. Engage the research community, manufacturers, health professionals, programme managers, national health advisory groups, and development partners to promote innovation and pursue the research and development agenda for developing new tools and treatments for neurological disorders.
- 215.Collaborate with stakeholders on the prioritization and allocation of scarce resources, balancing the tensions between country-driven choices and the need for research efforts in order to sustain development and

commercialization of new diagnostic tools and treatments for neurological disorder using technological innovations.

4.2 RESEARCH CAPACITY BUILDING

- 216. The development of national health research systems should be strengthened and supported including optimizing the performance of biomedical, clinical, interventional and translational research for neurological disorders.
- 217.Concerted action to build research infrastructure, strengthen human resource in research and development, and increase collaboration among the research community, manufacturers, health professionals and programme managers, is needed to catalyze neurological research and development, particularly in LMICs.

Actions for Member States

- 218. Strengthen national institutional capacity for research and development in neurological disorders including enhanced research infrastructure, equipment and supplies in research institutions, harnessing the use of big data and artificial intelligence.
- 219.Promote research on neurological disorders by increasing the uptake and training of new researchers in the field, supporting competence of researchers to conduct quality research, enhancing research workforce retention and incentivizing innovation by investing into existing academic institutions and multidisciplinary agencies and supporting the establishment of national reference centres and networks.

Actions for the Secretariat

- 220.Engage WHO collaborating centres, academic institutions, research organizations and alliances to strengthen capacity for research on neurological disorders at the country level.
- 221.Provide technical assistance upon request to strengthen national and regional capacity to incorporate neurological research and innovation in national and regional policies
- 222. Facilitate harmonized global research efforts in neurology and foster regular communication and information exchange between stakeholders to build a globally connected research community and support greater research capacity building specially in LMICs.

Actions for international partners

- 223.Support national efforts to strengthen capacity for research, development and innovation and knowledge exchange, including institutional capacity building, research collaborations and the creation of research fellowships and scholarships, for all aspects related to the prevention, diagnosis, treatment and care of neurological disorders.
- 224. Assist in translating evidence into practice by supporting the development and implementation of health workers skill building and training to foster evidence-based and culturally-appropriate interventions to promote the recovery, rehabilitation and palliative care of people with neurological disorders.

4.3 DATA AND INFORMATION SYSTEMS

- 225.Systematic collection of population-level and routine health information systems data based on a core set of across the life course provides the basis to guide evidence-based actions to improve services and measure progress towards implementing national programmes for neurological disorders and brain health.
- 226.Systematic monitoring and evaluation through accurate usage of health and social care data can provide the best available evidence for service delivery and can improve the accessibility and coordination of care for people with neurological disorders across the life course.

Actions for Member States

- 227. Integrate monitoring of neurological disorders into routine information systems and across all levels of care and identify, collate, routinely report and use core data, disaggregated by sex, age and other equity measures in order to improve neurological care service delivery, promotion and prevention strategies and provide an understanding of the social determinants of neurological disorders.
- 228. Analyze and publish data collected on the availability and evaluation of utilization of services for neurological disorders to improve care and delivery of programmes.

Actions for the Secretariat

229.Offer technical support to Members States to

- develop and/or reform national data collection systems, in order to strengthen multisectoral data collection for neurological disorders.
- build national capacity and resources for systematic collection, analysis and facilitate the use of data related to neurological disorders.
- develop a core set of indicators and targets in line with this action plan, other global action plans, WHO monitoring frameworks and national circumstances to monitor outcomes.

Actions for international partners

- 230.Provide support to Member States to establish surveillance/ information systems that capture core indicators on neurological disorders, enable an assessment of change over time, and provide an understanding of the social determinants of neurological disorders.
- 231. Advocate for the involvement of people with neurological disorders, their families and carers in the collection, analysis and use of data on neurological disorders.